Chapter 10
Medical Family Therapy in Palliative and Hospice Care

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Contemporary advancements in health care and medical technology are allowing patients to live longer now than they ever have before. We are seeing these trends in longer life across all age groups—from increased survival during childhood from illnesses that were heretofore rapidly fatal to combating normative age-related declines (and thereby prolonging senescence) in the elderly. With these trends come marked increases in the likelihood of being diagnosed with a serious or terminal illness during one's lifetime (Centers for Disease Control and Prevention [CDC], 2011). Such illnesses and their unique health trajectories are generally treated under the medical specialties of Palliative and Hospice Care (CDC, 2010; Meier, 2011). Providers engaged in these treatment teams must attend to patients' physical functioning within a context where getting better is not presumed. Treatment teams must thereby attend to foci like quality of life, emotional suffering, loss, meaning making, and spirituality as part of everyday practice.

Medical Family Therapists (MedFTs) are well-equipped to engage in Palliative and Hospice Care teams by nature of the systemic orientations they bring in connecting biopsychosocial-spiritual (BPSS) facets of patients' and families' lives (Engel, 1977, 1980; Wright, Watson, & Bell, 1996). In this chapter, the authors describe key characteristics that distinguish and define work in Palliative and Hospice Care environments. We frame practical skills needed in these domains using Hodgson, Lamson, Mendenhall, and Tyndall's (2014) MedFT Healthcare Continuum and present research-informed recommendations for behavioral healthcare with patients, families, and other care providers situated in these interdisciplinary teams.

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Clinical Vignette

[Note: This vignette is a compilation of cases that represent treatment in Palliative and Hospice Care. All patients' names and/or identifying information have been changed to maintain confidentiality.]

Megan is a 52-year-old woman who recently discovered a lump in her breast while on vacation with her husband, Joe. She was diagnosed with invasive stage 2C breast cancer, but it was still operable. A treatment plan was developed after advisement from her oncologist and medical team—which was comprised of surgeons, pathologists, radiation oncologists, plastic surgeons, oncology nurses, nurse breast care coordinators, medical social workers, a psychiatrist, and behavioral health clinician (MedFT). At this point, she also met with a Palliative Care consultant who talked to Megan to clarify the prognosis, goals of treatment, expectations, and preferred ways to maintain her quality of life. Megan underwent surgery for a double mastectomy and then began radiation. The second phase of her treatment included 12 rounds of chemotherapy and hormone therapy.

Both Megan and Joe were professionals in their careers. Megan ran a successful consulting firm, and Joe was an entrepreneur who had recently sold his business and was now investing in start-ups. Their daughter, Sophie, was a sophomore in college; she was living out of the state. Megan took a leave of absence from her firm with an unknown return date. Joe continued his investments and even began taking on more patients. Sophie continued at college with plans to come home during the summer break.

As time went on, the impact of treatment manifested in both physical and emotional exhaustion; the family began to meet regularly with the MedFT. Megan discussed feeling ashamed for not keeping up the appearance as the "fighter" that her husband, daughter, and family had come to expect. Sessions with the MedFT first involved only Megan but later included Joe. Individual and couple coping mechanisms were discussed, along with communication strategies for enhancing the couple's intimacy and ways to talk about Megan's illness with others included in Megan's social worlds.

Despite the aggressive treatments Megan underwent, her 6-month scan revealed metastasis to multiple organs. It was recommended that treatment be discontinued and that she begin seeing a Palliative Care team to address symptoms related to quality of life. Megan was furious and scared. She lacked the ability to communicate her emotions at the time and thereby placed blame on the healthcare system, its limits in scientific knowledge, and herself. Joe refused to take this as an option and began another passionate project—specifically, "shopping around" for different oncologists and treatment modalities (including homeopathic remedies).

Months later, the oncologist and Palliative Care consultant met with Megan and Joe to communicate that she likely had less than 6 months to live. The healthcare team met with the whole family to discuss Megan's prefer-

ences and allow for discussion around fears related to loss and the dying process. Family members assisting in care talked through strategies and created schedules to facilitate ease of transition from hospital-based Palliative Care to home-based Hospice Care. Visitation by family and friends, caregiver respite, and communication about Megan's progress and transitions via Caring Bridge were among the strategies discussed.

After the family meeting, Megan began her transition into Hospice Care. She is now in her home, receiving services from a community Hospice organization. Megan receives small doses of chemotherapy and increasing doses of pain medication to help alleviate the discomfort caused by spreading tumors.

The complex coordination needs of Megan's healthcare system engaged the MedFT to track the family throughout the process. Through meetings with Megan and her family at their home, the MedFT facilitated conversations to help them process existential beliefs and meaning making concerning illness and death. The family appreciates these additional psychosocial and spiritual services, framing them as helpful in preparing for Megan's impending death.

This case illustrates potential ways that a MedFT can function in Palliative and Hospice Care settings. Instead of working with a patient until his or her acute illness-related crisis has diminished, our work is more about accompanying patients during their suffering, helping them speak frankly with their healthcare team and loved ones, and helping to create and keep a web of supportive relationships that are meaningful. Managing life-threatening or life-limiting illnesses requires attention to issues of meaning making and the myriad of current and potential future losses that can be experienced with them. The MedFT's role can be to bring deeper insights and understandings to these complex psychosocial issues.

What Are Palliative and Hospice Care?

Palliative and Hospice Care have experienced significant growth and expansion in the United States over the past several years (Dumanovsky et al., 2015). Many opportunities thereby exist for the inclusion of MedFTs in contributing to and achieving the goals of these teams. Their involvement is particularly critical through attention and intervention on the larger psychosocial and spiritual issues experienced by patients, families, and healthcare teams (Babcock & Robinson, 2011). Because many illnesses in Palliative and Hospice Care are rare or complex, they are accompanied with a high level of uncertainty regarding their future trajectory(ies). This can cause additional stress and strain on relationships between patients, family members, and healthcare team members (Karlsson, Friberg, Wallengren, & Öhlén, 2014; Lobb et al., 2013; Oishi & Murtagh, 2014; Zambroski, 2006).

There is often misunderstanding among health professionals, patients, and family members about the definitions and goals of Palliative and Hospice Care and their relationship(s) to one another (Brickner, Scannell, Marquet, & Ackerson, 2004; Center to Advance Palliative Care [CAPC], 2011; Hanratty et al., 2006; Jones, 2006). While in other countries the terms Palliative and Hospice are typically synonymous, in the United States they are considered two distinct care services.

Palliative Care is a specialized type of medical care with the overall goal to reduce suffering and maintain or improve quality of life for both the patient and family. Oftentimes, it is offered alongside curative treatment and can be provided at any point along the illness trajectory of a serious illness, including those that are curable, chronic, or life-threatening (National Consensus Project for Quality Palliative Care, 2013). Palliative Care has been shown to increase quality of life (Armstrong, Jenigir, Hutson, Wachs, & Lambe, 2013; El-Jawahri, Greer, & Temel, 2012; Laguna et al., 2012; Sidebottom, Jorgenson, Richards, Kirven, & Sillah, 2015) and is increasingly being utilized earlier in the illness trajectory to help alleviate symptoms for patients diagnosed with chronic, progressive conditions such as pulmonary disorders, chronic heart failure, renal disease, and progressive neurological conditions (Curtis, 2008; Selecky et al., 2005; Selman, Beynon, Higginson, & Harding, 2007). *Hospice Care* refers to a philosophy of care that includes the alleviation of symptoms and enhancement of quality of life for patients whose life expectancy is less than 6 months and/or for those who have chosen to stop or are no longer benefitting from curative treatment (Center for Medicare & Medicaid Service, 2013). Eligibility for Hospice Care typically includes a cessation of curative treatment for a terminal illness with a continuation of treatments that enhance quality of life or treat symptoms.

To further understand the uniqueness of Palliative and Hospice Care, it is helpful to contrast them to our current model of *curative care*, which includes active treatment of disease in order to extend one's life-span (Kaur & Mohanti, 2011). Unlike Palliative or Hospice Care, curative care does not prioritize symptoms such as pain and suffering as much as it focuses on recovery from disease. Both Palliative and Hospice Care emphasize alleviating suffering and improving quality of life. Palliative Care focuses on the simultaneous acts of curing (active treatment) *and* maintaining the quality of life for those patients who have serious illness, while Hospice Care provides pain and symptom management in order to ensure patient comfort when a patient receives a terminal diagnosis, and cure is not possible. Additional similarities and differences between curative, Palliative, and Hospice Care can be found in Figure 10.1.

Treatment Teams in Palliative and Hospice Care

Both Palliative and Hospice Care include interdisciplinary, team-oriented approaches that attend to healthcare, pain and symptom management, patient and family goals, emotional and spiritual needs, and overall quality of life. The composition of

	Curative Care	Palliative Care	Hospice Care
Recipients of Care	Anyone with an acute, chronic, or serious illness	Anyone with a serious illness regardless of life expectancy	Anyone with an illness with a life expectancy of 6 months or less
Goals of Care	Cure the illness	Improve the quality of life while living with a serious illness	Improve the quality of life at the end-of-life
Treatments	Active treatment of the disease (e.g., surgery, treatments)	Pain and symptom management to reduce suffering alongside curative care	Pain and symptom management to reduce suffering
Locations	Hospitals, clinics	Hospitals, clinics, long-term care facilities, Hospice sites	Homes, long-term care facilities, hospitals
Treatment Teams	Typically includes physicians, nurses, behavioral health/mental health, and other health professionals based on the individual needs of each patient	Typically includes physician, nurses, behavioral health/mental health, chaplains, and other health professionals based on the individual needs of each patient	Typically includes physicians, nurses, behavioral health/mental health, chaplains, home health aides, volunteers, and other health professionals

Figure 10.1 Similarities and Differences between Curative, Palliative, and Hospice Care

Palliative and Hospice Care may extend from home-based outpatient to inpatient care in a large medical center that treats a wide variety of illnesses or conditions. In terms of delivery structure, Palliative Care is typically a team-based consultation service that may be comprised of a number of disciplines and offered across hospitals, outpatient medical clinics, and long-term care facilities (Campion, Kelley, & Morrison, 2015; Dumanovsky et al., 2015). Hospice is a more structured, organized care delivery system and is provided in hospitals, long-term care facilities, and patients' homes. Palliative Care team composition may vary in size and disciplines; Hospice teams are regulated to include physicians, nurses, behavioral health, chaplains, home health aides, and trained volunteers.

The current Palliative and Hospice Care workforce is inadequate due to lack of expertise and the growing population of those with serious illness (Hughes & Smith, 2014; Lupu, 2010). While many of the healthcare competencies required by Palliative or Hospice specialists are the same as those required by a general practitioner (e.g., assessing and managing physical and psychosocial symptoms, strong communication skills, and assistance with patient and family decision-making), some healthcare team members are able to receive additional training and credentialing in Palliative and Hospice specialties. Currently, additional credentialing is available for physicians, nurses, chaplains, and social workers.

Palliative and Hospice Care teams include a variety of professional disciplines (e.g., chaplains, child life specialists, pharmacists, physical and occupational therapists, and behavioral health/mental health specialists), alongside family caregivers and volunteers (who provide personalized support and caregiving). Complexities in billing and reimbursement for services, involving multiple professionals, disease-specific specialties, and multiple care provision sites, require that teams also include billing specialists, care coordinators, and a variety of other administrators (Claxton-Oldfield, 2015; Patterson, Peek, Heinrich, Bischoff, & Scherger, 2002; Peek & Heinrich, 2000). The following list describes typical roles of these care teams' most visible personnel:

Palliative/Hospice physician/medical directors. This director is someone with training in Palliative/Hospice Care and another area of specialty such as oncology or pediatrics. They provide medical directives into the management of patient symptoms and may have additional skills in communication and bioethics.

Personal physicians. It is common for the team to include the patient's physician who has cared for his or her underlying medical condition. This may include an oncologist, neurologist, primary care physician (PCP), or others.

Nurses. Nurses in Palliative and Hospice Care participate in administering medications, monitoring vital signs, and attending to activities of daily living (ADLs). They help guide families through the illness process, including hospitalizations, home care, and end-of-life care. Hospice and Palliative Care nurses are typically registered nurses.

Behavioral health providers (BHPs). The BHP is the behavioral health/mental health provider who helps to assess, diagnose, treat, and connect appropriate referrals specific to psychosocial, financial, discharge planning, and end-of-life psychosocial needs. Helping patients complete advance directives, educating about the psychosocial impact of illness and caregiving, and providing community resources are a few typical tasks.

Chaplains. The chaplain is a staff member who is trained in specific and general pastoral services and assists with spiritual and emotional needs of patients, families, and staff members. He or she helps support patients and families through connections in their religious or spiritual beliefs as they move through the course of the illness.

Child life specialists. Child life specialists provide support to the child, his or her siblings, and other family members while helping them understand a child's illness and the various treatments he or she need to undergo. They will also work with children who are directly involved with adults who are receiving Palliative or Hospice Care to help them understand on a developmentally appropriate level the treatments their family member may receive and the biopsychosocial changes they may be experiencing. Play, dialogue, art, music writing exercises, and other approaches are used to facilitate understanding.

Home health aides (Hospice). Hospice home health aides are trained to provide personal care to patients in their homes and can be hired privately or are

offered through a home health or Hospice organization. They provide support in the following areas: nutrition, physical exercise and stretching, care for incontinence, bathing, grooming, oral hygiene, and communication with family and other medical staff. The home health aide offers education on patient care to family members/support persons so that they will feel comfortable providing day-to-day care to the patient.

Trained volunteers (Hospice). Hospice volunteers are commonly trained and provided by Hospice programs to extend support such as running errands, preparing meals, providing respite to the family members, and providing emotional support and companionship to patients and family members.

Complementary and alternative treatments. In various care settings, alternative treatment modalities such as acupuncture, chiropractic, imagery, hypnosis, and Reiki are being integrated alongside traditional biomedical treatments (Bardia, Barton, Prokop, Bauer, & Moynihan, 2006). In addition, animal-assisted therapy is sometimes used as a complementary intervention (Engelman, 2013).

Fundamentals of Palliative and Hospice Care

Fundamentals of Palliative and Hospice Care that a MedFT should know will differ depending on illness type, care team composition, service delivery format, and location of care. General considerations that supersede these specifics are detailed below:

Common Illnesses in Palliative and Hospice Care

Because Palliative and Hospice Care cover an array of conditions and illnesses, it is imperative that a MedFT understand the overarching typologies of various illnesses and their respective trajectories (Murray, Kendall, Boyd, & Sheikh, 2005; Rolland, 1994). Some of the most common diseases managed with Palliative Care are cancer, congestive heart failure, chronic obstructive pulmonary disease (COPD), Alzheimer's, Parkinson's, amyotrophic lateral sclerosis (ALS), and multiple sclerosis (MS). If an individual with any of these illnesses reaches a point in their progression at which they are determined to have 6 months or less to live, they will be transitioned to Hospice Care. About 60% of Hospice utilization is from individuals who are diagnosed with cancer, but increasingly more diseases are being included to include many that are seen in Palliative Care including stroke, coma, and kidney and liver diseases (Obermeyer et al., 2014).

Medications Used in Palliative and Hospice Care

While diagnoses in Palliative and Hospice Care can vary, being familiar with medications for common symptoms is helpful as many of the conversations among patients, family members, and medical team members are situated around the addition, discontinuation, or dosing of medications. Because of the focus on alleviation of suffering, treatment teams in both Palliative and Hospice Care work toward improving quality of life and easing painful symptoms of illness and treatment such as pain, fatigue, shortness of breath, nausea, loss of appetite, constipation, delirium, dehydration, difficulty sleeping, and malnutrition (Wilkie & Ezenwa, 2012). Becoming acquainted with the common medications used to treat these symptoms and illness-specific symptoms is best practice for MedFTs. A useful beginning resource is the World Health Organization's (WHO) *Essential Medicines in Palliative Care* (2013).

Psychosocial Care

Patients and family members in Palliative and Hospice Care face an increased emotional adjustment to the various symptoms, diagnoses, medications, treatments, uncertain prognoses, reactions of others, etc. To address these significant psychological impacts, the National Consensus Project for Quality Palliative Care (2013) recommends specific criteria for appropriate psychosocial care (see Figure 10.2), and meeting these quality care standards is an essential role of being a MedFT.

- Mental health professionals with specific skills and training in working with patients and families with serious illnesses
- Assessing for psychological needs
- Treating psychiatric diagnoses
- Promoting adjustment to the condition or illness
- Using validated and context-specific assessment tools to provide regular, ongoing assessments of psychosocial reactions to the illness
- Providing patient and family/support person education about the disease or condition and decision making and coping strategies
- Providing treatment of psychiatric diagnoses whether as a consequence of the illness or as a comorbid condition
- Family/support person education
- Regular assessment of treatment efficacy and patient-family preferences
- Appropriate referrals
- Grief and bereavement support

Figure 10.2 Criteria for Appropriate Psychosocial Care

Meaning making. Receiving a life-threatening diagnosis often causes an individual to reflect on the meaning of life and can bring up spiritual, religious, or existential questions (Chochinov et al., 2007; Grant et al., 2004; Harstäde, Andershed, Roxberg, & Brunt, 2013; Seibaek, Lise, & Niels, 2013). As patients and families face these challenges, they work to create personal meanings to help make sense of what is happening (Wright, 2009). These meanings are unique as they reflect each individual's own personal characteristics, experiences, social context, and cultural influences and inform how a patient and family will respond to the illness. To help alleviate patient suffering in this domain, issues of meaning and spirituality are an important consideration and need to be addressed by the entire healthcare team (Gordon & Mitchell, 2004; Richardson, 2014). MedFTs can participate in helping address these issues by conducting spiritual assessments and guiding conversations regarding these issues. Common assessments that can be used include the interview tool called FICA (*F*aith, *I*mportance/Influence of beliefs, *C*ommunity involvement, and *A*ddressing issues in providing care; Puchalski, 2006). Another is a standardized self-assessment called FACIT-Sp (*F*unctional *A*ssessment of *C*hronic *I*llness *T*herapy-*S*piritual Well-Being; Peterman, Fitchett, Brady, Hernandez, & Cella, 2002) that focuses on meaning and faith. The SBI-15R (*S*ystems of *B*elief *I*nventory; Holland et al., 1998) attends to beliefs, practices, and support. Conducting an appropriate assessment, making connections and collaborating with chaplains and other community spiritual advisors, and providing continuing supportive efforts in this realm are recommended as part of a comprehensive care plan (National Quality Forum, 2006; Sulmasy, 2002).

Grief and bereavement. Grief and bereavement are primary themes in Palliative and Hospice Care; these must be attended to with both patients and surviving family members throughout an illness's course (Guldin, Vedsted, Zachariae, Olesen, & Jensen, 2011; Grassi, 2007; Milberg, Olsson, Jakobsson, Olsson, & Friedrichsen, 2008). Sadness from the myriad of losses is important to normalize as patients and family members may begin experiencing symptoms of anticipatory grieving at any point in the illness trajectory (D'Antonio 2014; Simon 2008). While in Palliative Care, death may not be imminent, anticipatory grief (Evans, 1994; Shore, Gelber, Koch, & Sower, 2016) is commonly experienced by both patients and family members as there are many losses that are deserving of grieving along the way. From the loss of a planned future to the day-to-day feelings of loss regarding changes in family structure or functioning, patients and family members may not be sure when it is appropriate to feel sadness. Providing psychoeducation regarding what emotional responses to expect, and normalizing these, can be helpful for both the patient and family members. As patients move closer to death, they may feel increased sadness, withdraw emotionally, and lose interest in connecting with loved ones or medical professionals. It is important to assess and differentiate between these types of behaviors in terms of typical responses and/or those suggesting clinical depression (Irwin et al., 2008; Rayner, Loge, Wasteson, & Higgson, 2009).

When death occurs, it can affect the psychological and physical well-being of loved ones for the duration of their lives (Hudson et al., 2012; Trudeau-Hern & Daneshpour, 2012). The *National Consensus Project for Quality Palliative Care, Third Edition* (2013) provides special considerations for grief and bereavement care. These include appropriate education and skill in this area; ongoing assessment regarding loss and grief in patients and families; initial and developmentally appropriate assessment to identify patients at risk for complicated grief, bereavement, and comorbid complications; intensive support and prompt referrals to appropriate professionals; follow-up bereavement support for a minimum of 12 months after the death of the patient; and culturally appropriate information and support that are sensitive to patient and family preferences. Focusing on end-of-life tensions, conflicts, and forgiveness of past neglects are important areas of family work throughout the illness process, death, and beyond (Kissane & Bloch, 2002).

The Dying Process

Beyond assisting patients and families in the psychosocial-spiritual aspects of the dying process, another fundamental of Palliative and Hospice Care concerns the biological process of dying (Persson, Ostlund, Wennman-Larsen, Wengstrom, & Gustavsson, 2008). And while not all Palliative Care patients are facing imminent death (like those in Hospice Care), their illnesses are serious enough that early death carries a potential likelihood. As a MedFT, it is helpful to have knowledge and experience in the process of dying as there are opportunities to assist patients, family members, and healthcare team members in the alleviation of emotional and psychosocial suffering related to it. Having witnessed the death of a seriously ill individual firsthand may provide perspective and understanding that can aid in helping the patient and family member's experience of death (Aoun, Currow, Hudson, Kristjanson, & Rosenberg, 2005; Hebert, Prigerson, Schulz, & Arnold, 2006; Kwak, Salmon, Acquaviva, Brandt, & Egan, 2007). Volunteering in Palliative or Hospice Care settings can also provide exposure to issues of death and dying, which can help in confronting personal biases, challenging previous experiences, and providing further insight into beliefs about death that are important to be aware of prior to entering these settings. By gaining exposure to these care environments, the MedFT can better learn to provide support in ways that can be both personally and professionally challenging (but also essential).

It is important for MedFTs to become more comfortable in talking about the topic of death and being able to support and explain these occurrences to loved ones. Exposure to death and dying brings with it a multitude of sights and sounds, for example, that most people are not familiar with. These sequences follow typical, but also unique, processes as a person's body begins to shut down organs and prepare for death (Berry & Griffie, 2010; Emanuel, von Gunten, & Ferris, 1999). Specific components of the dying process include changes in breathing (including long pauses between breaths and cycling between fast and slow breathing), decreases

and/or cessation of appetite and thirst, increased restlessness and agitation, withdrawal from communicating, and increased periods of sleep. Patients may report seeing people who have already died in their dreams, through visions, and/or via hallucinations. They may begin talking actively about their deaths. Blood pressure can drop significantly, leading to the hands, arms, feet, and legs feeling cold to the touch and/or bluish in color. These biological processes (in part of in whole) provide signals that death is coming; they can be used to help prepare loved ones.

The process of death can be very draining for family members and friends, even when they are mentally prepared. Family members may need to receive comforting words about their concerns and to be encouraged to speak to the dying loved one even in situations wherein he or she is no longer in consciousness. Families should receive guidance, too, in discussing any rituals, prayers, traditions, and how a person's body is to be handled after the death. Advanced discussions about decision-making and goals of care can help families prepare for these experiences; they should be offered before death is imminent.

Decision-Making and Goals of Care

There are many issues to consider when engaged in decision-making and goals of care in Palliative and Hospice settings. For instance, patients, family members, and healthcare professionals may hold differing opinions regarding treatment goals (Bakitas, Kryworuchko, Matlock, & Volandes, 2011; Blank, Graves, Sepucha, & Llewellyn-Thomas, 2006; Erlen, 2005). Physicians may encourage a family to continue an aggressive course of treatment; patients and family members may be more concerned about the pain and suffering associated with such treatment. Alternatively, physicians may hold little hope for cure and encourage a transition to Hospice Care, whereas families may wish to exhaust every possible treatment option. These differing priorities can lead to misunderstandings and difficulties in making treatment decisions. MedFTs can be one of the multidisciplinary professionals who participate in family team meetings to help clarify, reframe, and normalize the myriad of ways in which those involved make decisions (Hudson, Quinn, O'Hanlon, & Aranda, 2008). Many of the terms used in these meetings are outlined in this chapter's glossary (e.g., advanced care planning, advance directive, living will, and death with dignity).

Cultural considerations in decision-making. While illness and death are universal human experiences, personal meanings and preferences around illness and dying are very much a cultural experience (Ho et al., 2013). Attending to issues of culture and diversity is a critical component of the decision-making considerations in Palliative and Hospice Care (López-Sierra & Rodríguez-Sánchez, 2015; Thompson, Bugbee, Meriac, & Harris, 2013). Culture can be understood to include ethnicity, gender, social class, family beliefs, religion, worldview, and other influences (Hardy & Laszloffy, 1995). All of these dimensions contribute to a person's cultural identity and can influence patients' and family members' behaviors, beliefs, and values in relation to illness and decision-making.

Culture can influence healthcare decision-making, preferences for communication, and specific processes of handling end of life (Galanti, 2015). While most patients want to be told when their illness becomes life-threatening (Lowey, Norton, Quinn, & Quill, 2013), some cultures prefer that patients not be included in these conversations as it can be believed to only add suffering or, perhaps, even hasten death. For example, individuals from the Hmong culture often believe that only God knows when someone will die, so attempts to warn of an impending death can be interpreted as meaning that medical team members are planning to kill the patient (Fadiman, 1997). Another consideration that often comes into play is religious beliefs, as some dictate which medical interventions are allowed and which are not. For instance, Jehovah's Witnesses do not approve of blood transfusions; they consider this an act that would be disobedient and disrespectful of God. Additionally, individuals from different regions and races have different preferences regarding end-of-life choices about drug treatments, utilizing (or not) assisted breathing devices, and/or where they die (Barnato, Anthony, Skinner, Gallagher, & Fisher, 2007). These differences in preferences for care can be very difficult for the healthcare team, as some decisions may feel unethical from their own cultural standpoint (especially when said standpoint is informed by Western values of patient autonomy in decision-making and Western medicine inclination to pursue all possible treatments). In these sensitive scenarios, it is helpful to have someone who can act as a "cultural broker" to help both sides understand the values and preferences more fully within a broader social and cultural context (Renzaho, Romios, Crock, & Sonderlund, 2013).

Working with Children

Another fundamental to understand relates to differences between adult and pediatric populations in Palliative and Hospice settings (Knapp, 2009; Meier & Beresford, 2007). Caring for children with serious illnesses requires unique skills and programs (Himelstein, Hilden, Boldt, & Weissman, 2004; NHPCO, 2015) and an understanding of children's physical, emotional, cognitive, and social development (Rushton, 2004). For example, children may lack the cognitive or emotional understanding of their condition and its consequences. Adolescents may be able understand these issues, but they are not legally able to make decisions regarding their own care. This presents parents with the additional role of healthcare advocate with the legal responsibility for healthcare decision-making (complicated by assessing the youth's ability—or not—to provide consent for said treatment). While pediatric Palliative Care is growing (Feudtner et al., 2013), unfortunately many local communities do not have the professional services needed to assess and treat these illnesses. This often results in families needing to travel long distances for treatment—separating them from essential social support and often disrupting parental employment and insurance coverage—which strains both finances and relationships (Williams-Reade et al., 2015).

Self of the Therapist and Compassion Fatigue Prevention

It is not uncommon for MedFTs working with serious illnesses to witness repeated long-term suffering and death. This necessitates vigilant attention to self-care practices, self-of-the-therapist reflection, and compassion fatigue prevention. Healthcare professionals must learn to help family members cope with grief and loss while at the same time face their own feelings about it (Edwards & Patterson, 2006; Kumar, D'souza, & Sisodia, 2013; Rolland, 1994). One of the professional side effects of working in this specialty area is the development of a deep awareness of mortality, grief, and loss in our own lives (Meier, Back, & Morrison, 2001). Put simply: because the potential for significant levels of stress is very high while working with this patient population, self-care should be tantamount (Mendenhall & Trudeau-Hern, 2013).

A potential consequence of avoiding self-care and/or not addressing self-of-the-therapist issues is compassion fatigue. Physical indicators of compassion fatigue include a chronic sense of exhaustion, insomnia, headaches, digestion issues, and other physical symptoms (Figley, 2002). Psychological indicators of compassion fatigue include feeling overwhelmed about the workload, case intensity, and case content and a slow progressive detachment from relational interactions. Over time, there is a risk of losing baseline compassion, along with declines in empathy and warmth toward patients and families (Mendenhall, 2006). There will be times that illness, loss, and death are a part of your personal life, and this can cause your professional work in Palliative and Hospice Care to feel additionally burdensome and isolating (Becvar, 2003). Recognizing and processing these feelings can be beneficial to both MedFTs and patients (Negash & Sahin, 2011; Sanchez-Reilly et al., 2013).

Palliative and Hospice Care Across the MedFT Healthcare Continuum

Patients and family members in Palliative and Hospice Care are in need of comprehensive services that can attend to their unique biopsychosocial-spiritual needs. The MedFT framework serves useful while guiding healthcare delivery from a biopsychosocial-spiritual, relational, and systemic lens. Providers delivering care from this lens possess unique skills which can significantly alleviate symptoms of suffering and improve overall coping mechanisms for patients and family members. Leading with a relational lens, MedFTs can help to foster improved communication with healthcare team members. As MedFT continues to develop as a sibling field to Marriage and Family Therapy (MFT), so will the depth of skills and involvement in directing tertiary care in core competencies that will further become guide research, policy, and practice. Tables 10.1 and 10.2 highlight the specific skills for healthcare professionals as they move across Hodgson, Lamson, Mendenhall, and Tyndall's (Hodgson et al., 2014) MedFT Healthcare Continuum.

Table 10.1 MedFTs in Palliative and Hospice Care: Basic Knowledge and Skills

MedFT Healthcare Continuum Level	Level 1	Level 2	Level 3
Knowledge	General understanding of chronic illness typology, disease trajectory, and the interplays between Palliative Care and Hospice Care. Recognition of the biopsychosocial-spiritual connection to a patient's overall health outcomes. Familiarity with typical psychosocial stressors associated with chronic illness, grief, and bereavement.	Knowledge of PCP, Palliative, and Hospice Care professionals within care settings. Aware of the differences and similarities between Palliative Care and Hospice treatment teams (and the types of illnesses most commonly present in each). Working relationship with mental health referral sources, support groups, and community resources. Ability to initiate and activate change within the healthcare system to create the inclusion of caregivers' health and well-being. Attends additional training and/or utilizes research-informed literature based on grief and loss in clinical practice.	Familiarity of illness genograms and BPSS interviews when working with individuals, couples, and families. Comfort in utilizing these in clinical practice (and in teaching these skills to healthcare team members).
Skills	Can deliver psychoeducation to healthcare team members, patients, and family members. Aware of and can utilize mental health screeners already in place at a care setting. Provides and maintains connections to referral sources. Utilizes strength-based models of practice and provides psychoeducation to patient, family, and healthcare professionals.	Encourages healthcare team members to screen for mental health issues. Conducts or coordinates support groups for caregivers and/or provides psychosocial resources for them. Actively participates in supervision that addresses self-care.	Actively incorporates family members into treatment plans and interventions. Regularly screens for common mental health conditions using instruments that include (but not limited to) the PHQ-2, PHQ-4, PHQ-9, and GAD-7.

Table 10.2 MedFTs in Palliative and Hospice Care: Advanced Knowledge and Skills

MedFT Healthcare Continuum Level	Level 4	Level 5
Knowledge	Utilizes advocacy practices for family members' preferences and values during decision-making times, and highlights systemic impacts of treatment throughout the family system. Understands and addresses illness meanings, tends to issues of blame and defenses, and facilitates processing losses associated with illness.	Works regularly with families from all diagnoses and phases along the continuum of illness trajectories as a fully integrated member of the healthcare team. Facilitates exploration, case consultation, and/or Balint groups to help attend to existential issues related to hope and the meaning of life and death with patients, families, medical team members, and oneself.
Skills	Adept in delivering short- and long-term therapy requiring a comprehensive team, keeps comprehensive progress notes, and provides updates at team meetings. Develops and advances self-care plans that recognize the risk of buildups of unprocessed feelings and responses to the depth of loss being dealt with. Administers screening assessments such as FICA, FACIT-Sp, and the SBI-15R.	Proficient in training and supervising interns, participates in administrative roles, and provides psychosocial education to hospital staff through formal and informal presentations. Actively participates in treatment team meetings, ethics committees, community volunteer organizations, support groups. Self-care plan moves beyond existential issues to balancing of time commitments and personal/professional boundaries.

MedFTs operating at *Levels 1 and 2* may not be part of an integrated behavioral healthcare team, but may see patients who have reached a non-critical status with their illness. They could see a family member of a patient who has reached non-critical status, too, or a loved one of somebody who has died from a serious illness. If a MedFT is in a practice in which they occasionally see patients or family members from Palliative or Hospice Care, it is important to collaborate with the primary physician and behavioral health providers who may be following this patient. This MedFT should possess a general understanding of chronic illness typology, disease trajectory, and the interplay between Palliative Care and Hospice Care. There should also be a recognition of the BPSS connection to a patient's overall health outcomes and typical psychosocial stressors. At these levels, care likely is not delivered past the individual patient level, but there should be a deeper understanding about the importance of the supportive role(s) that family and caregivers play. These MedFTs are also able to screen for symptoms of depression and anxiety, make appropriate referrals, and communicate these symptoms and/or plans to family members, caregivers, and the larger treatment team. For example, a MedFT working with Megan

(in our clinical vignette) would be able to monitor and observe changes in her mood, recognizing that her levels of exhaustion are connected with the aggressive postoperative chemotherapy and radiation that she is undergoing. The MedFT would be able to recognize when changes could be potential indicators for depression and then relay that information to Megan's treatment team. Psychoeducation around typical individual, couple, and family emotional responses to chronic illness and prolonged treatment is important at these initial levels.

A clinician working in *Level 3* is likely to be co-located within a tertiary setting and has theoretical foundations of care rooted in family systems theory. He or she will go beyond holding the ideologies of the BPSS framework, put these into practice within their respective care teams. Clinicians at this level advocate for team-based care (e.g., consistent team meetings to discuss illness continuums with the medical team members, family members, and the patient). Skills extant at this level not only facilitate working with people in the same room; they help to create shared treatment goals by taking into account the dynamic interplays between medical, familial, and relational systems. For example, a MedFT would be able to facilitate a family meeting with both medical teams to discuss treatment plans and patient/family wishes to open the door for a deeper conversation regarding thoughts and feelings around treatment preferences and transitions of care. A MedFT would have the skills to empathize, normalize, and help process the anger, fear, confusion, and anxiety Megan and Joe are having regarding the news her treatment had been unsuccessful and Palliative Care was being suggested.

A MedFT functioning at *Level 4* would be advancing a higher degree of collaboration. MedFTs at this level consistently bring a family-centered approach to treatment team decisions, keeping family members' preferences and values in mind when decisions are made, and reminding treatment teams to think about the systemic impacts of treatment throughout the family system. Delivering short- and long-term therapy would be prudent and would require a comprehensive treatment plan. At this level, MedFTs are adept in care dynamics between Palliative and Hospice Care—recognizing that not all Palliative Care patients will transition to Hospice and that most all patients in Hospice will have had touches with a Palliative Care team. In the case of Megan, her treatment ended abruptly as the risks outweighed the benefits. A MedFT would be able to help the family process many of the existential and meaning-making questions that would arise—along with unspoken thoughts around death and dying. The MedFT will seek to provide emotional processing for healthcare team members as they deal with the vicarious trauma and grief associated with working with Megan's family (and other families like them). This can put MedFTs in a difficult position, as there may be no one to help process their own grief as they regarded to be a primary support person for other team members. MedFTs' self-care plans should be in place and include identifying colleagues or outside support persons who can regularly engage in discussions about the emotional aspect of this work.

MedFTs at *Level 5* regularly work with families from all diagnoses and phases along the continuum of illness trajectories, and they do this as fully integrated members of the Palliative and/or Hospice Care team. They may be sought out for their

input at various treatment team meetings, ethics committees, community volunteer organizations, and support groups. MedFTs train and supervise interns and may participate in administrative and educational roles.

MedFTs at *Level 5* also provide psychosocial training to hospital staff and community partners through formal and informal presentations. They may still be actively involved in care, but may also be situated in clinical research and the operational aspects of care. For instance, a MedFT working within the tertiary care setting would be developing educational programming for providers and staff, attending and contributing to research and process improvement for clinical practices, as well as promoting health and well-being on a community level. In Megan's case, a MedFT at this level would likely be the behavioral health coordinator or director of a division of behavioral health services that oversees the coordination and supervision of providers meeting with the family. Self-care plans for these MedFTs now expand to include boundaries regarding how often they will manage time commitments to the myriad of professional commitments that they maintain and endeavors in which they take part.

Research-Informed Practices

Inclusion of mental health professionals on teams working with serious and terminal illness is not a new concept; chaplains and behavioral health providers have been by the bedsides of dying patients since the inception of Hospice Care (Doka, 1993). As MedFTs rapidly integrate into healthcare settings, the possibility of working with Palliative and Hospice patients is almost a certainty. Gaining evidence-based competencies in working with patients and families during these times is a suggested requirement of systemically trained therapists who are employed in healthcare settings (Gamino & Ritter, 2010). However, barriers to evidence-based practices in these specialties are in early stages of growth due to the sensitive nature and vulnerability of these patient populations. Large randomized control trials are not conducive, nor feasible, due to the unpredictability of illness and the dying processes of each disease. Adapting evidence-based or research-informed interventions within these fields is a first step in growing the body of Palliative and Hospice Care literature regarding this topic.

Individual Approaches

The primary focus of research done in Palliative and Hospice Care is targeted toward brief interventions that are psychoeducational and supportive in nature. Psychotherapeutic approaches to end-of-life and chronic illness care include person-centered techniques concentrating on meaning making and existentialism as an important resource for coping. From these come modalities such as

meaning-centered psychotherapy (Breitbart, Gibson, Poppito, & Berg, 2004), existential psychotherapy (Chochinov, 2006), dignity therapy (Martínez et al., 2016), art therapy (Pratt & Wood, 2015), music and movement therapy (Gallagher, Lagman, Walsh, Davis, & LeGrand, 2006), and individual psychotherapy interventions such as CALM (Managing *C*ancer *a*nd *L*iving *M*eaningfully; Lo et al., 2014).

Along with these aforementioned approaches, therapeutic techniques with Palliative and Hospice Care populations attempt to address multifaceted concepts of grief and loss. Loss is a thread that runs through all illness experiences. Because it is not a task to complete, process-oriented models of care fit well into therapeutic care delivery structures advanced in Palliative and Hospice Care. MedFTs in these settings are encouraged to learn therapeutic models that teach skills related to meaning making (Wynne, Shields, & Sirkin, 1992), narrative framework (White & Epston, 1990; Williams-Reade, Freitas, & Lawson, 2014), illness beliefs (Wright, 2009), non-illness identity (Gonzalez, Steinglass, & Reiss, 1989), storytelling (Kleinman, 2009); legacy (Piercy & Chapman, 2001), agency and communion (McDaniel, Doherty, & Hepworth, 2014; McDaniel, Hepworth, & Doherty, 1992), and individual psychoeducation on distress and coping (Manne, Babb, Pinover, Horwitz, & Ebbert, 2004). McDaniel et al. (2014) provide a thorough and comprehensive overview of these specific modalities in their chapter entitled *Caregiving, End-of-life Care, and Loss*.

Family Approaches

When a patient is diagnosed with a serious illness, it is a stressful psychological event for themselves and, in some cases even more so, their family members (Edwards & Clarke, 2004; Mitschke, 2008; Rolland, 2005). Upon diagnosis, families are expected to assimilate an overwhelming amount of information; they are asked to rapidly make informed decisions about care options, negotiate ever-hanging healthcare service and insurance systems, and come to terms with the impact(s) of a seriously ill family member/loved one of themselves and others. For a family, illness brings with it new stressors—while at the same time it can exacerbate old and/or already existing stressors and difficulties (Kristjanson & Aoun, 2004; Schmitt, Santalahti, & Saarelainen, 2008). Normalization of family members' responses to these challenges (e.g., guilt, sadness, fear) is often the first step in MedFT care (McDaniel et al., 2014). Brief solution-focused therapy for couples aimed to elicit social support and feelings of equity (Kuijer, Bunk, Jong, Ybema, & Sanderman, 2004); couples psychoeducation to minimize negative emotional outcomes (Baucom et al., 2009); emotionally focused couples therapy to address attachment, empathy, and marital satisfaction (McLean, Walton, Rodin, Esplen, & Jones, 2013); and family focused grief models of care such as family focused grief therapy are used more readily in this population (Kissane et al., 2006; Kissane et al., 2003). Northouse, Katapodi, Song, Zhang, & Mood (2010) published a large meta-analysis aimed to examine randomized controlled trials (RCTs) that have been conducted regarding

family caregivers of cancer patients; findings showed that interventions fell under three types: (a) psychoeducation, (b) skills training, and (c) therapeutic counseling. Interventions were aimed to reduce caregiver burden, improve patient and caregiver coping, increase self-efficacy, and improve quality of life. The need for further research regarding the impacts that cancer has on dyadic- and family- level functioning is ever present. This burgeoning scholarship—while still limited—is similarly supported as it relates to couples' work with dyads coping with cancer (Traa, De Vries, Bodenmann, & Den Oudsten, 2015).

Community Approaches

Community volunteers and family caregivers have been essential in the Palliative Care and Hospice Care movement. Recognition of psychosocial-spiritual aspects of care is taught to all lay persons who volunteer within these tertiary care settings. Support groups and peer support have been utilized as an important intervention for patients and families with the aim of alleviating distress. Many of these support groups are community-based and rely heavily on volunteerism (Hudson, Aranda, & McMurray, 2002; Ussher, Kirsten, Butow, & Sandoval, 2006; Weis, 2003). Whether professionally trained or skilled volunteers, typical concerns that should be addressed for patients and families include contexts such as culture, work, school, and housing—and how these contexts may impact each other and overall illness experiences (Evans & Ume, 2012; Johnson, 2013). In addition, it is important to remember that patients who have a serious illness often experience changes in social functioning. For children, participation at school or in extracurricular activities may be compromised. For adults, it may be their church community or work. Attending to these relationships can be an important aspect of care (Prince-Paul, 2008). All of these efforts, too, are advanced alongside working, raising children, caring for aging parents, and grieving the many day-to-day losses brought on by serious illness. Given the significant burden associated with caring for patients with serious illness, standards and policies for Palliative and Hospice Care provision—which focus on addressing psychosocial needs of family caregivers—have been established (Hudson & Payne, 2011). Embracing the energies and support from community members—as outlined here—is strongly supported and encouraged.

Conclusion

The number (and needs) of patients and families connected to Palliative and Hospice Care is growing. As health systems adopt paradigm shifts toward embracing patient- and family-centered philosophies of care, clinicians trained in MedFT will be at the forefront. With their systemic BPSS training, MedFTs have the knowledge and skills to participate as clinicians, researchers, educators, and policy makers. Along

the way, the roles that they play will go beyond demonstrating competency in the abovementioned fundamentals of care. MedFTs are actively assisting in the development and testing of new systemic interventions that bring more relational understandings of Palliative and Hospice work. They are evaluating, refining, and advocating for evidence-based practices that ease patients' and family suffering, and they are training future generations of providers to carry forward this mission.

Reflection Questions

1. Look up the state-by-state report card on Palliative Care by the *Center to Advance Palliative Care* and the *National Palliative Care Research Center* (www.capc.org/reportcard/) to find out about your state's data. See how it compares to other states. In what ways could care in your state be improved?
2. Engage in the CDC's online course on advance care planning module called *Advance Care Planning: An Introduction for Public Health and Aging Services Professionals* (http://www.cdc.gov/aging/advancecareplanning/care-planning-course.htm). Reflect on the role you could play in your setting regarding advance care planning.
3. Create a medical genogram of your own family and then for a family you are already working with. A good clinical resource to read prior to doing this (to have available during the activity) is McGoldrick and Gerson's (1985) *Genograms in Family Assessment*. Consider such questions as: (a) How does observing death from illness in your family make you suited as a match for this family? (b) What understanding do you have about illness and loss that another clinician may not have? (c) As you were experiencing this in your own family, what do you wish would have been different? (d) What are patterns of coping have you witnessed that you would like to keep and build upon? (e) What are patterns of coping that you have witnessed that you would like to release? (f) How can you use your personal experiences to intervene with this family?
4. Beginning this work with an appreciation for its intensity means we need to be proactive about self-care and carving out times for self-reflection. Create a list of your best self-care activities, and look to see how often you are doing them and how realistically you can increase them. Then create another list of how you will know when you begin to feel compassion fatigue or burnout, and write down your indicators. Have a close friend or loved one fill out the same list for you. Create care plans for yourself based on your indicators, so you can get to self-care practices faster and more efficiently.

Glossary of Important Terms in Palliative and Hospice Care

Advanced care planning A process of communication between individuals and their healthcare agents to express wishes and preferences regarding care in the event they are unable to make their own decisions or speak for themselves

(Waldrop & Meeker, 2012). MedFTs can help patients and family members engage in advance care planning that can help prevent unnecessary suffering and improve quality of life toward the end of life and can aid caregivers in better understanding what the patient prefers (Houben, Spruit, Groenen, Wouters, & Janssen, 2014). Several documents and resources scan assist in this process and are listed at the end of this chapter. The decisions made in advanced care planning are reflected in an *advance directive*.

Advance directive A legal document that states your preferences regarding healthcare decisions in the event you are unable to speak for yourself. There are three main categories of advanced directives: "power of attorney," "healthcare proxy," and "living will."

Allow natural death (AND) A more recent terminology that can replace the DNR order. While a DNR/DNAR relates to CPR, an AND instructs that only comfort measures be taken to manage symptoms without interfering with the natural dying process.

Death with dignity A term commonly used to describe a physician-assisted death, physician-assisted dying, aid-in-dying, or medical aid-in-dying. It includes a process that allows for certain terminally ill patients (adults) to legally consult and request a lethal dose of medication from their primary care providers. Patients receive said medication from a pharmacist and then take it themselves (or have a family member administer it) in order to end life in a peaceful and dignified manner. This option is only available in certain areas (see Death with Dignity, 2016).

Do not resuscitate (DNR)/Do not allow resuscitation (DNAR) A medical order written by a primary care provider (Breault, 2011). It instructs healthcare providers not to do cardiopulmonary resuscitation (CPR) if a patient stops breathing or if his or her heart stops beating. The primary care provider writes the order only after talking about it with the patient (if possible), the proxy, or with the patient's family.

Healthcare proxy Designates an individual to make medical decisions on a patient's behalf if they are unable.

Living will Documents a patient's desired wishes about medical treatment at the end of life in the event they are unable to communicate. It can also be called a "directive," "healthcare declaration," or "medical directive."

Physician order for life-sustaining treatment (POLST) A more recent form developed to improve communication about goals of care, quality of life, diagnosis, prognosis, and treatment options between seriously ill or frail patients and healthcare professionals about wishes pertaining to life-sustaining treatments. (Polst Organization, 2016).

Power of attorney Authorizes an individual to make decisions on a patient's behalf in the event they become disabled or incapacitated. A medical power of attorney authorizes an individual to make medical decisions for a patient in the event he or she becomes unconscious or mentally incapable of decision-making.

Additional Resources

Electronic Resources

Advance Care Planning Conversation Guide. http://coalitionccc.org/tools-resources/advance-care-planning-resources/
Aging with Dignity (Five Wishes). http://www.agingwithdignity.org
American Academy of Pediatrics: Palliative Care for Children. pediatrics.aappublications.org/content/106/2/351.full
Caring Conversations. https://www.practicalbioethics.org/resources/caring-conversations
Consumer's Tool Kit for Health Care Advance Planning. http://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumer_s_toolkit_for_health_care_advance_planning.html
GetPalliativecare.org. http://www.getPalliativecare.org
NHPCO Children's Project on Palliative/Hospice Services (ChiPPS). http://www.nhpco.org/resources/pediatric-Hospice-and-Palliative-care
Pediatric Supportive Care for Children with Cancer. http://www.cancer.gov/cancertopics/pdq/supportivecare/pediatric/healthprofessional

Organizations/Associations

Association for Death Education and Counseling. http://www.adec.org/adec/default.aspx
Center to Advance Palliative Care's (CAPC) Pediatric Palliative Care. http://www.capc.org/Palliative-care-across-the-continuum/pediatric-Palliative-care
Children's Hospice and Palliative Care Coalition. www.chpcc.org
Hospice Action Network. http://Hospiceactionnetwork.org/
Hospice Association of America. www.Hospice-america.org/
Hospice Foundation of America. https://Hospicefoundation.org/End-of-Life-Support-and-Resources/Coping-with-Terminal-Illness/Hospice-Services
Initiative for Pediatric Palliative Care (IPPC). ippcweb.org
National Hospice and Palliative Care Organization. http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1
National Hospice and Palliative Care Organization 2015. http://www.nhpco.org/sites/default/files/public/Statistics_Research/2015_Facts_Figures.pdf

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