



# Introduction to End-of-Life Care for Mental Health Professionals

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The needs of individuals with life-limiting or terminal illness and those caring for them are well documented. However, meeting these needs can be challenging, particularly in the absence of a well-established evidence base about how best to help. In this chapter, we offer guidance in working with individuals at the end of life and the family, friends, and professionals caring for them. We first define palliative and hospice approaches to care and discuss barriers to this care. Then we describe the needs of individuals with life-threatening and terminal illness and their families. We end the chapter with some general intervention strategies for meeting these needs.

## BACKGROUND

Many older adults live years with progressive and often comorbid, debilitating illnesses. For example, one study of Medicare beneficiaries found that 62% of those 65 and older have two or more chronic conditions (Anderson & Horvath, 2004). Comorbidities can result in faster disease progression, problems diagnosing and managing new conditions, and complexities of care coordination across settings and providers. Individuals with advanced and terminal illness often face additional challenges. Preferences concerning life-sustaining treatments often are not discussed adequately, documented or adhered to, and existential and spiritual concerns may largely be ignored.

Individuals may endure multiple, prolonged hospitalizations, unnecessary interventions (e.g., intubation, ventilation), unrelieved physical and psychological symptoms (e.g., pain, fatigue, appetite and sleep problems, breathing difficulties, nausea/vomiting, constipation, delirium, depression, or anxiety), interpersonal stress, economic burdens and unmet practical needs (Conill et al., 1997; Emanuel, Fairclough, Slursman, & Emanuel, 2000; Field & Cassel, 1997; Fins et al., 1999; Foley, 2000; Nelson et al., 2001; SUPPORT Principal Investigators, 1995).

Palliative care is an approach to care that improves the quality of life of medically ill persons and their families through relief of suffering, pain and symptom management, psychosocial support, optimization of functional capacity, and respect for autonomy and the appropriate role of family and legal surrogates. Palliative care may be provided at any time during an individual's illness, without reference to a specified life expectancy, and can be provided in concert with curative approaches. Hospice usually refers to care provided during the last six months of life and often is linked to the specific programs offered under the Medicare Hospice Benefit. Individuals receiving hospice typically must agree to forego aggressive or curative treatments, though some interventions may be performed to maximize quality of life, such as blood transfusions to maintain energy levels in individuals with leukemia. Specific goals of hospice include self-determined life closure, safe and comfortable dying, and effective grieving (National Hospice Organization, Standards and Accreditation Committee, 1997). Both palliative care and hospice emphasize the needs of medically ill individuals and their families (National Hospice Organization, Standards and Accreditation Committee, 1997). Conditions for which hospice and palliative care are appropriate include cancer, HIV/AIDS, congestive heart failure, chronic obstructive pulmonary disease, organ disease, and dementia and other progressive neurological diseases.

Although hospice and palliative care is associated with better patient and family outcomes when compared to usual care (e.g., Cassarett et al., 2008), unfortunately, it is underutilized. For example, one study found that only one-fifth of Medicare-eligible individuals with terminal illness eligible for hospice services received services (Jennings, Ryndes, D'Onofrio, & Baily, 2003). In addition, many individuals who receive hospice services are referred very late in the disease course and a proportion of terminally ill persons and families believe that it is "too late" to benefit fully

(e.g., Schockett, Teno, Miller, & Stuart, 2005). Potential explanations for this underutilization include attitudinal and emotional barriers; socio-cultural factors affecting communication and decision-making patterns; disparities in access to, and receipt of care; and limited or misinformation about diagnosis and prognosis (Brickner, Scannell, Marquet, & Ackerson, 2004; DesHarnais, Carter, Hennessy, Kurent, & Carter, 2007; Feeg & Elebiary, 2005; Hallenbeck, 2003; Hancock et al., 2007; Rodriguez, Barnato, & Arnold, 2007; Spathis & Booth, 2008; Stuart, 2007).

## CHALLENGES IN PROVIDING HOSPICE AND PALLIATIVE CARE

*Attitudinal and emotional barriers.* Providers' beliefs and values may impinge on appropriate referral to, and receipt of, palliative care or hospice services. Hospice and palliative care may symbolize evidence of their patients' deteriorating courses and thus, the providers' own perceived failures at cure. Providers may be concerned about upsetting patients by discussing palliative or hospice care or worried about destroying their hopes or being viewed as "giving up" on them (Brickner et al., 2004; Feeg & Elebiary, 2005; Hallenbeck, 2003; Rodriguez et al., 2007; Stuart, 2007). As a result, providers may avoid talking about goals of care or end-of-life wishes. For example, in one study of primary care physicians of individuals with advanced AIDS, when asked to indicate why they sometimes do not discuss end-of-life care even when appropriate, many physicians cited fearing that such a discussion would destroy these individuals' hope (Curtis, Patrick, Caldwell, & Collier, 2000). In fact, this reason was the second most cited behind "too limited a time during patient consultations to broach such a sensitive topic." The challenge for providers and the medically ill persons they serve is to expand and redefine their views on hope (Gum & Snyder, 2002). Living with an incurable disease does not mean living without hope; it just means redefining it (Parker-Oliver, 2002; Sullivan, 2003). Although the goal of life prolongation may remain fundamental for some terminally ill persons, it can be supplemented with goals for comfort, dignity, legacy-building, intimacy, and continued involvement in decision making (Parker-Oliver, 2002; Sullivan, 2003).

Although physicians may avoid end-of-life conversations for fear of distressing patients, many individuals report feeling better able to make informed decisions when they have all the relevant information available and, as

a result, feel less distressed (e.g., Butow, Dowsett, Hagerty, & Tattersall, 2002). Good advance care planning is associated with increased patient satisfaction, sense of control and, reduced fears, anxiety, and emotional distress (Curtis, Engelberg, Nielsen, Au, & Patrick, 2004; Heaven & Maguire, 1997; Smucker et al., 1993; Tierney et al., 2001). In addition, family members report being more satisfied with care when they are regularly informed of their loved ones' conditions. Frank discussions do not require forcing individuals to admit to their impending death or confronting them with dying; however, confronting the medically ill person may be needed if apparent "denial" gets in the way of attending to issues that are important to the person. These discussions can be framed in terms of hoping for the best while preparing for the worst (Back, Arnold, & Quill, 2003) and focusing on that which is important to individuals with advanced, life-limiting, or terminal illness and their families in whatever time remains. Mental health providers often are integral to these conversations and to facilitating coping and adjustment.

*Sociocultural factors.* When interfacing with the medical system, individuals with advanced, life-limiting, or terminal illness and their families may be dependent on professionals of different cultural backgrounds, not to mention the often foreign culture of the medical system itself, the beliefs, practices, and communication styles of which can differ substantially from individuals' personal and cultural values. Western Medicine emphasizes individual autonomy, direct communication, preferences for disclosure and verbal expression of feelings and needs. It emphasizes surrogate decision making and substitute judgment (e.g., carrying out patients' wishes) in contrast to family-centered care that focuses on who in the family is making the decisions and the way in which decisions may be influenced by role obligations or relationships. Thus, the approach of Western Medicine may be inconsistent with many individuals' preferences for care (Blevins & Papadatou, 2006; Danis & Lavizzo-Mourey, 2003; Hallenbeck, Goldstein, & Mebane, 1996) or may even be harmful (Carrese & Rhodes, 1995). For example, some families prefer that the medically ill individuals not be told of their diagnosis, which can create tensions among family and health-care professionals particularly if it is unclear if this preference is shared by the ill person (e.g., the patient may give mixed messages about what he or she wants to know). Many medically ill individuals defer to a family member and identify that member as the decision maker, even when the patient has decision-making capacity.

When families are caught between competing values, they may struggle with goals of care (Blackhall et al., 1999; Blackhall, Murphy, Frank, Michel, & Azen, 1995). For example, a son acting as a surrogate decision maker using substitute judgment may recognize that his father would not want to be maintained on a ventilator but filial piety requires him not to withdraw treatment because a “good son” does not let his parent die. This tension may explain some of the cultural differences in preferences for life-prolonging interventions (Klessig, 1992). Providers will want to consider how to balance frank discussions about diagnoses and treatment options with respect for cultural and personal beliefs and values. These values often are richly apparent in how individuals with advanced or terminal illness and families make sense of their illness and cope with it.

Medically ill persons, along with the family members and staff who care for them, can maintain divergent beliefs about the patient’s illness, how the patient became ill (e.g., poor lifestyle factors, retribution or payback for past misdeeds, just one’s time) and the consequences of the illness. Explanations, or explanatory models of illness, can be as varied as the number of people involved in the care and sometimes these explanatory models can lead to misunderstanding and conflict (Kleinman, 1978). Elucidating and sharing these perspectives and beliefs can promote mutual understanding or at least, communicate respect and a desire to understand all participants’ perspectives (Kleinman, 1988; Kleinman, Eisenberg, & Good, 1978). Key domains that can help providers elucidate their own and their patients’ and families’ explanatory models of illness and potential areas of conflict include: (a) beliefs about the illness, underlying causes, course, and primary problems; (b) views on treatment, including appropriate options, as well as hopes and fears; and (c) ways in which providers can be helpful and who should be involved in the care and decision making (Kleinman, 1988; Kleinman et al., 1978).

Part of exploring explanatory models is being transparent about one’s intention to understand and learn about the experience of individuals with advanced or terminal illness (Hallenbeck et al., 1996). Individuals’ previous experiences with illness, dying, death, and loss can influence their reaction to their current situation and approach to care. For example, if they watched someone close to them die in uncontrolled pain, they may doubt providers’ reassurances about good symptom management. Individuals’ reactions also may be influenced by discriminatory health-care practices and behaviors (Crawley, 2002). Providers are encouraged to ask difficult questions such as

“It is important to me to know if you have ever felt unfairly treated by me or anyone else involved in your care” (e.g., Crawley, Marshall, Lo, & Koenig, 2002). Furthermore, it is important to listen to what medically ill individuals and their families perceive as being a competent provider. Competence may not be defined only through knowledge and skills but through interpersonal relatedness—someone who takes the time to meet with, and get to know, all involved family members.

*Health-care disparities.* People of color are more likely than Whites to experience social and economic disparities, resulting in unequal or poor access to, and utilization of, medical care (Smedley, Stith, & Nelson, 2003). Hospice and palliative care services are no exception (Krakauer et al., 2002). Unequal access to, and receipt of, care may be compounded further by ineffectual outreach, poor care coordination among treatment teams and providers, poor access to prescriptions for narcotics, or simply lack of information or familiarity with these services, both on behalf of individuals with advanced disease and providers.

*Limited or misinformation.* Another potential barrier to good hospice and palliative care is lack of knowledge. Physicians often lack knowledge regarding patient preferences for pain control, place of death, or financial or religious factors that influence care preferences (DesHarnais et al., 2007; Hancock et al., 2007). Providers also may lack basic information about hospice and palliative care. For example, in one study of physicians, 84% were unable to identify appropriate hospice diagnoses (Brickner et al., 2004). Part of the difficulty in identifying appropriate referrals to hospice may be related to difficulty with prognostication, particularly when the disease trajectory is uncertain, as is the case for noncancer diagnoses such as chronic obstructive pulmonary disease (COPD) and heart failure (HF) (Curtis, 2008; Spathis & Booth, 2008; Stuart, 2007). See Chapter 2, “Trajectories of Chronic Illnesses,” (Gabriel) for a more detailed discussion of disease trajectories and issues of prognostication. Prognostic uncertainty not only interferes with appropriate referral, but leaves individuals with advanced disease being unclear about diagnosis and prognosis (Andrucioli et al., 2007), which may result in postponing advanced care conversations. In addition, providers may be uncertain about how much information individuals with advanced disease want (e.g., extent of disease, goals of treatment) or may misjudge how much information they and their families have absorbed or understood (DesHarnais et al., 2007; Hancock et al., 2007), given that patients and

families' abilities to hear and process everything that they have been told can be impaired by factors such as anxiety or health-care literacy.

## NEEDS OF INDIVIDUALS AND THEIR FAMILIES

The needs of individuals at the end of life have been well documented (Block, 2001; Emanuel et al., 2000; Greisinger, Lorimor, Aday, Winn, & Baile, 1997; Lev, 1991; Singer, Martin, & Kelner, 1999; Steinhauer, Christakis, et al., 2000; Steinhauer, Clipp, et al., 2000). People at the end of life report the need for good symptom management and to maintain control where possible. Yet, as discussed earlier in this chapter, many individuals report a high symptom burden. They may wrestle with existential and spiritual questions, psychiatric illness/symptoms or physical symptoms such as dyspnea, pain, and extreme fatigue. As symptom burden and functional declines increase, individuals experience diminished autonomy and control. They may fight to regain or assert control.

Individuals at the end of life hope not to be a burden on their families or society and often seek to find ways to help others through sharing their wisdom, modeling a meaningful path through the dying process, and teaching. They strive to make meaning of their life and death, preserve dignity, remember personal accomplishments, deal with failures and regrets, and maintain a sense of purpose and identity. They want to be prepared for death such that they know what to expect about their illness, have their affairs in order, and believe that their families are prepared for their impending death. Yet often, terminally ill individuals struggle with issues of identity, value, purpose, and meaning. They report a lack of preparation for dying and death. They worry about how their illness affects family members and about how their family will manage after they die. Practical matters, such as financial and legal arrangements, may be left undone. Family members also may struggle to make sense of the individual's illness and life even after the person dies.

Individuals at the end of life typically want to have closure in their relationships, to have said good-bye, resolved unfinished business, and reconciled differences. They want to feel cared for and affirmed as a whole person—being known as a person with a rich and varied history, not just as a patient or disease entity; they want to be seen, heard, and touched. Yet often their history is diminished as they become “the patient with head and neck cancer.” Individuals at the end of life want to maintain

good relationships, particularly with health-care professionals with whom they feel comfortable talking about dying, death, and personal fears. Yet often, communication with providers does not address these topics and individuals may feel abandoned, confused or unsure of where to turn when curative or life-prolonging interventions are no longer available.

## GENERAL INTERVENTION STRATEGIES

There are some general intervention strategies that can be useful in assisting individuals at the end of life and their families address the aforementioned needs (Balaban, 2000; Block, 2001; Lo, Quill, & Tulsky, 1999; National Hospice Organization, Standards and Accreditation Committee [NHO], 1997; Quill, 2000; Vachon, 1998; von Gunten, Ferris, & Emanuel, 2000). This chapter provides an overview of these strategies; subsequent chapters in the book provide specific strategies in greater detail.

*Assist with advanced care planning and end-of-life decisions.* Individuals at the end of life can face a myriad of treatment decisions such as withdrawing/discontinuing life-prolonging treatments (e.g., mechanical ventilation) or electing not to pursue life-prolonging treatment (e.g., declining chemotherapy or radiation, forgoing artificial nutrition/hydration). They may be uncertain, or have strong preferences about who is, and is not, to be included in treatment decisions. They may be overwhelmed with the entire process and need a sounding board. Mental health providers can listen, offer basic information about illness and the dying process, identify medically ill persons' and their families' values and goals for living and dying, clarify treatment options, obtain advanced directives and, evaluate factors that can influence decision making and decisional capacity (e.g., depression, pain, dependency, religiosity, value of quality of life, fear of dying process, and the influence of family members). See Chapter 6, "Advance Care Planning" (Gabriel & Kennedy), for a more in-depth discussion of advanced care planning.

*Respond to financial, legal, social or practical concerns.* Individuals at the end of life may be weighed down by any number of practical issues—selling a family business, updating wills, completing final arrangements, arranging transportation and lodging for long-distance family members, or renegotiating household roles and responsibilities. These issues can stress the entire family. Mental health providers may find that these practical concerns are among the most salient issues for individuals and, therefore, need to be attended to at least simultaneous to other issues, if not first.



*Promote coping with loss and opportunities for grief work.* Individuals at the end of life often experience a myriad of losses—loss of health, function, independence, autonomy, control, predictability, mental clarity, sense of purpose or meaning, status in the family, future hopes and dreams, or normalcy. Providers will want to create the space to explore the meaning and impact of these losses, particularly grief over current and anticipated losses in both the medically ill individuals and their families. How individuals make sense of loss, or the lack thereof, is critical to adjustment. Chapter 9, “Grief and Bereavement Care” (Otis-Green), offers a more detailed discussion of grief and loss.

Mental health providers can identify factors that tend to influence adjustment to any stressful life event—including living with a life-limiting or terminal illness—such as preexisting psychiatric conditions, personality and cognitive style, coping efforts, intra- and interpersonal resources, and concurrent stressors. Mental health providers can reinforce and bolster coping by identifying how individuals with advanced disease may have coped in the past with loss or other stressful life events, and how their capacities to utilize these strategies may be compromised by the illness and associated symptoms, such as fatigue or diminished cognitive function. Symptoms may challenge individuals’ abilities to manage their mental health proactively and force them to modify existing strategies or generate entirely new ones. For example, individuals who typically cope through physical activities may be encouraged to shift from biking to walking, from a motorized scooter to a wheelchair. Those individuals who cope through gathering information but now have memory problems could be encouraged to keep a notebook of questions and written responses. Those individuals who cope through support and social interaction may be encouraged to limit activities during the day so to conserve energy for a family visit later that evening. Flexibility, distress tolerance, and a focus on values and meaning are critical to adjustment. Maintaining a sense of perceived efficacy and control also can be critical, particularly for many individuals who are hospitalized or in long-term care given their diminished sphere of control. For hospitalized individuals, it can be useful to discuss with other providers caring for the person how to facilitate or maintain control within the parameters of the medical setting, such as the possibility of skipping late night medications or setting appointments with staff. See Chapter 11, “Health-Care Teams” (Kasl-Godley & Kwilosz), for further discussion of care coordination with other disciplines when working with individuals at

the end of life who are hospitalized. Chapter 12, “End-of-Life Care in Long-Term Care Settings” (Lewis), highlights issues salient in long-term care.

*Address existential issues such as the nature and sources of suffering and promote meaningful quality of life and continuity with oneself.* Often as a result of the multitude of losses, individuals’ basic sense of who they are is threatened. They may feel reduced by the disease, with the disease robbing them of any sense of purpose, meaning, or even personhood. Many individuals at the end of life report a diminished sense of dignity, believe they are a burden to others, or express a waning will to live and a growing desire for death (Chochinov, Hack, & Hassard, 2002). They can experience spiritual or existential angst, crisis of faith or hopelessness. Providers’ and medically ill individuals’ tasks include identifying aspects of the individuals’ identities that transcend the illness or physical decline and seeing them for the individuals they have been, rather than the disease with which they live. Fruitful areas to explore are things that the medically ill person values, ways to continue to contribute that accommodate the illness, one’s legacy (ethical wills can be particularly useful here), religious/spiritual beliefs, evaluations of self-worth and sources of meaning and purpose. Chapter 3, “The Cultural Context of Spirituality and Meaning” (Strada), explores further some of the spiritual and existential issues with which individuals grapple at the end of life.

Mental health providers may find themselves needing to sit with and validate individuals’ sufferings while raising the possibility that life still can have meaning in the mist of suffering; that life still holds meaning and purpose enough to sustain continued existence. It is important to focus equally on what gives individuals purpose, value and meaning as sources of guilt, regret, remorse, and the need for forgiveness and reconciliation. Therapeutic approaches such as life review, Acceptance and Commitment Therapy (ACT), and Dignity Therapy and Meaning-Centered Group Psychotherapy (MCGP) are particularly useful to this end.

Dignity Therapy and Meaning-Centered Psychotherapy were developed specifically for individuals at the end of life to promote meaning-making, a sense of purpose and self-worth. Dignity Therapy is based on a model developed by Harvey Chochinov and colleagues that seeks to promote individuals’ desire to go on living in the face of impending death by helping them identify and share meaningful, important aspects of their lives, their hopes, and their wishes for their loved ones, life values, and future goals (Chochinov, 2002, 2006; Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002;

Chochinov, Hack, McClement, Kristjanson, & Harlos, 2005; Chochinov et al., 2002). Conversations are centered on three domains. The first domain covers concerns that result from the illness and threaten to, or actually impinge on, individuals' sense of dignity. The second domain consists of a repertoire of beliefs (dignity-conserving perspectives) and behaviors (dignity-conserving practices). Dignity-conserving perspectives include issues related to continuity of self, role preservation, generativity/legacy, autonomy/control, maintenance of pride and hope, acceptance, and resilience or fighting spirit. Dignity-conserving practices consist of living in the moment, maintaining normalcy, and seeking spiritual comfort. The third domain is a social dignity inventory describing the quality of interactions with others that enhance or detract from individuals' senses of dignity. The content of sessions is recorded, transcribed, edited, and eventually compiled into a document that can be bequeathed to an identified loved one (Chochinov et al., 2005).

Meaning-Centered Psychotherapy shares a similar focus to Dignity Therapy. Based on the principles of Viktor Frankl's logotherapy, this approach seeks to enable individuals to make the most of whatever time they have remaining through an enhanced sense of meaning and purpose using a combination of didactics, themed discussion, and experiential exercises (Breitbart et al., 2010; Breitbart & Heller, 2003; Gibson, Tomarken, & Breitbart, 2006; Greenstein & Breitbart, 2000). Participants are assigned readings and homework tailored to specific meaning-centered themes.

A distinctive aspect of psychotherapy with individuals at the end of life is that it often requires modifications in practice, particularly in medical settings, and typically necessitates different use of the therapeutic context and relationship. Psychotherapy tends not to follow the typical, 50-minute outpatient model in which individuals are self-referred and request assistance. Mental health providers must be comfortable checking in with individuals, unsolicited, and learn how to engage individuals who may not conceptualize their symptoms in psychological terms and/or who are skeptical about mental health care, particularly from psychologists or psychiatrists. In addition, individuals may have fluctuating energy and cognitive function and their functional status can change rapidly. As a result, therapy goals may need to be very focused and time-limited, with the expectation that every session may need to stand on its own. Sessions may be brief but frequent, (e.g., three 15 minute check-ins) or infrequent but lengthy (e.g., monthly family conference for 75 minutes).

Related to the challenge of needing to rethink the structure of therapy is rethinking the process. Psychotherapy with people at the end of life may involve a greater pull for self-disclosure, though the guidelines for self-disclosure as being in service of the patient still apply. In addition, hospice and palliative care often demands flexibility, good distress tolerance, and a high tolerance for ambiguity and lack of structure. The pace is rapid and the manner in which issues unfold can be unpredictable. Particularly when working with hospitalized individuals, providers need to be comfortable “seizing the moment” and dropping planned activities if a family member unexpectedly arrives on the unit or a staff member requests assistance with an individual.

When working with individuals at the end of life, mental health providers can offer a space in which individuals are allowed to experience and express their feelings, without being told “Don’t talk that way” or “Stay focused on the positive” or without having the topic changed because it is too difficult for others to tolerate. Sometimes providers’ greatest interventions are to bear witness to the suffering, validate the experience, and affirm the individual’s humanity—complete with flaws, regrets, failings, goodness, resiliencies, and fundamental worth to others. Trying to “fix” or lessen the feeling can be invalidating, if not problematic. However, therapists do not have to be solemn all the time; individuals with advanced or terminal illness often welcome the opportunity to converse lightheartedly about life not just their impending death. See Kastenbaum (2000) and Schneidman (1978) for additional discussion of psychotherapy with dying persons. See Haley, Larson, Kasl-Godley, Neimeyer, and Kwilosz (2003) for a discussion of psychotherapy at end of life in the context of a broader discussion of roles for psychologists in end-of-life care.

*Identify opportunities for completion of unfinished business, preparation for death, and bereavement.* Providers will want to explore with individuals with advanced, life-limiting or terminal illness and their families whether they have said and done what is important to them and, if they have issues left unfinished, why. One helpful framework for thinking about unfinished business is outlined by Ira Byock in his book, *The Four Things That Matter Most* (2004). The fundamental tenet of the book is that although people cannot undo the past, they can express forgiveness, gratitude, and affection, thereby increasing the likelihood of healing and reconciliation. Byock exhorts that, “it is never too late to say ‘I love you,’ or premature to say, ‘Thank you,’ ‘I forgive you’ or ‘Will you please forgive me?’ (pp. 4–5) . . . [and]

to say good-bye in a way that affirms our relationship and acknowledges our connection to one another” (p. 6).

Mental health providers can assist both individuals with advanced and terminal illness and their families in attending to unfinished business, which can be one of many factors that may put family members at risk for complications in the bereavement process (Kissane & Bloch, 2008). Other factors include secondary stressors (e.g., financial strains), multiple losses, the degree to which family members define themselves by their relationship to the ill person, and psychological vulnerabilities (Prigerson, Vanderwerker, & Maciejewski, 2008; Schulz et al., 2006; Tomarken et al., 2008). Unfortunately, when individuals are referred late to hospice, they have less opportunity to attend to these issues, which may put them at risk for complications in bereavement (e.g., Kelly et al., 1999). For example, one study found that hospice enrollment of three days or less before death may be a risk factor for later depression in bereaved caregivers (Kris et al., 2006). See Chapter 10, “Complicated Grief” (Strada), for an overview of complicated or prolonged grief.

Family-focused grief therapy is a promising therapy approach that considers how to help families develop coping resources in order to adapt to changes in the family system that result from the illness and promote adaptation during bereavement (Kissane et al., 2006; Kissane & Bloch, 2008; Kissane, Bloch, McKenzie, McDowall, & Nitzan, 1998). Common issues addressed in this therapy include care provision, suffering, changes in intimacy, discussion of death and goodbyes, cultural and religious practices, needs of family members, historical influences on the family and grief (Kissane & Bloch, 2008). Chapter 4, “Working with Family Caregivers of Persons with Terminal Illness” (Feldman & Llamas), discusses additional strategies that may assist families in adapting to the stressors inherent in caring for individuals with advanced and terminal disease.

*Treat and prevent distressing symptoms.* As discussed earlier in the chapter, individuals at the end of life can be encumbered by physical and emotional distress. Distress is treated most effectively when both the underlying causes and meaning/significance of the symptom are considered. We provide a few illustrative examples.

*Perceived burden.* Individuals with advanced, life-limiting, or terminal illness often are acutely aware of the emotional and physical demands exacted by their illness on those family, friends, and even medical providers caring for them. Concerns about being a burden on others may evoke a desire to

protect others and influence decisions regarding choice of place of care, advance directives, or even acceptance of treatment. Perceived burden is associated with loss of dignity, suffering, depression and a desire for hastened death (McPherson, Wilson, & Murray, 2007). Providers will want to explore how individuals with advanced, life-limiting, or terminal illness perceive and make sense of the impact of their illness on others, the accuracy of this perception, and the way in which it may be influencing their decisions. However, it is equally important to elicit caregiver input because, although caregivers acknowledge the demands of this role, they usually also identify benefits and express gratitude for the opportunity to be involved in caring for the ill person.

*Pain.* Effective pain management is the cornerstone of good palliative and hospice care. However, individuals with advanced, life-limiting, or terminal illness, their families and members of the treatment team may erect barriers to good management. Medically ill individuals may have particular beliefs about pain, such as it should be experienced and tolerated because it reflects retribution for past misdeeds, a characterological deficit if one cannot bear it, or simply an indication that one is still alive. Medically ill individuals also may be reluctant to report pain for fear of burdening staff, of seeming too demanding, or of reprisals for complaining. They may believe that the pain cannot be treated better or have concerns about possible side effects (e.g., “If I take this medication, I will be too lethargic or confused”). Individuals may fear “addiction,” often confusing it with dependence or tolerance, which can feed into physicians’ own misunderstandings about the use of pain medications and the likelihood of addiction. Individuals themselves, especially those with addiction histories now in recovery, may fear susceptibility to re-addiction or ostracism from supportive others. In addition, physicians may underestimate pain or overestimate the contribution of psychological factors to pain. Mental health providers can elucidate these factors and their role in pain management, in addition to providing effective psychological interventions to manage pain as adjunctive treatment to pharmacological approaches. See Chapter 7, “Pharmacological Management of Pain” (Timmins), and Chapter 8, “Nonpharmacological Approaches to Pain and Symptom Management” (Wallio & Twillman).

*Fatigue and asthenia.* Fatigue is characterized by weariness, or exhaustion resulting from physical or mental exertion. Weariness or exhaustion without physical or mental exertion is asthenia. Treatable causes of asthenia include

dehydration, sleep disorders, infection, anemia, metabolic or endocrine abnormalities, and chronic pain (Hinshaw, Carnahan, & Johnson, 2002). Fatigue can result from dyspnea, the direct effects of cancer or anti-cancer treatment as well as cancer-related symptoms and deconditioning, coexisting infections, or poor nutrition/appetite loss (Okuyama et al., 2008) and may co-occur with pain and depression (Rao & Cohen, 2004); this latter relationship seems to be mediated in part through functional status (Barsevick, Dudley, & Beck, 2006). Individuals often experience emotional distress as a result of fatigue due to not only illness-related functional declines and reduced ability to engage in daily activities but from the meaning often attributed to the symptom—that one's disease is progressing, that one is helpless and useless and no longer capable of doing anything one once did. Although it may be accurate that the disease is progressing, providers can encourage individuals to reconsider how they approach tasks and activities. For example, individuals can be encouraged to pace activity, alternating physical activity with rest and try to reduce the demands of everyday living; modify pleasurable activities or identify new ones that can provide the same function with less physical demands; and set priorities to ensure that valued or important activities can be continued and less important activities let go.

*Cognitive dysfunction.* Individuals' cognitive function influences everything from their ability to make sense of a medical diagnosis to being able to participate in their own care. Without an accurate understanding of medically ill individuals' cognitive status and the factors contributing to any changes, medically ill persons and their providers may underestimate or overestimate ill persons' abilities to participate in their own care. Overestimations may result in staff feeling frustrated by medically ill individuals' apparent noncompliance. For example, an ill person who is not taking his medications as prescribed may be labeled as noncompliant or resistant when, in fact, his memory deficits prevented him from encoding the information initially. Presenting the information repeatedly using concrete language, breaking information into single steps, and utilizing environmental supports (e.g., reminders, medication sets, or memory notebooks) enables the medically ill person to be "compliant."

Underestimations may result in leaving medically ill individuals out of the decision-making process or providing more assistance than necessary with activities of daily living (ADLs), which can diminish medically ill individuals' sense of efficacy, independence, and control. Underestimation also can result in deciding not to implement therapeutic interventions because of the

perceived inability to participate (e.g., offering pharmacotherapy but not psychotherapy for depression on the assumption that medically ill individuals may not be able to engage in daily thought records when they still could benefit from behavioral activation or life review). Medically ill individuals may be deemed to lack capacity to make decisions. However, although individuals with cognitive impairment may have difficulty articulating clear answers to questions about treatment preferences, with time they may be able to offer information that demonstrates rationality of decisions and consistency of choices with past values and preferences.

Mental health providers can mitigate against these unintended effects by being well versed in differential diagnoses, particularly dementia, delirium, and terminal delirium. Terminal delirium characterizes the advanced stages of dying and typically is refractory to intervention, which may be a function, in part, of nonreversible causes such as tumor burden/secretions, renal/hepatic failure, or vascular complications. However, the etiology often is multifactorial and potentially reversible causes still should be ruled out, such as dehydration, urinary tract infections, constipation, pain, medications (e.g., opioid toxicities), hypercalcemia, or vitamin deficiencies; hypoxic and metabolic encephalopathies are less likely to be reversible (Friedlander, Brayman, & Breitbart, 2004; Goy & Ganzini, 2003; Morita, Tei, Tsunoda, Inoue, & Chihara, 2001). Individuals may experience agitation, moaning, day-night reversals, illusions, and hallucinations. Hallucinations can be pleasant—dead relatives, guardian beings, young children, or babies—or unpleasant—bugs are common.

When present, delirium is distressing for individuals, their family members, and treatment providers. It interferes with the recognition and control of other physical and psychological symptoms, impinges on communication, and typically curtails delirious individuals' abilities to attend to unfinished business (Breitbart & Alici, 2008). Management of terminal delirium may look somewhat different than management of delirium in medically, but not terminally ill individuals. For example, diagnostic workups may not be performed if they are inconsistent with the focus on comfort. Interventions may be complicated even when reversible causes are identified; for example, rehydration may not always be possible when the patient has fluid retention due to organ failure.

Nonpharmacological interventions include maintenance of structure/routine, presence of familiar belongings or people, reduction or elimination of



noise or excess stimulation, psychoeducation, and reassurance (e.g., that the patient is safe, being well-cared for, or that the hallucinations—although the experience of which is real to the patient—are not real). In addition, providers will want to look for potentially meaningful clues to unfinished life tasks, as well as to current unmet needs, in the behavior of delirious individuals. Even in terminal delirium, delirious individuals may continue to have periods of relative lucidity and family should be encouraged to take advantage of that time (Namba et al., 2007) although they may need modeling of how to engage delirious individuals appropriately.

Families often are distressed by delirium (Morita et al., 2007). It can be frightening to witness, evoke fear and helplessness, and is associated with generalized anxiety in the caregiver (Buss et al., 2007). Agitation can be particularly troubling to families, yet they may feel ambivalent about aggressively managing this symptom pharmacologically if the medications have sedating effect thereby reducing the possibility of meaningful communication. In addition, families often misinterpret the causes of delirium, attributing the behavior to opioids, pain, psychosis, or even death anxiety. Families also may be concerned about the impact of delirious individuals' behaviors on other patients or staff. Families benefit not only from discussion of management strategies and psychoeducation (e.g., explanations of the putative causes, expected course), but from normalization of delirium as a common, manageable experience.

*Promote and support interpersonal relationships with family, friends, and staff.* Hospice and palliative care views the family, including people with whom individuals with advanced, life-limiting, or terminal illness share strong ties but who are not biologically related, as the “unit of care.” Illness impacts families along the disease continuum, from diagnosis to death, and members must integrate the experience of the patient's illness into their ongoing life. Illness can trigger changes in roles, relationships, communication, and finances (Becvar, 2000; Covinsky et al., 1994; Hull, 1990; Rolland, 1994).

Family members may experience conflict over changes triggered by the illness (e.g., perception of needs of the medically ill person, equability in caregiving roles, appropriate involvement of health-care professionals), and long-standing conflicts may be exacerbated by the stress of the illness. In addition, family members may be struggling with how to assist the ill person in maintaining his or her identity and place within the family system while also accommodating the individual's shifting roles and needs. Family

members may have difficulty making sense of treatment, tolerating the ambiguity and uncertainty regarding prognosis, and the medically ill person's dying and eventual death, and may avoid planning for life after the person dies (Doka, 1993). Mental health providers can assist with addressing all of these issues. As mentioned earlier, Chapter 4 provides additional practical guidelines for families caring for individuals with advanced or terminal illness.

*Treat psychological distress, psychopathology, and/or mental illness.* Psychological distress exists along a continuum, from normative reactions, subclinical symptoms to clinically significant syndromes. Symptoms may be new onset or recurrent, triggered by the stress of living with a life-limiting or terminal illness or by caring for someone with the life-limiting or terminal illness. Recognizing that both individuals with advanced, life-limiting, or terminal illness and their family members may be affected, mental health providers will want to talk with individuals with advanced, life-limiting, or terminal illness and their families about their respective histories, exploring potential triggers, typical coping responses and their relative effectiveness, communication skills, and personal resources and strengths (e.g., resiliency, positive expectancies such as hope and optimism, meaning-making, ability to regulate emotions, humor).

Individuals with no prior psychiatric history who have handled prior stressful life events relatively well may experience elevated clinical symptoms or a diagnosable disorder for the first time, which can be particularly alarming. Others may experience powerful grief reactions, may withdraw from loved ones or express a desire for their dying process to end, none of which may be pathological. For example, it is not uncommon for people at the end of life to be focused inwardly and appear disengaged and removed from those they love but they are not depressed or distressed. Knowledge of normative versus non-normative responses can mitigate against both underpathologizing ("He seems fine to me—he is just grieving" when the person is actually depressed) and overpathologizing (e.g., "He said that he wanted this to be over—we better initiate a psychiatric hold" when the person is expressing normative suffering). Lack of knowledge of normative versus non-normative responses can leave providers feeling stuck as to whether or how to intervene. Mental health providers can inform end-of-life care by identifying relevant psychiatric history and discriminating between diagnosable disorders, elevated, but subclinical symptoms, and normative responses to

the dying process. Chapter 5, “Serious Mental Illness,” explores these issues in greater detail.

Working with individuals at the end of life is a privilege, which at times carries significant opportunities and burdens, beautifully elucidated in the closing chapter of this book, “Embracing the Existential Invitation to Examine Care at the End of Life” (Otis-Green). Thus, attention to one’s own emotional reactions, self-care, and peer consultation/support is critical as reinforced in Chapter 16, “Professional Self-Care” (Strada). We hope that the information covered in this chapter and the entire book allows you to embrace this privilege and walk away excited about what you might do differently in addressing the palliative and end-of-life needs of individuals with advanced, life-limiting, or terminal illness and their families, while being mindful of the increased need to take care of yourself and your colleagues.

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