
Opportunities for Psychologists in Palliative Care

Working With Patients and Families Across the Disease Continuum

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Interdisciplinary palliative care services have been rapidly expanding in health care settings over the past 10 years, particularly through the establishment of interdisciplinary palliative care teams. Relatively few of these teams formally include psychologists, although their skills of enhancing patients' and families' well-being and lessening suffering make an enormous contribution to the care provided. In this article, we define palliative care in broad terms, distinguishing it from hospice and end-of-life care. Using a case-based approach, we then explore the contribution of psychologists to the patient- and family-centered approach espoused by palliative care, including the knowledge, skills, and self-awareness needed to work effectively with these very ill patients and their families. We close with a call to action to better train and integrate psychologists into the rapidly growing field of palliative care.

Keywords: palliative care, hospice, professional competencies, psychologists, collaborative or interdisciplinary practice

The meaning of life always changes, but . . . it never ceases to be . . . we can discover this meaning in life in three different ways: (1) by creating a work or doing a deed; (2) by experiencing something or encountering someone; and (3) by the attitude we take toward unavoidable suffering.

—Viktor E. Frankl, *Man's Search for Meaning*

Primarily care psychologists are usually oriented toward prevention of disease, promotion of healthy behaviors, and management of acute and chronic health conditions. But what happens when disease advances and/or dying becomes a more immediate possibility? Shifting focus can be difficult. Primary care psychologists are in a prime position to help patients, their families, and other health professionals navigate and coordinate care along the disease continuum and maximize quality of life no matter what the patient's prognosis. To paraphrase the words of Frankl (1992), primary care psychologists may be in a position to help patients, families, and interdisciplinary teams—through their collective actions—affirm hope, meaning, purpose, and *continued living* in the midst of suffering. We argue that by acquiring a palliative care perspective, primary care psychologists can improve not only patient and family well-being but that of their health care team and medical system. In doing so, psychologists contribute to the transformation of the delivery of health

care such that all patients with serious illness have accessible, high-quality care.

In this article we describe hospice or end-of-life care as a subgroup of the larger field of palliative care and briefly identify the venues in which palliative care is commonly provided. We then outline competencies needed for ethical and effective psychological practice with patients and families at all stages of serious illness, and we provide strategies to assist psychologists in acquiring these competencies.

Consider the case of Mr. Simmons, a 79-year-old African American man who has just been hospitalized for the second time in six weeks for uncontrolled congestive heart failure after having a large myocardial infarction. His prognosis ranges from a few weeks to a few years, and he still has a wide range of disease-directed therapies from which he may benefit. If those therapies do not control the disease process, he may be a candidate for invasive interventions such as intravenous inotropic therapy, a ventricular assist device, or even a heart transplant. The medical decisions themselves are complex enough to warrant added psychological support for the patient. Mr. Simmons also has a wife and children who are overwhelmed by fear and uncertainty about his survival; these issues overlay family dynamics and psychosocial issues that existed before this illness. A clinical psychologist plays a critical role in helping this patient and family address the psychosocial and spiritual dimensions of these complex issues.

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What Is Palliative Care and Where Might It Occur?

Many misconceptions exist about the definition of palliative care and its relationship to hospice or end-of-life care. *Palliative care* is a broad term that refers to care provided at any point in the trajectory of an illness for the purpose of alleviating physical and psycho-social-spiritual suffering, enhancing quality of life, effectively managing symptoms, and offering comprehensive, interdisciplinary support to the patient and family throughout the course of illness, regardless of stage of disease (National Consensus Project for Quality Palliative Care, 2009; World Health Organization, 2007). Palliative care also helps patients and families make difficult medical decisions that enable them to work toward their goals, especially as outcomes become more uncertain. Palliative care ideally begins at the point of initial diagnosis of a serious, potentially life-limiting illness and can be delivered concurrently with other therapies that are intended to cure a disease or prolong life. If disease-directed therapy stops working, palliative care can become the main focus of care. Although the primary focus is enhancing quality of life, palliative care also may positively influence the course of illness and even extend life if provided early enough (Temel et al., 2010).

Palliative care also encompasses care provided through the later stages of serious illness and dying. In the later stages of serious illness, palliative care includes “end-of-life care,” which might involve referral to a formal hospice program as well as support of the family through the bereavement period. Hospice refers to an aspect of palliative care devoted to alleviating symptoms and enhancing quality of life during the last six months of life for patients who accept that disease-directed therapy can no

longer benefit them. Hospice is often linked to the specific programs offered under the Medicare hospice benefit, and Medicare is the primary source of payment for hospice care (Sengupta, Park-Lee, Valverde, Caffrey, & Jones, 2013). Individuals receiving hospice care typically must forgo active disease-directed therapy, though interventions intended to maximize quality of life will be continued and even enhanced. However, individuals can receive disease-directed treatment for medical problems other than the terminal illness under Medicare. Furthermore, if an individual’s condition stabilizes or improves, he or she can disenroll from hospice care and return to regular Medicare coverage. It is important to note, though, that with the passage of the Affordable Care Act, the Centers for Medicare and Medicaid Services has authority to change hospice payment methods, and consideration is being given to how to allow patients to receive hospice and curative care simultaneously and to better integrate palliative care into the continuum of services beneficiaries receive (Stevenson, 2012). The overall number of patients and families served by hospice has increased over the years, as have the proportion of individuals served with noncancer diagnoses and the proportion of individuals living in skilled nursing homes (National Hospice and Palliative Care Organization, 2013).

In addition to meticulous symptom management and minimization of physical and psycho-social-spiritual suffering, 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 care emphasize the needs of both medically ill individuals and their families (National Hospice Organization, Standards and Accreditation Committee, 1997). However, at the present time, palliative care is largely a consultation/recommendation service, whereas hospice is a comprehensive system of care delivery that is capitated and requires that the patient be terminally ill and accepting of a purely palliative approach.

Palliative care can occur across the entire continuum of care: the treatment-intensive hospital setting; assisted living or long-term care facilities; ambulatory care medical clinics; telehealth and other outreach programs; and home care programs. Hospice services can be provided in the home, nursing homes, residential facilities, or on inpatient units.

Palliative Care as a Catalyst for a Transformation in Care

Many individuals live years with chronic, progressive, and often co-morbid, debilitating illnesses (Anderson & Horvath, 2004). Co-morbidities can result in faster disease progression, problems diagnosing and managing new conditions, and complexities of care coordination across settings and providers. Six out of 10 of the leading causes of death identified in 2009 are chronic diseases—heart disease, cancer, stroke, chronic respiratory disease, Alzheimer’s disease, and diabetes (National Center for Health



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Statistics, 2011)—and thus diseases for which people usually have time to prepare for the terminal phase. Yet individuals often feel unprepared for dying. Moreover, their health care providers may be equally unprepared. Preferences concerning life-sustaining treatments often are not discussed adequately, documented, or adhered to, and existential, spiritual, relational, and family concerns may be largely ignored. Individuals may endure multiple prolonged hospitalizations, potentially unnecessary or unwanted interventions (e.g., intubation, ventilation), unrelieved physical and psychological symptoms, interpersonal stress, economic burdens, and unmet practical needs (Emanuel, Fairclough, Slutsman, & Emanuel, 2000; Steinhäuser et al., 2000; Teno et al., 2004; Teunissen et al., 2007).

Seriously ill individuals may feel confused about treatment options or abandoned and unsure about where to turn when curative or disease-directed interventions are no longer available. They often struggle with issues of identity, value, purpose, meaning, and faith and may experience their personal identity and humanity as diminished as they become “the patient with head and neck cancer”. As symptoms burgeon and function declines, seriously ill individuals can experience diminished autonomy and control. They may fight to regain or assert control. They may 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 unfinished. Family members also may struggle to make sense of the individual’s illness and life even after the person dies. Poor communication may become the norm within and across all levels of the patient’s medical and psychosocial system as medical options for a “cure” are exhausted (e.g. Cherlin et al., 2005). Ironically, it is at this

time that patients, family members, and health care teams may benefit most from enhanced communication to maximize understanding of the patient’s options and collaboration among professionals.

Mr. Simmons, mentioned earlier, was at first inclined to avoid direct questions about his prognosis or the downside of various treatment options. Although weak, he struggled to make friendly banter when his doctor rounded each day—making efforts to reassure everyone that he would be “just fine” once the cardiac team “worked their magic.” In contrast to Mr. Simmons’s upbeat demeanor, his wife appeared very worried and sad. She was initially reluctant to share her concerns in front of her husband, but she responded to an invitation to speak with a psychologist on the palliative care team. After a discussion with the medical members of the team, the psychologist was able to help Mrs. Simmons learn more about her husband’s treatment options and prognosis. Mrs. Simmons and the psychologist then were able to discuss these complexities with her husband and adult children, and to help frame some questions about ventricular assistive devices that the patient and his wife might then ask the cardiologist and family physician.

Palliative care offers seriously ill individuals and their families an opportunity to think about goals for their care in light of what is known about their prognosis, treatment options, and the available means for enhancing quality of life. Thus, patients and their families will be better prepared for these challenges should their disease progress to a terminal phase. Research bears out this assertion: Individuals receiving palliative care and hospice have better outcomes than those receiving usual care (Casaretto et al., 2008; Hearn & Higginson, 1998), particularly with pain control and symptom management (Higginson et al., 2003), reduced hospital admissions (Higginson & Evans, 2010), increased patient satisfaction (Gade et al., 2008), and reduced costs (Morrison et al., 2011).

Who Provides Palliative Care?

Ideally, both primary care practitioners and specialists who care for seriously ill patients can provide basic elements of palliative care (e.g., basic pain and symptom assessment and management, advance care planning) in the routine course of providing health care to patients at all stages of serious illness. In reality, not all medical providers are trained to provide even basic palliative care, although this situation is slowly changing. In cases where symptom management or family dynamics are more challenging, patients and/or family members frequently require the added services of palliative care specialists. Specialist palliative care providers are those clinicians who have received formal specialty training and appropriate credentialing in the field and whose work is primarily involved with palliative care (National Consensus Project for Quality Palliative Care, 2009). At present, physicians can be board certified in hospice and palliative medicine, and nurses can be certified in hospice and palliative nursing. Social workers and chaplains can obtain specialty credentials in hospice and palliative care. To date, there is no formal certification for specialty practice in palliative care for psychologists, although there are a small number of post-



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doctoral fellowships¹ that offer advanced training for psychologists in this area.

Most commonly, specialty palliative care is provided in hospital settings by palliative care consult teams composed of a physician, nurse/nurse practitioner, social worker, and chaplain (Billings & Pantilat, 2001), though the teams may be expanded to include a wider range of professionals or, in contrast, be reduced depending on resources and patient volume. For example, programs in nonhospital settings or in smaller medical centers may have relatively few disciplines represented and are much less likely to include psychologists. Palliative care consult teams assist the primary treatment team with goals of care discussions, treatment planning, symptom management, emotional and spiritual support, and communication among and between medically ill individuals, family members, and health care providers. Clear communication about care preferences helps align individuals' preferences with actual care received, and fully informed patients with high disease burdens and poor prognoses frequently choose less aggressive care. The palliative care consult team also may help initiate referrals with community hospice or home care agencies depending on treatment goals. There is tremendous opportunity for psychologists to contribute to this meaningful work; this article reports on our experience doing so.

What Knowledge and Skills Are Necessary for Psychologists to Engage in Effective Palliative Care?

Analogous to the position taken by Karel, Gatz, and Smyer (2012) concerning geriatric mental health care, we maintain that primary care practitioners, including psychologists, in-

creasingly will be expected to provide basic elements of palliative care (e.g., pain and symptom assessment and management, advance care planning, and basic psychosocial and spiritual support). Education and training in this area must be better integrated into the standard preparation for a career in psychology, especially for those who plan to work in hospitals or with patients with serious medical disorders. We offer guidance regarding knowledge and skill domains that will enable psychologists to effectively and ethically participate in palliative care, including end-of-life care. Specific knowledge and skill competencies are outlined below.

Biological Aspects of Illness and the Dying Process

Psychologists need to be aware of the disease trajectories of patients with whom they are working, including those trajectories characterizing cancer, organ failure, progressive neurological conditions, and frailty (Lynn & Adamson, 2003). It is important to understand the challenges of prognostication and the ways in which these challenges affect treatment planning and medical decision making. Health care providers are inclined to overestimate the amount of time a person has left (Christakis & Lamont, 2000), and this overestimation tends to increase when providers have a close and long-standing relationship with a patient. These overestimates also are particularly pronounced when the disease trajectory is uncertain, as with noncancer diagnoses such as chronic obstructive pulmonary disease (Curtis, 2008), heart failure (Stuart, 2007), chronic kidney disease (Davison, 2011), chronic liver disease (Hope & Morrison, 2011), and dementia (Sachs, Shega, & Cox-Hayley, 2004).

Primary care psychologists also should have some knowledge of the basic pathophysiology of common diseases and symptoms experienced by palliative care patients (e.g., pain, fatigue, nausea, dyspnea, insomnia, wasting syndromes, delirium, and constipation) and be aware of approaches to symptom management, both medical and psychological. For example, anxiety frequently coexists with dyspnea, and fear about suffocation is prevalent (e.g., Gardiner et al., 2009). A primary care psychologist should be prepared to offer psychoeducation as well as brief cognitive and/or behavioral treatments to help anxious patients experience symptom relief. Depending on patient and family preferences, family members can be included in these interventions, such as brief relaxation exercises, and then can reinforce these approaches with the patient as appropriate.

Finally, psychologists should become familiar with physical changes common to active dying (e.g., changes in breathing, urine output, circulation, terminal delirium) (Hallenbeck, 2003). They should gain enough experience

¹ For example, the Department of Veterans Affairs offers Interprofessional Fellowships in Palliative Care, which focus on advanced practice training of psychologists, social workers, chaplains, physicians, nurses, and pharmacists.

to be comfortable in the presence of a dying person and to be able to guide and comfort others, correct misperceptions, and address fears.

Mr. Simmons, for example, was extremely afraid of suffocation toward the end of his life based on what he had witnessed during his father's death from emphysema. The psychologist was able to hear the story and provide a witnessing presence to the patient's grief over his father's death. She was then able to reassure him that the clinical team was committed to relieving shortness of breath using both state-of-the-art heart failure treatment, as well as opioids that are effective in relieving the sense of dyspnea. She also was able to alert other members of the interdisciplinary team to Mr. Simmons's fears and experiences so that they too could help reassure him.

Psychological, Sociocultural, Spiritual, and Interpersonal Factors in Chronic, Advanced, Life-Limiting, and Terminal Illness

Psychologists need to be aware of the salient emotional challenges that characterize living with chronic or life-limiting illness. Individuals can be emotionally distressed, which can magnify symptoms (e. g., Clarke & Kissane, 2002) or even precipitate psychopathology (Chochinov & Breitbart, 2009). Individuals may experience fear and anxiety related to new diagnoses, uncertain prognosis, possible disease progression, and ultimately, dying. Individuals may experience depression associated with a diminished sense of purpose, dignity, and control and with perceived burden and dependence. These reactions may accompany a waning will to live and a growing desire for death (Chochinov et al., 2002). Individuals may report relationship strain or tension related to treatment demands and associated symptom and caregiver burden or longstanding family dynamics. They may experience spiritual or existential angst, crises of faith or hopelessness, questions of meaning, unfinished business, guilt, or grief. However, psychologists also need to be mindful of the positive emotions and sense of well-being that individuals can experience, often producing expressions of gratitude, compassion, forgiveness, spiritual comfort, and posttraumatic growth.

Psychologists must be familiar with a range of developmental, demographic, and sociocultural-spiritual influences on the experience of serious illness, the dying process, and preferences for end-of-life care.

For example, Mr. Simmons and his family were Christians, with deeply rooted beliefs about the sanctity of life, the power of prayer, and the possibility of miracles.

Cultural and religious traditions and beliefs such as these can influence patients' and family members' understanding and experience of illness; their preferences, wishes, and decisions about care; and how they cope with dying and death (Crawley, 2005; Kwak & Haley, 2005). Although mindful of the importance of these factors, providers also should be aware that some apparent cultural or racial differences may be due to other factors such as low health literacy (Volandes et al., 2008). The primary care psychologist must be comfortable pursuing knowledge or information about these diverse influences. In addition, the

age and life stage of the patient and family profoundly affect the experience of the patient and family (e.g., a young child who is ill vs. an older adult). Pediatric palliative care has its own specialized skills and knowledge separate from those for adult palliative care (e.g., Himelstein, Hilden, Boldt, & Weissman, 2004).

Normal and Abnormal Grief and Bereavement

Psychologists working with individuals with chronic, advanced, or terminal illness need to be aware of the loss and grief experienced by these individuals. These patients lose health, function, independence, autonomy, control, predictability, and mental clarity, as well as status in their family, future hopes and dreams, and a sense of belonging. They can lose their sense of "normalcy." Often as a result of these losses, individuals' basic sense of identity is threatened. They may feel reduced by the disease and robbed of any sense of purpose, meaning, or even personhood. Creating opportunities for individual patients and their families to explore the meaning and impact of current or anticipated losses becomes paramount in order to help them forge new meaning in the face of adversity (Nadeau, 2001; Neimeyer, 2001; Walsh & McGoldrick, 2004). Narrative-based therapies may be particularly helpful. Even if new meaning cannot easily be found, sharing one's angst and loss with a caring professional lessens the isolation of the experience.

Psychologists must be able to identify normal grief and distinguish it from complicated or prolonged grief (Dillen, Fontaine, & Verhofstadt-Deneve, 2008; Prigerson et al., 2009). Although there is considerable evidence from studies of spousal loss that the majority of bereaved individuals are psychologically resilient and experience little or no depression after the death of their loved ones (Bonanno, 2004; Galatzer-Levy & Bonanno, 2012), it is important to be aware of factors that put family members at risk for complications in the bereavement process as well as those factors that are protective. Risk factors include secondary stressors (e.g., financial strains); multiple, concurrent losses (Tomarken et al., 2008); the degree to which family members feel close to or dependent on (Johnson, Zhang, Greer, & Prigerson, 2007) or define themselves by their relationship to the ill person (Mancini, Robinaugh, Shear, & Bonanno, 2009); controlling parents (Johnson et al., 2007) or separation anxiety experienced when the patients were children (Vanderwerker, Jacobs, Parkes, & Prigerson, 2007); psychological vulnerabilities such as depression and perceived burden (Schulz, Boerner, Shear, Zhang, & Gitlin, 2006); experiential or behavioral avoidance (Shear, 2010); intolerance of uncertainty (Boelen, van den Bout, & van den Hout, 2003); rumination (Stroebe et al., 2007); lack of preparation for the death (Barry, Kasl, & Prigerson, 2002); deaths occurring in hospitals (Wright et al., 2010); and unresolved family issues (Kissane & Bloch, 2008). Factors that can be protective against complications in bereavement include an ability to make sense of loss; an ability to find personal meaning or compensatory benefit in the experience; an ability to regulate one's emotional state and maintain equilibrium between positive and negative emotions;

spirituality and general resiliency characteristics such as self-esteem, hardiness, and positive expectancies (Bonanno, 2004; Neimeyer, Baldwin, & Gillies, 2006); and being psychologically prepared for the impending death (Barry et al., 2002).

Psychologists also need to be aware of evidence-based methods for differentiating and then working with both normative and complicated grief and for distinguishing these conditions from major depression and anxiety (Boelen & van den Bout, 2005) and posttraumatic stress disorder (PTSD; Bonanno et al., 2007). Psychologists need to be able to provide psychoeducation and support for normative grief (for those individuals seeking support) and to know when to refer individuals for specialized treatment given complications in bereavement (Wittouck, Van Autreve, De Jaegere, Portzky, & van Heeringen, 2011). Approaches include complicated grief disorder treatment (Shear, Frank, Houch, & Reynolds, 2005; Shear & Mulhare, 2008), narrative-based interventions (Neimeyer, 2001, 2006), cognitive behavioral therapy (Boelen, Keijsers, van den Hout, & van den Bout, 2007; Boelen, van den Bout, & van den Hout, 2006), grief therapy (Worden, 2008), and family focused grief therapy (Kissane & Bloch, 2008).

The case of Mr. Simmons illustrates the importance of monitoring the grief process and concomitant mood changes of both patients and family members. At one point, Mr. Simmons became more withdrawn. Ordinarily, even in the most challenging times in his treatment, he enjoyed visits from his grandchildren, but now even that did not perk him up. He began talking about stopping all treatment and “letting go,” but it seemed premature to many on the treatment team. The psychologist was asked to reevaluate Mr. Simmons, and in conversation learned that he was indeed ruminating about death and had stopped enjoying aspects of life that ordinarily had given him pleasure. He believed that he was a burden and that the family would be better off without him. He had been depressed several times in his past, and this response felt very similar. He agreed to a trial of antidepressant medication prescribed by his primary care physician, and the psychologist agreed to meet regularly with him and with his family, continuing to help them open up communication, share their feelings about what was happening, and eventually find a common sense of understanding of Mr. Simmons’s illness and its meaning for the family members who participated (Neimeyer, 2001, 2006). Over the next several weeks, the patient rediscovered his will to live and his enjoyment in life, and his family strongly reaffirmed his worth to them and their desire for him to live as long as he could.

Communication and Facilitation of Advance Care Planning

Communication is a cornerstone of good palliative care. Communicating in a direct and compassionate manner, in which providers listen more than talk and can tolerate and manage their own emotions, strengthens the provider–patient relationship, improves the patient’s and family’s ability to plan and cope, and supports the patient and family emotionally. Communication influences adherence to treatment regimens, rate of recovery, satisfaction with care, pain control, and psychological functioning (Epstein & Street, 2007; Mager & Andrykowski, 2002).

In addition to good communication skills, psychologists also need skills in advance care planning given that providers, patients, and family members have varied levels of experience and comfort with this type of shared communication and collaborative decision making (King & Quill, 2006; Tulsy, Chesney, & Lo, 1995). Although some providers may avoid difficult advance care 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, they feel less distressed (e.g. Butow, Dowsett, Hagerty, & Tattersall, 2002). In fact, good advance care planning is associated with increased patient and family satisfaction, a sense of control, and reduced fears, anxiety, and emotional distress (Smucker et al., 1993; Tierney et al., 2001). Helpful approaches include framing these discussions in terms of “hoping for the best while preparing for the worst” (Back, Arnold, & Quill, 2003), focusing on that which is important to individuals with advanced, life-limiting, or terminal illness and their families in whatever time remains, and asking family members to take turns sharing what they know about the illness (King & Quill, 2006). See Clayton, Hancock, Butow, Tattersall, and Currow (2007) for suggested guidelines for advance care planning conversations.

To inform advance care conversations, psychologists need to know the types of treatment decisions commonly encountered by patients, including choosing or electing not to start life-prolonging interventions; withdrawing or discontinuing life-prolonging treatments; requesting treatment that is near futile; and completing advance directives, making final arrangements, or updating wills. They also need to know the factors that affect the decision-making process, including the patient’s cognitive capacity, symptom burden, and affective state; the family’s communication and problem-solving styles; and other general factors such as family or patient religious preferences, cultural values and norms, and fears or other attitudes about the dying process.

Assessment of Common Physical and Mental Health Conditions

Primary care psychologists need a working knowledge of domains commonly assessed in palliative care, as well as measures used to assess these domains, and the psychometric properties and normative data (in medical populations) for these measures. Major domains of interest include functional status, pain, spirituality, mood and anxiety symptoms, nonpain physical symptoms, social support, and grief (Agnew, Manktelow, Taylor, & Jones, 2010; National Consensus Project for Quality Palliative Care, 2009).

Primary care psychologists also need to discriminate between normal and pathological responses to life-limiting illness. For example, psychologists may be asked to distinguish the common desire for suffering to end (without a specific plan to end suffering) from suicidal ideation and associated requests for hastened death or to distinguish normal fears about serious illness or death from clinically significant levels of anxiety that require treatment. In addition, psychologists can help ascertain the extent to which

reactions are due to the illness at hand and/or due to a chronic or antecedent mental health problem.

Psychotherapy for Patients With Chronic, Life-Threatening, or Terminal Illness

Primary care psychologists need knowledge of standard, evidence-based psychotherapies for common mental health disorders (e.g., depression, anxiety, PTSD, substance abuse) but also must be aware of the limited evidence available regarding the effectiveness of these approaches in palliative and hospice care settings. Psychologists must be prepared to extrapolate “best practices” appropriately when the evidence base in a hospice and palliative care patient population has yet to be developed. However, the evidence base supporting the use of motivational interviewing (e.g., Benzo et al., 2013; Brodie, Inoue, & Shaw, 2008), life review (e.g., Ando, Morita, Akechi, & Okamoto, 2010; Xiao, Kwong, Pang, & Mok, 2013), cognitive-behavioral therapy (e.g., Sage, Sowden, Chorlton, & Edeleanu, 2008), and acceptance and commitment therapy (e.g., Feros, Lane, Ciarrochi, & Blackledge, 2013; McCracken & Jones, 2012; Wetherell et al., 2011) in palliative care is building. Acceptance and commitment therapy is especially fitting given its focus on values-based living and living fully in the midst of suffering. Psychologists often find themselves needing to sit with and validate individuals’ suffering while raising the possibility that life still can have meaning in the midst of suffering. Sometimes providers’ greatest intervention is 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 in many circumstances.

Psychologists also will want to know about treatment approaches that address issues common to living with a life-threatening or advanced illness, such as existential distress (e.g., LeMay & Wilson, 2008). Two promising approaches developed specifically for individuals with advanced illness to promote meaning-making, a sense of purpose, and a sense of self-worth are meaning-centered group psychotherapy (Breitbart & Applebaum, 2011; Breitbart et al., 2010, 2012) and dignity therapy (Chochinov, 2012; Chochinov et al., 2011; Hack et al., 2010; Hall et al., 2009). Meaning-centered group psychotherapy is based on the principles of Viktor Frankl’s logotherapy (Frankl, 1988) and 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, discussion, and experiential exercises. Participants are assigned readings and homework tailored to specific meaning-centered themes. Dignity therapy is an approach developed by Chochinov and colleagues (Chochinov, 2012; Chochinov et al., 2011) 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 past and current lives, their hopes and wishes for their loved ones, and their life values and future goals. The content of sessions is recorded, transcribed, edited, and

eventually compiled into a document that is then bequeathed to an identified loved one.

In addition to familiarity with specific psychotherapeutic approaches and the associated evidence base, psychologists also will want to be aware of some of the more unique or salient aspects of providing psychotherapy with individuals with advanced or life-limiting illness. Psychotherapy typically demands cognitive flexibility, high distress tolerance, and a high tolerance for ambiguity. The pace can be rapid and the manner in which issues unfold can be unpredictable. Rather than waiting to develop a therapeutic rapport with a patient, providers need to be comfortable “seizing the moment” and tackling difficult issues even when they have no prior relationship with a patient. Psychologists need to be able to critically evaluate and modify their practice to accommodate their patients’ medical status (e.g., fatigue, cognitive impairment, pain) and to help colleagues of other disciplines do the same.

Like other forms of psychotherapy in medical settings, psychotherapy as part of palliative care will rarely follow the typical, 50-minute outpatient model in which individuals are self-referred and requesting assistance. Psychotherapy also may involve a greater pull for self-disclosure, though the guidelines for self-disclosure in the service of the patient still apply, and the potential for stronger emotional and countertransference responses is important to recognize (see Katz & Johnson, 2006). Psychotherapy in this setting necessitates reflective practice and a high degree of self-awareness, particularly because dying and death is a universal experience that evokes complex feelings in patients, families, and providers alike. See Kastenbaum (2000) and Schneidman (1978) for additional discussion of psychotherapy with dying persons, and see Haley, Larson, Kasl-Godley, Neimeyer, and Kwilosz (2003) and Qualls and Kasl-Godley (2011) for a discussion of psychotherapy at the end of life in the context of a broader discussion of roles for psychologists in end-of-life care.

Assessment and Treatment of Families

In palliative care, the family, defined as anyone with whom the patient shares strong emotional ties, whether or not they are biologically or legally related, is the unit of care (McDaniel, Doherty, & Hepworth, 2013). Primary care psychologists require basic knowledge of family systems and dynamics and the ways in which illness affects families along the disease continuum, from diagnosis to death.

Illness can trigger changes in roles, relationships, communication, and finances (Becvar, 2000; Covinsky et al., 1994), and family members may experience conflict over these changes. For example, they may have differing perceptions of the needs of the medically ill person, of the equability of care-giving roles, and of the appropriate level of involvement of health care professionals. In addition, families may struggle 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, may have difficulty tolerating the ambiguity and uncertainty regarding prognosis, and may be

avoidant of planning for life after the person dies (Doka, 1993). Moreover, families vary in their ability to communicate effectively about distressing issues, to make decisions collaboratively, and to remain committed to one another through transitions and crises (King & Quill, 2006; Kissane, 2003; Rolland, 2003). Some families are prone to conflictual patterns of interaction due to longstanding problems such as substance abuse, physical/sexual abuse, or untreated mental illness. These longstanding conflicts may be exacerbated by the stress of serious, life-limiting illness.

Primary care psychologists should have strong family assessment skills (Zaider & Kissane, 2009) enabling them to identify areas of conflict for the family, to discern the family's ability to tolerate and resolve conflict, and to modulate chronically conflictual patterns of interaction that may prevent the family from participating productively in collaborative medical decision making on behalf of the patient (King & Quill, 2006; McDaniel, Campbell, Hepworth, & Lorenz, 2005a, 2005b; Rabow, Hauser, & Adams, 2004; Wilkins, Quill, & King, 2009). It can be helpful for the psychologist to assess for unfinished business with the patient, that is, to assess whether members of the family system have said and done what is important to them and, if not, why. Byock (2004) outlined a helpful framework for this work, building on the fundamental tenet that while people cannot undo the past, they can express forgiveness, gratitude, and affection, thereby increasing the likelihood of healing and reconciliation.

In the case of Mr. Simmons, it was clear that his family had many strengths, including a shared religious faith, a history of good communication among most family members, and a deep commitment to help each other through crises. Two of his three grown children were married with children of their own and enjoyed both geographic and emotional closeness with their parents. They visited Mr. Simmons frequently in the hospital and were greatly saddened, but understanding, when he made the difficult decision not to undergo placement of a ventricular assistive device when other disease-directed treatments did not improve his condition. However, Mr. Simmons's youngest son, Robert, lived in another state and was clearly not as close to his father. He flew into town after learning of Mr. Simmons's advanced illness but was not present for the earlier family sessions. He was shocked and angry to learn that his father was not going to do "everything possible" to prolong his life. When he vehemently accused Mr. Simmons of "giving up," arguments broke out between Robert and his siblings. Recognizing that Robert needed time to catch up with the family's decision making, the attending physician and psychologist who facilitated the meeting firmly but gently interrupted the arguing and invited the older siblings to share what it had been like for them to learn of their father's decision. This invitation helped shift the tone of the meeting from anger to sadness, allowing the family to begin to mourn together for the first time. It emerged that Robert had not seen his parents in two years because of a previous disagreement about Robert's financial difficulties. In a subsequent meeting, the psychologist was able to help father and son make amends by recognizing that they were both "strong willed" and "in some ways more alike than any other members of the family." This reframing of differences helped strengthen Robert's bond with his father and allowed him to begin to address the unfinished business that festered prior to his father's serious decline.

Psychologists should be familiar with how to facilitate family meetings (e.g., Dumont & Kissane, 2009; Gueguen, Bylund, Brown, Levin, & Kissane, 2009) and use family-centered treatment approaches such as medical family therapy (McDaniel, Campbell, Hepworth, & Lorenz, 2005b; McDaniel, Doherty, & Hepworth, 2013; Glick, Berman, Clarkin, & Rait, 2000) and family focused grief therapy (Kissane & Bloch, 2008; Kissane et al., 2006), which capitalize on evidence-based family assessment in order to help families develop coping resources in the face of illness-related changes in the family.

Interdisciplinary Teams, Consultation, and Professional Self-Care

Psychologists working with individuals with serious illness and their families find themselves interacting with an array of health care professionals and teams; the needs of these individuals often are extensive and can exhaust the expertise and training of any one discipline (Geriatrics Interdisciplinary Advisory Group, 2006; Hall, 2005). Thus, psychologists need knowledge of types of teams—multidisciplinary, interdisciplinary, transdisciplinary—and models of team development. It also helps to know about the function and organization of the teams caring for seriously ill patients—the structure, context, process, and productivity of these teams (Heinemann & Zeiss, 2002)—and the factors that affect team organization, such as stages of team development, type of health care setting and its resources, professional training models and interdisciplinary roles, and attitudes toward palliative care and mental health (Hiroto & Kasl-Godley, 2013). For example, when providers misunderstand each other's qualifications and skill sets, or try to inappropriately constrain colleagues' professional responsibilities, the team context (e.g., experience on the team), process (e.g., communication, navigating stressful situations), and productivity (e.g., coordinating patient care) often suffer (Heinemann & Zeiss, 2002).

Psychologists also need skills in managing team dynamics, such as interprofessional communication and collaboration, conflict management, and team-building activities (Heinemann & Zeiss, 2002; Hiroto & Kasl-Godley, 2013; Interprofessional Education Collaborative Expert Panel, 2011; Speck, 2006). Conflict is a normal aspect of interdisciplinary team function that must be brought to the surface and negotiated for the team to work effectively. Conflict can result from a variety of larger systems factors including scarcity of resources, the stress of large caseloads, and poorly managed organizational change. It can be exacerbated by problematic team dynamics such as deficiencies in team leadership, poor communication, or ambiguous team roles and responsibilities (Larson, 1993; Lickiss, Turner & Pollock, 2004; Yeager, 2005). If there is not adequate team communication, patients' family dynamics can influence team dynamics, and vice versa, such that teams can unwittingly mirror or amplify family conflict (King & Quill, 2006).

One challenge for interdisciplinary teams is how to cover the salaries of all team members, especially in fee-for-service, noncapitated systems. Reimbursement for all

services provided may not be possible, as not all members of a team may be able to bill for their work and having separate billing/reimbursement practices for every individual on the team is not viable. Some psychologists are salaried, as in the Department of Veterans Affairs (VA) system; some cover their salary through billing and reimbursement under Health and Behavior and Mental Health CPT codes (while ancillary or overhead costs are absorbed by other departments or the institution); and some bill as members of the treatment team rather than as psychologists.

In addition, self-care is a core competency for psychologists. Without this skill, psychologists working in palliative care will not be able to sustain the work. Psychologists will want to be familiar with risk and protective factors for burnout. Acting in ways that are inconsistent with values or having a chronic mismatch between providers' expectations or needs and their work settings (e.g., regarding workload, control, values, fairness, interpersonal relationships) may be a particular risk. Equally important is awareness of ways to maintain psychological health such as self-compassion and mindfulness/meditation practices.

Mr. Simmons's interdisciplinary team at times experienced challenges that seemed to parallel those of his family. Having been hospitalized twice on the same cardiac care unit, Mr. Simmons was well-known to the staff, who had grown quite fond of him and his family. During the period of time when Mr. Simmons's son Robert was struggling with his father's treatment decisions, similar conflict on the care team arose between those who felt that the patient should be strongly encouraged to consider more aggressive treatment, such as the placement of a ventricular assistive device, and those who believed that an invasive procedure would be too much for him. The palliative care psychologist worked with the chief resident on the unit to organize an "informational team meeting" at change of shift to include nursing and social work staff of both day and evening shifts, since the latter had not had an opportunity to participate in as many team and family meetings. With the cardiology resident on hand to more fully inform staff of the potential risks and benefits of the intensive treatments that Mr. Simmons had considered, the psychologist invited staff to ask any questions or share any reactions they might have. Eventually several staff members began to disagree about whether the patient had been given "every chance to get as much treatment as possible." The psychologist interrupted the discussion as it was escalating to argument by interjecting, "It's normal to have strong opinions and even differing opinions when working with such a difficult case." The cardiology resident then was able to reiterate that the patient and his family had been given comprehensive information about treatment options in support of their own decision making. At this point, the psychologist shifted the direction of the meeting to ask how everyone was coping with the challenge of working with a patient who was "so very likeable but also so seriously ill." With this intentional focus on staff members' own reactions and coping, the team was able to share their common sense of sadness about Mr. Simmons and to consider together ways of dealing with the anticipated loss of a beloved patient.

A Call to Action

For psychologists who wish to practice palliative care, a variety of resources are available to prepare for this chal-

lenging but rewarding work. Among the resources available are the *Clinical Practice Guidelines for Quality Palliative Care, Second Edition* (National Consensus Project for Quality Palliative Care, 2009); the report of the Interprofessional Education Collaborative Expert Panel (2011); on-line curricula such as the American Psychological Association's End-of-Life Issues continuing education program (<http://www.apa.org/ed/ce/resources/eol.aspx>) and the End-of-Life Care Curriculum for Medical Teachers (<http://www.growthhouse.org/stanford>); and train the trainer programs such as Education in Palliative and End-of-Life Care (EPEC; <http://www.epec.net>) and the End-of-Life Nursing Education Consortium project (ELNEC; <http://www.aacn.nche.edu/elneec>). Interested individuals also can pursue specialty internship and advanced fellowship training (e.g., VA Interprofessional Palliative Care Fellowship programs may include psychology training; VA Clinical Psychology Postdoctoral fellowships with an emphasis in geropsychology often include exposure to hospice and palliative care rotations). Psychologists also can participate in informal consultation, cross-training, and co-treatment with colleagues in other disciplines with specialty training in hospice and palliative care. They can get involved in professional organizations such as the National Hospice and Palliative Care Organization (NHPCO), the Center to Advance Palliative Care (CAPC), and the American Academy of Hospice and Palliative Medicine (AAHPM).

As educators, psychologists can look for opportunities to incorporate and expand appropriate palliative and end-of-life content and bereavement content into undergraduate and graduate school curricula through specific clinical training opportunities, research programs, coursework, and other didactic offerings. There should be a basic curriculum for all psychologists and a more in-depth curriculum for those planning to work in palliative care. Curricula should include supervised clinical experiences with patients and teams as well as structured educational exercises such as rounds, conferences, journal clubs, seminars, case-based discussion, and role playing. Attention to the clinician's emotional responses is paramount (e.g., Block et al., 1998).

It is also important for psychologists to identify and outline research priorities that include evaluating best practices in mental health integration; testing the comparative effectiveness of various individual, group, and family therapies for patients with serious, life-limiting illnesses; and developing effective psychotherapies for special populations of patients such as the seriously and persistently mentally ill. Psychologists also can contribute to policy and practice guidelines for palliative care and hospice. Psychologists have historically been absent from work groups or national consensus groups pertaining to this field, even when these groups were making recommendations regarding psychological issues. This article is a call for this situation to change.

Regardless of whether one works as a practitioner, an educator, or a clinical researcher designing and evaluating treatments, the field of palliative care offers unparalleled opportunities to change lives for the better. Moreover, by helping seriously ill patients and their families find con-

nection and healing in the midst of medical suffering, we ourselves are privileged to find deeper meaning in our own lives through these powerful and inspiring human encounters.

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