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END-OF-LIFE ISSUES, GRIEF, AND BEREAVEMENT

WHAT CLINICIANS NEED TO KNOW

Edited by
SARA H. QUALLS
JULIA E. KASL-GODLEY

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Preface

End-of-life care is recognized as a critical component of geriatric health care, but is really a component of health across the lifespan. Choices made early in life obviously influence quality of life and decision options at the end of life. The lifespan framework for health care reminds us that end-of-life care is but one more step in a lifelong process. However, awareness that life will end helps us ask questions about values, preferences, choices, and motivations at all ages. Research evidence that death is not as anxiety-provoking for older adults as it was in mid-life does not imply that death awareness is not salient. Indeed, care choices in later life are often viewed differently in the conscious presence of death than in the absence of that awareness. We believe that deep reflection and understanding of end-of-life care enriches clinical understandings of mental health service providers who work with older adults in any context.

Despite its considerable stigma, or perhaps because of it, end-of-life care has ended up being an innovative leader in reconceptualizing health care. Indeed, in recent years, hospice and palliative care models have led the way into integrated care. The models that guide end-of-life care inevitably include multiple disciplines, typically operating as an interprofessional team. The rich interconnectedness of care provided by professionals representing several disciplines has been fostered explicitly in end-of-life care. Many use hospice care as an ideal against which to compare extraordinarily fragmented, pathology-focused, high-tech medical models that dehumanize us at the times when we most need genuine *care*. Human-to-human *care* is at the core of excellent health- and wellness-service systems. Ironically, those working at the very end of life seem to have moved farther faster than any other domain of health care in generating new models and standards.

Perhaps it is obvious then why this book is included in Wiley's Clinical Geropsychology series that is designed to invite and educate practitioners who serve older adults. Within the field of Psychology, a set of competencies for geropsychologists were defined within the Pikes Peak Model for Training in Professional Geropsychology (Knight, Karel, Hinrichsen, Qualls, & Duffy, 2009). End-of-life care is an explicit component of those competencies. Mental health providers working with older adults simply must develop the competencies needed to work with end-of-life care issues, challenges, concerns, opportunities, and so forth.

The book series on Clinical Geropsychology was launched out of an annual Clinical Geropsychology conference held in Colorado Springs for five years between 2005 and 2009. The book series paralleled the conference, with the shared goal of providing advanced training to experienced mental health providers seeking postlicensure learning opportunities related to geriatric mental health. The structure of any book reflects a creative process; these books reflect interpersonal as well as intrapersonal creativity. The editors of each book in this series could describe the unique challenges to summarizing each entire field in a way that is useful to practicing clinicians. The first book, *Psychotherapy for Depression in Older Adults* (Qualls & Knight, 2006) took up the challenge of summarizing a vast and growing literature in a way that was practical for clinicians treating depressed older adults with complex presentations of symptoms and in contexts that extend far past our empirical research base. The interdisciplinary nature of a rapidly emerging new field was the challenge of the second book, *Changes in Decision-Making Capacity in Older Adults: Assessment and Intervention* (Qualls & Smyer, 2007). The third book faced yet a different challenge: building an empirically based approach to clinical work with older families despite the extremely limited base of clinical outcome research (*Aging Families and Caregiving: A Clinician's Guide to Research, Practice, and Technology*, Qualls & Zarit, 2008).

The book you hold faced yet another unique challenge—how to keep visible the raw, poignant existential issues faced daily by clinicians doing this work while guiding the reader into what is known about practice models, patterns, and research. This book emerged from the 2008 conference, designed by the conference presenters over a lovely dinner on a warm Colorado summer evening in the shadow of Pikes Peak. The authors of this book were the conference faculty, selected for their rich clinical experience that was grounded in research as well as existential self-awareness. The vast majority provide end-of-life clinical care daily and train students to do the same.

The task of writing with the authentic voice of a clinician who is working in the trenches as well as the authoritative voice of the research evidence base required finesse. We believe they succeeded remarkably, but you will be the judge as to whether the book is genuinely useful to you.

The book opens with an overview chapter (Kasl-Godley, Chapter 1) that orients the reader to what is unique about end-of-life care from other types of mental health services. A series of clinical issues are then addressed in chapters that include the details needed by any clinician new to the field. Exactly how does dying occur, and how does it vary across illnesses (Gabriel, Chapter 2)? What are the meaning and spiritual issues that are nearly inevitably visible in end-of-life care (Strada, Chapter 3)? How are families engaged in end-of-life care, and what services do mental health clinicians provide them (Feldman & Llamas, Chapter 4)? How does the presence of a mental disorder alter end-of-life experiences and care, and how should providers address disorders that appear at the end of life (Kasl-Godley, Chapter 5)? What are the tools and strategies involved in advanced care planning, and how do they play out during end-of-life care (Gabriel & Kennedy, Chapter 6)? Pain management is a huge issue at the end of life, with pharmacological (Timmins, Chapter 7) and nonpharmacological (Wallio & Twillman, Chapter 8) approaches available to mental health providers. Bereavement and grief also are inevitable processes at the end of life, whether normal (Otis-Green, Chapter 9) or complicated by other factors (Strada, Chapter 10).

Mental health providers often find that their work is influenced as much by the settings of professional practice as by the technical skills of their profession. Kasl-Godley and Kwilosz (Chapter 11) offer a guide to the interprofessional team as a common care context within hospice and palliative care service systems. Lewis (Chapter 12) guides the reader through unique aspects of end-of-life care that occur in the institutional and residential environments of long-term care. Ethical, legal, and policy contexts also exert significant impact on care services. Twillman and Lewis (Chapter 13) describe current policy issues that influence services so directly that they require attention and engagement by providers. A unique chapter in this book is the essay on hastened death policy and practice that receives so much media attention today (Canetto, Chapter 14). Wakin (Chapter 15) describes a community planning process by which one community created an end-of-life ethical guidebook for providers as the culmination of many, many, many community conversations.

Ultimately, end-of-life care is emotionally and existentially evocative for the clinicians who work with the fragile linkages between life and death on a daily basis. Strada (Chapter 16) offers words of wisdom, guidance for the journey, and other recommendations about self-care that is needed to sustain capacity to provide care. Finally, Otis-Green (Chapter 17) invites us to embrace the existential opportunities that are embedded in end-of-life care because they will enrich our lives as humans as well as providers.

We hope you find this book as rich as we have found the process of creating it.

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CHAPTER
1

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

Julia E. Kasl-Godley

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; sociocultural 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 (Andruccioli 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; Steinhauser, Christakis, et al., 2000; Steinhauser, 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 though 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., opiod 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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CHAPTER

2

Trajectories of Chronic Illnesses

Michelle S. Gabriel

INTRODUCTION

Although everyone dies, not all people have had direct exposure to the dying process, even as adults. The U.S. culture is a death-denying culture. Death happens behind closed doors, and more often than not, in an institution versus in a home. The purpose of this chapter is to describe for the mental health provider what the dying process looks like and to introduce some of the key issues that face patients and families as well as the providers who care for them.

The picture of dying has changed over the centuries. Prior to the early twentieth century, dying was most often an acute event with a sudden onset and short duration. The average life expectancy was 47 and the death rate for the year 1900 was 1,720 per 100,000, with the major causes of death as infectious diseases or communicable diseases (Field & Cassel, 1997). Because death happened over a relatively short period of time and because of the lack of medical interventions and technology to address the main causes of death, medicine focused primarily on comfort. Dying often occurred in the home setting with the family as the primary caregivers.

The current picture of dying in America has shifted. The average life expectancy is 78 and the death rate in 2004 was 800 per 100,000, a decrease of more than 50% than in 1900 (Miniño, Heron, Murphy, & Kochanekek, 2007). The major causes of death are chronic illnesses, such as heart disease or cancer. The main reasons for the increase in life expectancy and the decline in death rate stem from medical advancements, such as the invention of antibiotics and improved medical technology, which have allowed health-care providers to prevent or treat once fatal conditions. With the advancement of medical technology, medicine's focus has shifted to curing illness where it can, or helping people to live as long as they can with chronic illnesses. And because of the successes of medical technology in treating acute events, which previously would have caused death, people are now dying of chronic illnesses over prolonged periods of time, even over the course of years as seen with dementia patients. Extended families and even nuclear families are less likely to live in the same city or even state. And for people with adult children living in the area, often both are employed, or have children of their own to take care of, making it difficult to also care for an ailing or dying family member. As a result, caregiving of the actively dying has shifted to relative strangers and dying takes place more often in institutions such as acute hospitals, skilled nursing facilities, or residential facilities compared to the home setting.

DYING TRAJECTORIES

For the geriatric population, there are typically three types of dying trajectories as depicted in Figure 2.1.

Short Period of Evident Decline

The first trajectory shows a steady decline with a short terminal, or dying, phase. This trajectory best describes the dying trajectory for someone with cancer or amyotrophic lateral sclerosis. The slope of the decline remains fairly constant barring any unforeseen complication from the illness, making prognostication—estimating the amount of time a person has left—a little easier. This pattern often allows for patients and families to plan for the death. Although most people prefer not to think about their own death or the death of a loved one, having some forewarning allows for completion of important tasks or projects, and allows for opportunities among family to say goodbye. People often start the grieving process ahead of the actual death, which is known as anticipatory grieving.

Long-Term Limitations With Intermittent Serious Episodes

The second trajectory depicts slow decline with periodic crises, followed by death. This trajectory describes the pattern of death as seen in people with congestive heart failure (CHF) or chronic pulmonary obstructive disease

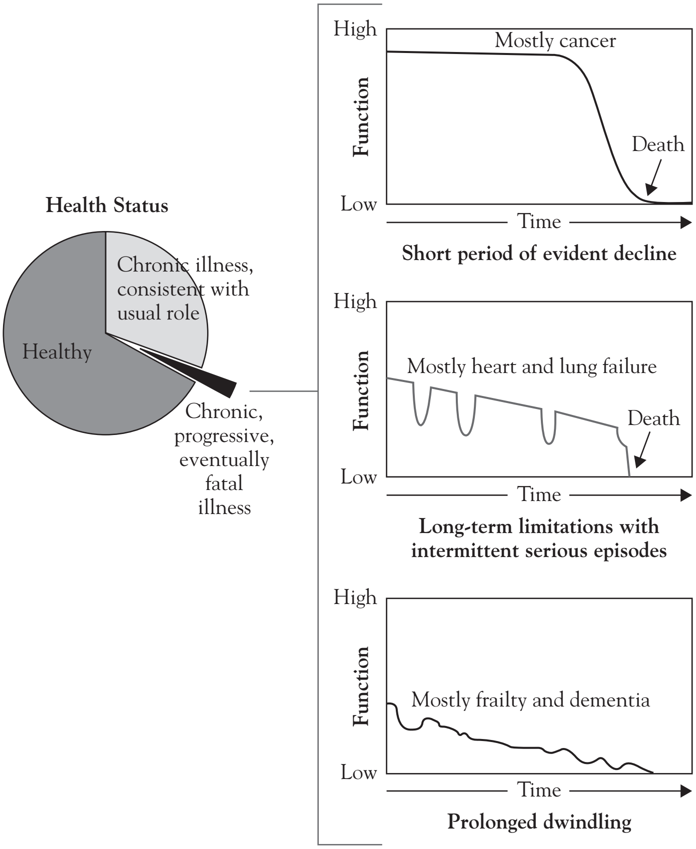

Figure 2.1 Three Trajectories of Chronic Illness in the Elderly
***Source*: Lynn and Adamson, 2003. Used with permission.**

(COPD) as just two examples. As the graph shows, the decline can be slow, but interspersed with crises often requiring acute medical interventions. For example, a man with CHF may be hospitalized for an exacerbation. He may require intensive care to stabilize his condition, using intravenous medications and continuous monitoring. From this crisis, he may recover, but often as the disease progresses, he may not recover back to his previous level of functioning. Early on in the disease, these crises can be separated by years, but as the disease progresses, health status decreases and the time between crises diminishes. One challenge in prognostication for this trajectory is the uncertainty that comes with each crisis. Will the person survive the hospital admission? In what condition will they be in when discharged? People and families of people with these types of illnesses often have difficulty in talking about transitioning to comfort care during a hospitalization because in their previous experiences, "Dad's always pulled through." Supporting patients and families throughout the chronic illness is an important role that mental health providers play.

Prolonged Dwindling

A third trajectory is described as a lingering, expected death. As seen with dementia patients or just with general decline with old age, this process can take years or even decades. A person's health status declines slowly over time. People may or may not have acute crises, such as an infection or stroke, but those crises can be treated, and they could recover close to their previous baseline. In the case of dementia, this type of trajectory can be devastating for patients initially, because they know of the irreversible and prolonged course of the disease, and then for family and caregivers, who have to find ways to support their loved one during this process. The financial toll of caregiving alone is immense, whether families take on the direct responsibility thereby sacrificing earned income or by hiring professional caregivers or paying for skilled care (Care at the End of Life, 1999; Centers for Disease Control and Prevention and the Kimberly-Clark Corporation, 2008). The need to adapt to a changing functional status and changing roles within the family structure is challenging. Often, a provider helps support these patients and families by identifying resources and support groups, and by facilitating ongoing discussions of overall goals for the individual as the disease progresses. Gallagher-Thompson and Coon (2007) reviewed evidence-based psychological treatments for reducing stress and improving quality of life for caregivers of elders with significant cognitive impairment; the same interventions reviewed may help patients and their families adapt to the changes that occur at end of life.

PROGNOSTICATION AND MEDICARE GUIDELINES

Prognostication, defined simply, is to predict an outcome. In the context of a chronic or terminal illness, a prognosis is the amount of time a health-care provider believes remains in light of an individual's illness. Prognostication is an art and a science. Over time, it can become easier for health-care providers to give a more accurate range of prognosis, but even then, sudden unexpected changes can occur that would change the overall prognosis. Even in illnesses such as cancer, where decline is predictable, no provider has the crystal ball. In fact, studies have shown that providers often tend to overestimate the amount of time a person has left by an order of three to five (Christakis & Lamont, 2000; Heyse-Moore & Johnson-Bell, 1987; Maltoni et al., 1994). This overestimation tends to worsen when providers have a close and long-standing relationship with a patient.

In helping to anticipate whether an individual is approaching end of life, a useful question for providers and individuals and families alike is, "Would you be surprised if your patient/you/your loved one died in the next year?" Although providers can initiate discussions about end-of-life wishes and individuals' hopes and goals throughout their lives, if the answer is yes, it is especially important to have these discussions. Taking the time ahead of a crisis to plan for the future helps to avoid inappropriate interventions that may have been unwanted should an acute event occur.

In considering the previously mentioned illness trajectories, the National Hospice and Palliative Care Organization generated some medical guidelines for specific diseases to help health-care providers and hospice agencies determine whether an individual has six months or less to live should the disease follow its natural course. These guidelines were established in 1996 and served the main purpose of justifying hospice appropriateness so that Medicare would reimburse the hospice agency for care provided. More recent research questions the validity of these guidelines, but hospice agencies often use them in assessing patients referred for care to determine appropriateness (Daleiden, 2009). Table 2.1 summarizes the guidelines by disease. General guidelines that aid in indentifying end-of-life patients include a decline in functional status, weight loss greater than 10% in the past six months, frequent hospital admissions, or increasing frequency of hospital admissions and recurrent infections. *Fast Facts and Concepts* contain more up to date information on prognosis by various diseases (http://www.eperc.mcw.edu/EPERC/FastFactsandConcepts).

CHANGES ASSOCIATED WITH DYING AND THE SYMPTOM EXPERIENCE

Although dying trajectories vary by disease process, more often than not the picture of imminent death/active dying looks similar, barring an acute event such as a hemorrhage or myocardial infarction. This phase starts from

Table 2.1 Prognostic Criteria by Disease

Disease	Guidelines
Heart failure	• NYHA Class IV heart failure • Ejection fraction <20% • Several acute admissions for heart failure in the past year
Chronic obstructive pulmonary disease	• Oxygen dependent • At best, only able to walk a few steps without tiring • Unintended weight loss of >10% of body weight • Several acute care admits for COPD in the past year
Renal failure (kidney failure)	• Chronic renal failure with creatinine >8.0 off dialysis
Cirrhosis/Liver failure	• Spends most of time in bed • Multiple co-morbidities
Dementia	• Largely mute • Bed-bound • Urinary and fecal incontinence • Presence of co-morbid conditions in the past year
Strokes/Coma	Acute phase: • Coma or persistent vegetative state beyond three days duration • Dysphagia interfering with nutrition/hydration Chronic phase: • Poor functional status • Poor nutritional status • Recurrent medical complications

Source: National Hospice Organization (1996).

hours prior to the death up to days before the death. The dying trajectory itself is influenced by many factors, including illness course, withdrawal of life supports such as ventilatory support or medications, and patient choices (e.g., whether to initiate or continue treatments). Being knowledgeable of the clinical picture of dying helps providers intervene with patients and their families. The knowledge of the normal process of dying helps alleviate fears about dying that either patients or family members possess.

Symptoms Experienced at the End of Life

At the end of an advanced illness, people experience various symptoms. Often it is the presence of these symptoms that indicate an individual is nearing the end of his or her life. These symptoms may continue on during the imminent dying phase, but can be treated to relieve an individual's suffering. Common symptoms that individuals may experience include: dyspnea (shortness of breath), nausea, anorexia/cachexia, and fatigue. Healthcare providers need to assess for these symptoms, treating the primary cause if possible. However, when providers cannot treat the primary cause, they can treat the symptom. Table 2.2 lists possible interventions that may help ameliorate the impact of these symptoms.

Changes Associated With Active Dying

Dying is a personal experience and there is no *typical death*. However, there are many physical symptoms that people experience during the active dying process. Not every person will experience all of these symptoms and passing along this information to patients and families when educating them about the dying process is important.

Understanding the physical changes that happen to different organ systems helps to explain the various symptoms that may manifest during the dying process. Although people could be considered dying from the moment they are born, most often people consider someone who is dying to be at the end of his or her life on a time scale of weeks to months (i.e., hospice-eligible). When providers identify a patient as "transitioning," that is often defined as a patient who has moved to the actively dying phase and where imminent death is expected (i.e., minutes to hours). As the body shuts down, the body's instinct is to preserve the function of vital organs (e.g., heart and lungs) at the cost of other nonvital organs (e.g., kidneys, gastrointestinal tract). Table 2.3 highlights common physiological changes that can occur with the dying process.

Symptoms Associated With Dying

It is a useful intervention to normalize the different symptoms that occur during the dying process and to treat distressing symptoms as they happen. Preparing families to expect changes in levels of consciousness or to anticipate irregular breathing can make the experience less frightening. Table 2.4 highlights symptoms

Table 2.2 Potential Symptoms at End of Life

Symptom	Possible Causes	Interventions
Dyspnea	• Physiological changes associated with advance disease • Presence of a tumor impeding the airway	• Pharmacological—low doses of opioids and or inhaled medications, oxygen • Nonpharmacological—use of a fan on a person's face, elevation of pillows or the head of the bed
Anxiety (Pasacreta, Minarik, & Nield-Anderson, 2006)	• Physiological causes (e.g., endocrine disorders, cardiovascular conditions, metabolic conditions) • Side effects from medications • Distress from real or potential symptoms (e.g., anxiety associated with dyspnea, fear of pain during the dying process)	• Treatment of underlying physiological causes • Pharmacological—use of benzodiazepines, antidepressants, and others • Nonpharmacological *Prevention* strategies such as increasing opportunities for control and acknowledging fears. *Treatment* strategies such as presence of support person and teaching of anxiety-reduction strategies.
Anorexia/Cachexia (Kemp, 2006)	• Metabolic alterations • Disease process • Symptoms (e.g., fatigue, pain) • Side effects of medications • Distress	• Symptom management • Appropriate use of nutritional support • Education regarding the risks and benefits of nutritional support (i.e., lack of appetite at end of life is common and often related to advance disease; supplementing nutrition often does not reverse weight loss and can lead to other distressing symptoms, such as nausea) • Offer food for pleasure
Fatigue (Anderson & Dean, 2006)	• Disease process • Treatment related • Side effects of medications	• Establish reasonable expectations • Correction of possible etiologies (i.e., treat depression or pain, treat anemia if appropriate) • Pharmacological—use of psychostimulants or low-dose corticosteroids • Nonpharmacological—patient education, modify activity

Table 2.3 Common Physiological Changes That Occur With Active Dying

System	Changes
Neurological	• Comatose • Delirium or confusion
Cardiac	• Hemodynamic instability—decreasing blood pressure, elevated heart rate • Cool and mottled extremities • Weak peripheral pulses
Respiratory	• Shallow, rapid breathing • Irregular breathing pattern (e.g., Cheyne-Stokes) • Pulmonary congestion, increased secretions ("death rattle")
Renal	• Urinary retention • Oliguria (lack of urine production)

Table 2.4 Symptoms Associated With Active Dying and Possible Explanations to Be Used With Families

Symptom	Explanation
Death rattle—best described as noisy breathing. Families often fear that their loved one will die by drowning in secretions.	As someone is dying, he or she loses the ability to swallow, so saliva accumulates at the back of the throat. Breathing past these secretions causes the "death rattle." More distressing to the family (similar to someone who snores; doesn't disturb the person snoring, but disturbs the people around).
Oliguria—lack of urine output	As the body preserves the vital organs, less blood circulates to the kidneys, resulting in a decrease of urine (even if someone is receiving hydration through an IV).
Cool and/or mottled extremities	As the circulation focuses more on the heart and lungs, blood flow is diverted from the arms and legs, leading to the mottled appearance and the cool temperature.
Confusion/delirium	As the kidneys and liver shut down, waste products accumulate in the body that contributes to this symptom. Confusion and delirium can also be attributed to side effects of medications.
Coma (or inability to awaken the dying person)	Often, although not always, people who are dying become sleepier and less interactive. In part, this can be explained by the overall shutting down of higher functions, with only vital functions preserved (such as the heart beating and breathing). Can also be explained by the accumulation of metabolic waste products as described above.

that can often cause distress and ways providers can explain these symptoms to families.

Although pain is not always part of the dying process, it is one of the most feared symptoms. If a person has not had pain with the disease process prior to dying, it is not a symptom that would be expected during the active dying process, and reassuring people and families of this fact is really important. However, studies have shown that many people experience pain in the days to weeks preceding their death, which stresses the importance of health-care providers assessing for this symptom and families advocating for their loved one should they feel they are in pain (Coyle, Adelhardt, Foley, & Portenoy, 1995; SUPPORT, 1995).

Medications are available to treat pain as someone is dying. A common fear in using pain medications, specifically opiates, is the fear of hastening someone's death or the fear of addiction. Research demonstrates that treating pain with high doses of opiates does not hasten death (Bercovitch, Weller, & Adunsky, 1999). Treating pain and other distressing symptoms reduces stress on the body; not adequately treating pain has been shown to suppress the immune system, which in turn could lead to a hastened death (Page, 2003). Explaining this to families alleviates fears about using opiates to treat pain. The fear of addiction is often rooted in cultural values. Further examination of the fears that patients and or families have concerning addiction will help clinicians tailor the best response and educational intervention. Commonly, the point needs to be made that an actively dying patient simply cannot achieve the psychological state of addiction. Obviously, addiction requires time that a dying patient lacks.

One of the challenges with treating pain in a dying person is the difficulty in assessing and measuring pain, especially if the person is nonresponsive or unable to describe their pain. Providers should assume that any pain that existed and was reported prior to the actively dying phase will continue and its treatment should continue. Pain can also be assessed in nonverbal patients by examining behavioral cues such as grimacing, muscle tension, and moaning. If it is unclear for the reasons for changes in behavior, a trial of analgesics using the person as his or her own control is appropriate. If the behaviors that might indicate pain stop after the administration of medications, it is safe to assume that the person was in pain and that the treatment was appropriate. Another challenge that exists is for the provider to differentiate between a patient's pain and a family member's pain and suffering that they are then projecting onto his or her dying loved one, as exemplified by a family member requesting the provider to just "hurry things up." It is important for providers to assess how family members are coping and to validate their feelings. Equally important is to identify strategies to help families cope. Requests by family members to hasten their loved one's death cannot be honored, as it is illegal in all states for providers to administer medications for the purpose of hastening someone's death.

BARRIERS TO QUALITY END-OF-LIFE CARE

Many barriers still exist to providing quality end-of-life care. Aside from the existing health-care system, where the default is to do everything to prolong life unless documented otherwise, we as a society often fail to recognize that there are limits to modern medicine and its interventions. Too often, aggressive curative treatments are used inappropriately. Americans value both autonomy and use of any intervention that may give people a chance at survival, no matter what the cost or how small the chance. Combined, these values contribute to the inappropriate use of aggressive care at the end of life.

Another barrier to quality care at the end of life is the lack of adequate professional training across all disciplines. Studies that look at curriculum content for nursing and medicine showed that minimal pages were dedicated to this area, even though both nurses and physicians care for dying patients (Ferrell, Virani, & Grant, 1999; Rabow, Hardie, Fair, & McPhee, 2000). Whether doctors and nurses are mentored in learning about how to care for dying patients depends in part on the experience of the mentors; often there is no consistency or assurance of a standard level of care. Researchers and clinicians have looked at ways to improve the training of professionals in this area. Curricula have been created specifically addressing areas important in providing end-of-life care for various disciplines. These curricula include Education in Palliative and End-of-Life Care (http://www.epec.net), End of Life Nursing Education Consortium (http://www.aacn.nche.edu/ELNEC/), and Advocating for Clinical Excellence (http://www.cityofhope.org/education/health-professional-education/nursing-education/ACE-project/Pages/default.aspx). The American Psychology Association recently created online modules specific to end-of-life care (http://www.apa.org/ce/eol.html).

Other barriers to providing adequate care at end of life include: professional and personal discomfort with death, lack of preparation and communication regarding the progression of a disease process before a crisis occurs, delayed access to palliative care services, regulation of controlled substances, lack of a comprehensive plan of care for comfort care of the dying patient, and unrealistic expectations of medical interventions, such as resuscitation.

Resuscitation is often a sudden and unexpected event, usually without advance planning. Unrealistic beliefs about survival are fueled by portrayals of resuscitation in the media, such as on television shows like *ER* or *Chicago Hope*. In reality, outcomes are usually poor because most patients who arrest in a hospital setting are not in good health to begin with.

PREPARING FOR THE DEATH

In preparation for a death, especially one that is expected versus sudden, there are some skills and topics that are important to address: communication, advance care planning, final arrangements, and hospice. One key skill is that of communication. Although it is not the emphasis of this chapter to provide the reader with a set of communication skills, it is appropriate to address some issues. Many challenges exist with regard to communication. These challenges include: a lack of discussion on death and dying by providers; discomfort in talking about death and dying; a fear that by broaching the subject of death, it can take away hope; and a fear of burdening others. The first step to overcoming these barriers is to be aware of them.

Advance care planning is a process. There are many aspects involved, including durable power of attorney, both for health care and for finances, and living wills. Chapter 6 (Gabriel & Kennedy) addresses advance care planning in detail.

As people prepare for death, or after a death has happened, families must think about final arrangements. These arrangements include the specific funeral arrangements (e.g., whether to bury or cremate someone and the type of service, if any, to provide), and can include discussions of body/organ donation and autopsy. In working with families, sometimes there may be difficulty accepting the wishes of their loved one, and it is useful to help families to process this tension.

Discussion of Hospice

A chapter on end of life would not be complete without a discussion of hospice. In hospice, the goal of care is to provide comfort and support to patients and families when cure-oriented treatments are no longer desirable. Hospice care was systematized in the Medicare Hospice Benefit legislation passed in 1982 and implemented in 1983. As a package with hospice, a patient and family get visiting nurses, aides, social workers, chaplains, and volunteers. The core group required of Medicare-certified hospices must include a physician, nurses, social workers, and pastoral or other counselors. Hospice agencies often include additional providers, such as psychologists or massage therapists. Nurses are available by phone around the clock, and can make emergency visits as needed, which helps to avoid unnecessary emergency room visits. All medications related to the terminal illness or to treat distressing symptoms and to provide comfort are covered, as is durable medical equipment. There are four levels of hospice care covered by the Medicare benefit, ranging from routine home care to respite care in order to give a break to caregivers, continuous care if skilled nursing is required in the home temporarily, up to general inpatient level of care in times of crisis (e.g., pain crisis). A medical director is available for consultation. Beyond the death, bereavement support for the family is covered for one year. This last benefit truly manifests the hospice philosophy that the family is the unit of care.

Hospice care is not without its challenges, especially in U.S. society where the belief often exists that agreeing to hospice means giving up hope. Indeed, enrolling with hospice often requires foregoing care that prolongs life (i.e., stopping dialysis for someone with end-stage renal disease). In part, this "either/or" issue is a result of the financial limitations on hospice. Hospices are reimbursed by Medicare on a per diem basis; for every day that a person is on hospice, the agency receives an established rate based on level of care and location. However, no matter how few days a person is with the agency, they and their families still receive the intensive services, and then bereavement support for the year after the death. When people referred to hospice are actively dying, hospices lose money because the person is not on services long enough for the agency to recoup their costs in providing all the intense services during the days preceding the death. Now that there are many interventions that are truly palliative but that can also extend life (e.g., certain chemotherapies or blood transfusions), hospices are beginning to struggle with where to draw the line, because if they accept these patients, they will have to cover the costs of these interventions, which would be fiscally prohibitive.

By enrolling people earlier into hospices, both the patient and the family benefit from establishing relationships with the hospice providers. The hospice team has more time to assess and treat distressing symptoms that may occur with the disease, which then allows patients and families to focus on other important tasks during this time period. As Christakis (1998) notes, when people die soon after being enrolled onto hospice, there is not enough time for the team to assess the patient and family in order to develop and implement a comprehensive care plan. He also states that a late or last minute transfer to hospice can be disruptive because of the need to establish new caregiver and patient/family relationships. Providers are challenged to identify hospice-appropriate patients in a timely fashion and to facilitate the conversations that can inform patients and their families about the benefits of hospice.

CONCLUSION

This chapter reviews the way dying looks today, along with the several different types of dying trajectories. It also covers prognostication and its challenges, and includes a brief review of the Medicare guidelines for prognostication of noncancer diagnoses. Both the changes associated with dying and the symptoms experienced as a part of dying are reviewed. The chapter concludes with a discussion of barriers to quality end-of-life care and issues to be aware of in preparing for the death. As an appendix, there is a list of online resources that may be useful to the provider caring for people and families at the end of life. Being knowledgeable of what the dying process looks like, and what symptoms people experience, will help providers better meet the needs of individuals and their families.

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APPENDIX—GENERAL ONLINE RESOURCES FOR HOSPICE AND PALLIATIVE CARE

apa.org/pi/eol/

Main portal of APA that focuses on end-of-life issues and care.

prc.coh.org

City of Hope Pain and Palliative Care Resource Center.

www.capc.org

Web site for the Center to Advance Palliative Care.

www.caringinfo.org

Web site for Caring Connections, a program of the National Hospice and Palliative Care Organization targeting the public.

www.chcr.brown.edu/pcoc/toolkit.htm

The Toolkit of Instruments to Measure End-of-Life Care (TIME).

www.getpalliativecare.org

Web site providing information to the public regarding palliative care.

www.growthhouse.org

Web site aimed at improving care for the dying. Contains online texts and multiple resources on palliative care.

www.naswwebed.org

Sponsored by the National Association of Social Workers, offers an online course on *Understanding End of Life Care: The Social Worker's Role*.

www.nhpco.org

Web site for the National Hospice and Palliative Care Organization.

www.socialworkers.org/practice/bereavement/standards/standards0504New.pdf

PDF file of the National Association of Social Workers Standards for Palliative and End of Life Care.

CHAPTER

3

The Cultural Context of Spirituality and Meaning

E. Alessandra Strada

Aging is a complex process that affects individuals on multiple levels and has profound effects on quality of life. It involves multiple changes that impact on physical, psychological, and spiritual domains. Changes can be perceived as sudden and traumatic; others are more subtle and occur over a period of time, thus allowing the psyche to adapt to a new psychophysical reality. Aging may also bring the awareness of mortality closer to daily life. Awareness that the amount of time one has to live may be less than the time one has already lived, may cause psychological and existential suffering, especially if patients are experiencing regret about past experiences.

Although acquired experience and wisdom can help balance the difficulty adjusting to the losses involved in the aging process, including the awareness that death may be near, the challenges faced by older patients who are also faced with end-of-life concerns should not be minimized. This chapter reviews some of the concerns relevant to the lives of older persons facing advanced illness and end of life. It highlights risk factors and concerns. It also discusses protective factors and strategies that can minimize the struggles and suffering faced by this vulnerable and often underserved population.

END-OF-LIFE CARE AND OLDER ADULTS

Older adults with chronic and advanced illness face unique challenges as their physical conditions decline and they approach the end of life. They may experience several comorbid conditions, including high levels of emotional distress, which can complicate the clinical presentation. Even mental health professionals experienced in working with an older population may find themselves unprepared for the challenges inherent in the death and dying process. Therefore, it is useful to highlight some of the most common concerns in various quality-of-life domains faced by older adults at the end of life.

A thorough psychological assessment with this particularly vulnerable population will ideally identify issues related to the aging process, issues related to the dying process, and issues that are at the interface of aging and dying. For example, psychological difficulties experienced by persons adjusting to the loss of physical function, social roles, and personal identity due to the aging process should be addressed therapeutically, and differentiated from the preparatory grief experienced by those who are dying. The advantages offered by a thorough assessment and identification of issues that can be realistically addressed even if the prognosis is limited are twofold. First, it allows the dying person to maintain a higher level of psychological quality of life, facilitating adjustment in the face of multiple previously experienced, as well as future losses. Second, it allows clinicians to relate to the person as someone who is still fully alive, even in the face of death. Mental health providers specializing in palliative care recognize that hope is directly connected to a person's ability to identify and accomplish goals identified as instrumental in maintaining a sense of personal efficacy and control, as well as quality of life. Therefore, while illness progression may significantly affect the prognosis, clinicians may continue to help identify and accomplish realistic goals that may have a positive impact on well-being and overall quality of life. Identification of each person's unique concerns in the various domains of quality of life is the first step of the assessment process.

Older adults with advanced illness may face serious challenges when they attempt to navigate the medical system. Access to care is an important concern. Financial stressors may prevent older adults from seeking medical care in a timely manner, because they may be concerned that they would not be able to afford quality care. Additionally, they may not be aware of what services and resources may be available to help them deal with financial distress.

Immigration status and level of acculturation are also important factors that need to be taken into account. Older adults who are new to U.S. culture and may have little or no English can be particularly vulnerable in the medical system and need extra support. The person's ability to understand rights, and ask and receive information related to medical care may be compromised. Often, older persons familiar with cultures where the relationship between medical providers and patients is primarily hierarchical may have difficulty understanding and relating to the emphasis on personal empowerment, information gathering, and direct communication typical in U.S. mainstream medical culture. Older adults raised in cultures where physicians are considered absolute experts whose opinion should not be questioned may have difficulty asking questions, asking clarifications, offering suggestions, and developing a more collaborative relationship with their medical providers. The unexpressed concern that asking questions may be perceived by physicians as a direct challenge of their authority may prevent older adults, especially those without family members or other caregivers and advocates, from becoming directly engaged in their care and participating meaningfully in the decision-making process. In essence, palliative and end-of-life care often require complex decision making regarding ethical issues and treatment choices. Persons who do not speak English, who are not familiar with medical culture in this country, or who do not have primary caregivers who can be their advocates and negotiate the relationship between them and their physicians may experience significant loneliness and distress. Mental health providers may play an important role in guiding vulnerable older persons through the complexities of the health-care system.

Comorbid preexisting physical and psychological conditions may limit the options to remain at home, maintain independence, and retain a sense of control. A history of psychiatric illness can expose older persons to significant stress and suffering. Both preexistent conditions and conditions developed as a result of the progression of illness and impending death need to be addressed appropriately by professionals. Older adults whose psychiatric symptoms are well controlled by medication and other interventions can experience exacerbations or recurrence of active illness as a result of the stress caused by the necessity to face death. A history of multiple losses or unresolved grief can prevent the patient the development of adequate coping mechanisms for the uncertainty of illness and the fear of death (Bookwala & Shultz, 2000; Hatch, 2005; Knight & McCallum, 1998; La Rue & Watson, 1998; Myers & Harper, 2004; Weiss, 2005).

Older adults may be socially isolated and unable or unwilling to reach out for practical or social support. Even when they have family support, their caregivers may have become overwhelmed and overburdened by caring for them and be unable to meet all of their needs. These interpersonal challenges affect older adults' emotional and spiritual well-being and need to be addressed by the palliative and hospice team. It is important to remember that the palliative care and hospice team typically gets involved in patients' care when illness is already advanced and death may be close. The team is therefore presented with a snapshot in time of the patient's interpersonal, social, cultural, psychological, and spiritual context. Many older adults with advanced illness who may be approaching death have a history of multiple losses in their circle of friends and family. Comprehensive assessment of the older adult's current situation and historical context is crucial in order to develop an adequate psychological treatment plan. The assessment should particularly focus on past and current history of losses, prevalent grieving style expressed by the older adult and caregivers, past and current history of psychological and psychiatric disorders, current social support and interpersonal styles. The essential role of culture is to provide individuals with a set of rules that guide behavior and help provide a context for events. A person's cultural background not only has an important impact on the meaning-making process in the face of illness and approaching death, but also often represents the basis of attitudes and beliefs influencing the perception of what can be considered "normal" or "acceptable" behavior in society. As a result, culture typically guides the decision-making process and subsequent decisions, helping resolve internal conflict and reconciling different positions.

A person's culture is an essential expression of her or his unique way of being in the world, negotiating relationships, experiencing and expressing grief, and making sense of difficulties, including illness and death. Mental health professionals need to assess how medical culture has been integrated into the dying person's culture (Helman, 1994). Therefore, it can be useful to identify core cultural issues that become especially relevant when working with older adults with advanced illness, who may be approaching the end of their life. Key components of culture include: (a) learned behavioral patterns, (b) values, and (c) essential beliefs to explain the nature of the self, others, and the supernatural. Core values and essential beliefs about the nature of self and the world represent an important aspect of one's spiritual dimension, because they relate to how people make sense of experience and decide how to act in the face of challenges. Core cultural issues that may guide older adults' behaviors in their interactions with medical providers include levels of autonomy, ways of relating to authority figures, ways of understanding and relating to physical closeness in public settings, such as doctor's offices and hospitals, and communication style (Carrillo, Green, & Betancourt, 1999). Every encounter between a clinician and a patient could be conceptualized as a cross-cultural encounter. Individuals who share the same ethnicity, who share many cultural practices and even backgrounds, may still differ on several cultural dimensions. Clinicians may assume that they "bonded" with the patient and "speak the same language" from a cultural standpoint on the basis of perceived commonalities. However, it must be noted that the way older adults deal with advanced illness and death and dying is the expression of past personal experience and unique aspects of family culture. Therefore, to avoid making false assumptions that would create additional emotional burden for older adults and families, it is important that clinicians hold assumptions about intentions and behaviors lightly. When assessing understanding of impact and meaning of medical information, as well as plans to deal with it, it is always best to rely on information communicated directly by the patient and the family. Cultural dimensions that are especially relevant to the patient-clinician encounter in the context of palliative and end-of-life care are more subtle and require clinicians to be more attuned to emotional aspects of the communication. For example, patients differ in the way they manage intense emotions and express affect. Culture affects the way older adults deal with cognitive ambiguity, which is commonly experienced by patients with advanced illness.

Health care has a unique culture, manifested in health-care professionals' communication styles and behaviors toward patients. Therefore, it is beneficial to recognize that the patient-clinician encounter is a cultural, spiritual encounter and is fertile ground for misunderstandings and poor communication. For example, the phrase "The patient *failed* the last chemotherapy treatment and will now be followed by the palliative care service," is often used with the intent to convey a medical fact—that is, the chemotherapy treatment did not work for the patient, so curative or life-prolonging treatments are no longer a viable option and the focus of care should shift to symptom management and comfort. However, the use of the term "failed" applied to the patient has profound meaning reflecting the particular perspective of medical culture. Similar phrases should not be used in the presence of the patient because a careless use of language can have a negative impact on psychospiritual well-being.

An 80-year-old woman with advanced ovarian cancer was visited by her oncologist in her hospital room. The doctor communicated to her that regrettably, the last trial of chemotherapy had not been successful and the cancer had continued to spread. He added that trying other chemotherapies would not be helpful and that the focus of the care should shift to enhancing comfort and quality of life. The woman was understandably distressed by the conversation, but trusted her oncologist to recommend the best course of action. While the oncologist was still in the room, an oncology resident who had also been involved in the care approached the door and asked if he could come in. The woman agreed because she knew and liked the resident. The attending oncologist began updating the resident about the patient's conditions and said that the patient had *failed* the chemo and that pursuing further active treatment would not make sense. He also stated that he and the patient were in perfect agreement about the next steps to take and left the room telling the resident how pleased he was that he had such a good relationship with the patient. A few hours later, the patient was visited by her psychologist for a therapy session and started to cry. She stated:

> What does it mean I failed the chemo? I did not fail anything! I did my best to cope with the terrible side effects because I was hoping it would prolong my life and now I have to listen to the doctor, whom I thought was on my side, say that I failed? So, is it my entire fault that I have to die? Does God also think that I failed? So I did all that, endured all that suffering for nothing and now I have to hear not only that I am basically dying, but that it is my fault?
>
> *(verbatim from the recorded therapy session)*

The woman was so agitated and distressed that a breathing and relaxation exercise was immediately started to decrease the level of arousal. In light of the recent communication about her poor prognosis, a small dose of anti-anxiety medication had to be administered by the attending physician on the floor before she could fully engage in the therapy session and process her emotions. The story illustrates the importance of a clinician's self-awareness.

Core cultural values and spiritual beliefs are often interconnected. Recognizing and honoring those values is not only a manifestation of cultural sensitivity on the part of the clinician, but it also represents respect for the patient's spiritual life, as well as the meaning-making process. Making an effort to identify and honor core values important to patients and their caregivers and understanding the impact of language and behaviors on patient psychospiritual well-being is every palliative care clinician's responsibility.

The importance of self-assessment as a first step in facilitating communication with older patients cannot be overestimated. Because the topic of advanced illness and death and dying is so charged and sensitive, it is essential that providers develop awareness of the values that guide their communication with patients. Five questions that can help to identify belief systems are:

1. What is your belief system when it comes to person-provider communication? Do you believe that physicians should talk in an open and direct manner to adults about their diagnosis and prognosis?
2. How do you think one can maintain a sense of meaning and purpose in life, in the midst of illness and possible death?
3. What do you think about very sensitive topics, such as withdrawing life-support, voluntary suspension of nutrition and hydration?
4. How do you personally conceptualize hope in persons with terminal illness?
5. What do you think the role of the family should be in determining the level of information that should be given to the ill person? Do you believe it is acceptable that in some situations medical information should be communicated to the patient through the family? Or do you believe that all information should be directly communicated to patients?

Clarifying where you personally stand in regard to these issues will allow clinicians to be aware of personal agendas in interactions with patients. Hopefully, this awareness will allow you to set agendas aside, or at least hold them lightly, while pursuing the goal of helping patients and caregivers navigate the health-care system and make sense of declining health and approaching death.

THE ROLE OF COMMUNICATION IN MEANING-MAKING AND HOPE

Understanding personal and family norms related to direct or indirect communication is important, because it is directly related to the way older persons make sense of their physical condition. The U.S. medical cultural values direct communication with patients about diagnosis and treatment implications, as well as transitions of care and prognosis. According to this model, clear and direct communication allows older adults and caregivers to gather important factual information about realistic options. The underlying and implicit assumption in this model is that information is empowering because it allows older persons and caregivers to make decisions based on facts. In other cultures, medical providers commonly discuss medical information with family members, leaving them to decide the level of disclosure that will be acceptable to the person with illness and not cause what is sometimes described by caregivers as "unbearable" emotional distress.

Older adults especially identify adult children or other family members as the decision makers about medical issues. According to the same cultural model, the family has not only the right, but the responsibility to determine what information should not be transmitted to the ill person in the effort to protect him or her from despair. According to this model, truth, or parts of the truth, can be hidden from someone if revealing them would increase needless suffering. As a result, the direct communication model embraced by U.S. medical culture may at times clash with other cultural models that emphasize the importance of allowing the family to "protect" its members by not sharing all the medical information related to a poor prognosis. Communication among older adults, family members, and providers may become challenging and create emotional distress for all involved.

For example, in some cultures, while communicating truthfully with patients about diagnosis and prognosis is an important value, it needs to be balanced with the need to maintain hope that cure may be an achievable goal. Clinical psychologists and other clinically trained mental health professionals can have an important role in identifying cultural issues and belief systems that may impact on older adults' wishes about medical care. They can facilitate communication between families and the medical team, minimizing emotional distress for everyone involved. Psychotherapy can help older adults gently explore their understanding of hope and reframe it when it is clear that cure is no longer possible.

Hope is a dynamic construct that may evolve in the course of the illness. A woman with metastatic breast cancer described her personal conceptualization of hope in the following manner:

> When I was first diagnosed I was hoping for cure; I just wanted the cancer to go away. I know I am almost 70, but I just wanted to get rid of the cancer and go on with my life. And I did all the chemo, and I was really hoping it would kill all the cancer. But the cancer came back and now it's all over my

> body. And now I am still hoping for different things. I hope for a day without pain, I hope for a good bowel movement. Now I hope for things in the very, very near future, typically in the same day. I feel that hope is closer to me now; it's always very close. But hope does not go away. I will continue to hope for something until I die.
>
> *(verbatim from a recorded therapy session with a 68-year-old patient, approximately two months before she died)*

SPIRITUAL ASPECTS OF CARE

Spirituality is a complex construct for which many have attempted to capture its essence. As a result, several definitions have been offered, each focusing on one particular aspect of the construct, such as transcendence, or relationship with the divine. One definition that captures the richness of this construct and its potential for affecting people's lives was offered by Moberg (1996): "totality of man's inner resources, the ultimate concerns around which all other values are focused, the central philosophy of life that guides conduct, and the meaning-giving center of human life which influences all individual and social behavior." Even though there are many models of spirituality, it is possible to delineate some of the general characteristics of this construct, as recognized by various models in the literature. As such, spirituality pertains to a sense of relatedness to the transcendent dimension, with interpersonal, intrapersonal, and transpersonal components. Spirituality can be described as a multidimensional space that includes several aspects of its expression. It includes spiritual practices, beliefs, and types of spiritual experience. While spiritual practices represent observable behaviors, spiritual beliefs are influenced by culture and personal history. The two constructs of religion and spirituality can coincide, as in the case of people who belong to a religious organization, and also feel profoundly spiritual. Spirituality and religion share reverence for the sacred and the relationship with transcendence. Additionally, they may share the existence of community, even though many spiritual people do not join a community and consider themselves solo practitioners of their particular spiritual practice (Freke & Gandy, 2001; Reed, 1991; Touhy, 2001). However, there may be fundamental differences between the two constructs. Although religion involves a specific set of practices, beliefs, and rituals in an organized structure within an organizational context, spirituality may refer to a broader concept.

The concept of explanatory model of illness developed by Kleinman (1987) is typically used in the context of teaching effective ways of communicating with patients and caregivers, in an effort to create a bond between patients and providers based on understanding and respect. It is certainly true that helpful communication with patients about their diagnosis and prognosis depends on providers' abilities to develop an understanding of the meaning and implications from the perspective of the patient and the family. Asking the questions included in the explanatory model of illness will allow providers to unfold patients' belief systems about the illness, its meaning, and the implications. However, following the model of the explanatory model of illness will also allow clinicians to have access to spiritual beliefs that guide the meaning-making process that ultimately allows the patient to draw certain conclusions about the illness. Therefore, asking questions that explore patients' understanding of their journeys through illness can provide vital information about who the patient is from a cultural, spiritual, and existential standpoint.

- What do you call the illness?
- What do you think has caused the illness?
- Why do you think the illness started when it did?
- How does the illness work?
- Who should make decisions?
- How severe do you think the illness is?
- What kind of treatment do you think you should receive? What results do you expect?
- What are the main problems the illness has caused?
- What do you fear most about the illness?

The following questions are also useful. They are not part of the original model, but they expand the exploration.

- Has the illness changed who you are? If yes, in what way? If not, what has allowed you to continue to be who you are without getting lost?
- What do your loved ones think about this illness? Do they think about it as you do, or are there differences?

The importance of personal spirituality in the context of aging has recently received more attention in the literature. Spiritual concepts such as transcendence and self-transcendence have been used to focus attention on the developmental role of spirituality. Transcendence has been described as "detachment and separation from life as it has been lived to experience a reality beyond oneself and beyond what can be seen or felt" (Zerwekh, 2006). Self-transcendence has been described as a developmental process and as a protective factor in depression in middle age and aging (Ellerman & Reed, 2001).

Persons facing the end of life may often experience significant emotional, spiritual, and existential distress. Being able to understand accurately the nature of suffering and determine a possible diagnosis is often a challenging task that requires clinical skills, judgment, and ability of the part of the clinician (Puchalsky, 2002; Saunders, 1988; Speck, 1998). Some of the common causes of emotional distress in patients with advanced illness are depression, preparatory grief, and demoralization (Storey & Knoght, 2003; Strada, 2009). Formulating a correct diagnosis can be a challenge due to the similarity and overlap of clinical manifestations. It is, however, an important step in allowing the implementation of the appropriate treatment plan.

Gerotranscendence, originally described by Tornstam (2005), is an important construct that is receiving increasing attention because of its applications in clinical practice. It describes a particular level of ego development experienced by many older adults, independent of physical illness. Developing an understanding of this phenomenon is important, because some of its core manifestations can resemble social and interpersonal withdrawal that may be mistaken for depression. The term *gerotranscendence* refers to a complex interpersonal, emotional, and spiritual process that essentially brings the older adult to shift perspective from a material to a nonmaterial world. According to this principle, the rules and values that used to represent sources of meaning for the individual change, with a shift in personal sources of meaning that translates into increased internal life satisfaction. It is the result of a personal development, not a pathological process (Cumming & Henry, 1961).

The process of gerotranscendence can also help to understand an older adult with physical illness. A patient experiencing gerotranscendence described the following experience:

> It's not that I don't care about my grandchildren, or my friends. I am more focused on other things. These days I like to remember the past, but I also think about the meaning of life, about the meaning of my life, as a human

> being, you know? I mean, what is this all about? And I look at the stars at night and wonder about life on other planets and God. And I feel perfectly content just sitting there and contemplating. Social gatherings, even things I used to enjoy very much, like going to the theater, or the opera do not mean as much anymore. I am just happy being. I enjoy being alive, and contemplating my thoughts. And now that I know I am dying, being with myself is even more important.
>
> *(verbatim from a recorded therapy session with a patent with advanced lung cancer, eight months before he died)*

Here, the patient has no subjective feeling of emotional distress, but instead enjoys a deep contemplation of the past and the present. This internal movement toward transcendence does not represent a form of psychopathology and it is a process that should be supported.

Gerotranscendence needs to be differentiated from the natural, progressive disengagement from life activities that is often experienced by adults at the end of life. In this case there is less contemplation of transcendent realities and more withdrawal. This withdrawal should not be confused with depression as it does not cause a subjective experience of distress, flat affect, or inability to experience pleasure. These older adults may say they do not feel depressed and that they are satisfied with their current state, but they should be offered the opportunity to access pharmacological and behavioral treatments if they wish to experience more energy and feel more engaged.

However, clinicians must be aware that family members and other caregivers may perceive the apparent social withdrawal exhibited by the adult in either state as distressing and undesirable. Especially if he or she has advanced illness and is approaching death, family members often want to be able to “make the most” of the time that is left and often wish to be able to engage with the patient more fully. One family member commented:

> I don’t understand what is happening to my dad. He used to be so happy to see his grandchildren. Now when we come to visit he smiles, asks how everyone is doing, but does not seem interested in engaging with us. And the more we talk, the more tired he looks. I don’t understand. What are we doing wrong?

Clinical psychologists and other trained mental health professionals familiar with the construct of gerotranscendence and withdrawal at the end of life should be consulted to assist older adults and their loved ones understand both the processes and intervention options. Intervention with family members should be aimed at providing information about these natural states experienced at the end of life, facilitating their adjustment to their loved one's dying process and relieving unnecessary and distressing guilt. Some of the areas related to spirituality that clinicians should explore with dying loved ones are:

- Assessment of spiritual distress is an important step in determining the older adult's status and the appropriate referral and intervention.
- Pain and other distressing symptoms need to be adequately managed and are always a priority; untreated pain can create significant emotional and spiritual distress and cloud assessment.
- If the person has a spiritual and religious orientation, it would be important to ask general questions such as "What has given you strength during your life? What have been your sources of meaning? How has your spirituality/religion supported during your life? Is it supporting your journey now during the illness?"
- It is important to determine if the same sources of meaning and spiritual strength are still emotionally and spiritually holding the person as he or she deals with advanced illness and impending death.
- If the person is religious, what is the image of God?
- Ill persons may want to talk about their spiritual concerns in therapy; if this happens, it is best to gently explore the concerns.
- Clarify concerns, beliefs, and needs in order to make appropriate referrals and implement an adequate treatment plan.
- Identifying and mobilizing sources of spiritual support is an important intervention. (Lo et al., 2002)

Spiritual distress can affect not only the person's relationship with God or sources of spiritual strength, but also beliefs about self, about the world, and about the future. Distinguishing between spiritual and psychological distress can be challenging, because emotional and spiritual domain are often interrelated and affecting each other. Both depression and spiritual distress can manifest with a sense of loss of hope, loss of meaning, loss of value, and loss of relationships. Existential suffering is a multidimensional construct that includes both psychological and spiritual aspects. It has been described as, "The distress brought about by the actual or perceived threat to the integrity or continued existence of the whole person" (Cassel, 1991).

Mental health professionals who work with persons with advanced illness who are also approaching death will often find that patients voice spiritual concerns during regular psychotherapy sessions. They need to be able to create a therapeutic space that feels safe enough for patients to feel comfortable voicing various concerns, including spiritual ones. It is appropriate to include spiritual care professionals if the person agrees with the referral, but it is important to recognize that some may decide to share spiritual concerns with a therapist. Therapists should certainly respect their own level of comfort and professional boundaries, determining if they have difficulty incorporating spiritual concerns as part of the therapy. However, they must be aware that psychotherapy with older adults with advanced illness requires a broader framework, where spiritual concerns and issues related to meaning and purpose may be a priority for the person and belong in the therapeutic setting.

Dame Cecily Saunders, the founder of the hospice movement, described the nature of spiritual concerns.

> The realization that life is likely to end soon may well stimulate a desire to put first things first and to reach out to what is seen as true and valuable—and to give rise to feelings of being unable or unworthy to do so. There may be bitter anger at the unfairness of what is happening and much of what had gone before and above all a desolate feeling of meaninglessness.

SPIRITUAL SCREENING AND SPIRITUAL ASSESSMENT

Spiritual aspects of care represent one of the eight domains of palliative care. The important implication is that every palliative care and hospice patient should receive adequate and competent spiritual care that includes screening, assessment, and interventions to support the person's spiritual resources, as well as to address possible spiritual distress. The first step in the process of understanding the person's spiritual context and conducting an initial spiritual screening can be accomplished by team members of various disciplines: medicine, spiritual care, social work, psychology, and nursing. Although not all team members are qualified to provide spiritual interventions and address spiritual distress, members of the interdisciplinary team should be able to conduct a preliminary spiritual screening to identify potential areas that may warrant a referral to a spiritual care provider. Spiritual screening is a process involving general questions about the patient's spiritual and/or religious orientation and affiliation. It does not involve the conceptualization of a formal diagnosis of spiritual distress, or the provision of spiritual care interventions. A spiritual assessment is a formal process that may address spiritual beliefs, religious practices, and personal relationships with God or otherwise identified higher power. A spiritual assessment is typically performed by a licensed spiritual care provider and includes a treatment plan designed to address spiritual and/or religious concerns.

Recently, the importance of developing spiritual care guidelines in palliative care has been recognized. A consensus conference of palliative care providers highlighted the importance of incorporating regular spiritual screening and periodic assessment into the treatment plan. Spiritual concerns most frequently experienced by palliative care patients include anger toward God and loved ones, fear of abandonment by God and loved ones, loss of meaning and purpose, loss of hope, concerns about the relationship with the divine, and change in faith beliefs triggered by the progression of illness (Puchalski et al., 2002). The report also emphasizes the need for guidelines that define the appropriate level of spiritual screening, assessment of disciplines like psychology, social work, and nursing.

Two of the most commonly and widely used spiritual screening tools are SPIRIT (Maugan, 1996) and FICA (Puchalski, Lunsford, Harris, & Miller, 2006). The acronym SPIRIT stands for Spiritual belief system, Personal spirituality, Integration in community, Ritualized practice, Implications for medical care, and Terminal events planning. The acronym FICA stands for Faith and beliefs, Importance of spirituality in life, Community, and how to Address specific spiritual concerns. These two acronyms provide clinicians with a useful roadmap to guide a preliminary interview and understand the spiritual context of the older adult and the family. It is important that clinicians maintain an open mind and refrain from making easy, but potentially disruptive assumptions. For example, if the person's religious or spiritual orientation has been supportive in the past, it should not be automatically assumed that the same will happen during the current journey through illness and death. Personal spirituality and even relationship with organized religion may evolve and change during advanced illness and the dying process. Clinicians should be aware that spirituality, as well as the relationship with God or a higher power is a dynamic and often evolving process, not static one. Additionally, it should be recognized that spiritual and religious beliefs are not necessarily shared by everyone in the family. Therefore, older adults and caregivers may hold different spiritual and religious beliefs and may attribute different meaning to the illness and the impending death.

THE RELATIONSHIP BETWEEN SPIRITUALITY AND PSYCHOLOGY

For decades, there has been a complex relationship between psychology and spirituality that has generated a progressive disconnection between the two disciplines, resulting in the general avoidance of spiritual and religious issues on the part of mainstream psychology. The historical reasons for this disconnect can be traced to the development of modern psychology during the 19th and 20th centuries, a time characterized by the resurgence of scientific discipline and its efforts to challenge religious authority as the source of truth (Barbour, 1990). The assumptions of reductionism, materialism, and empiricism came to dominate the philosophical discourse and were accepted by Freud and the psychoanalytic movement, as well as the behaviorist tradition after that (Karier, 1986). These thoughts are well reflected in Watson's (1983) comment:

> Psychology, up to very recent times, has been held so rigidly under the dominance of both religion and of philosophy—the two great bulwarks of medievalism—that it has never been able to free itself and become a natural science.

However, there have been powerful dissenting voices, such as Jung and Adler, who increasingly criticized the dogmatic rejection of mental processes in favor of consciousness predicated on the growth of psychology as a discipline. Spirituality and religion started to be recognized as vehicles adopted by many human beings to make sense of the world, maintain well-being, and achieve self-realization (May, 1961). The question of whether mainstream psychology should integrate spirituality and religion into its discourse has remained. The controversy still continues, but these dimensions of human experience can no longer be ignored and practical steps integrating psychological and spiritual dimensions are needed for patient care (Bergin, 1991).

Many psychologists and other mental health and health-care professionals believe this positive change has not only benefited individuals who are receiving psychological interventions but also benefited the growth of psychology as a discipline (Bergin & Strupp, 1972). Individual psychologists may believe that spirituality should not be allowed in the therapy office.

Or, they may feel uncomfortable with the concept that psychology could be associated with the provision of spiritual care. Yet, providing psychotherapy to patients with advanced illness who may approach death requires psychologists to be aware of the potential spiritual concerns that arise with advanced illness and death. This also means that psychologists need to screen for and recognize spiritual distress, make appropriate referrals when necessary and, based on their level of training and experience, explore some patient concerns during the therapy session.

The need to make sense of a diagnosis of serious illness and integrate the approach of death is one of the most common clinical issues faced by palliative care patients (Strada & Sourkes, 2009). Psychologists working in the palliative care setting are familiar with the struggle involved in this process. The ability to identify cognitive, emotional, spiritual, religious, cultural, and social resources that can be mobilized to assist a person is recognized as an important part of the therapeutic work. Equally important is the ability of identifying possible sources of distress that may increase suffering for older adults and their caregivers (Teno et al., 2004). Understanding the spiritual and religious orientation, developing an appreciation for how it can support the person during the difficult journey through illness and death, and correctly identifying possible sources of spiritual or religious distress are parts of the important assessment psychologists make in collaboration with the other members of the team. In this important context, spirituality, meaning, and purpose, as well as religiosity, cannot dogmatically be conceptualized as outside the boundaries of psychotherapy. Working in palliative care requires psychologists to be able to explore and at times address spirituality as part of the personal value system shared by the patient and the family. It is important to develop and respect professional boundaries; psychologists should not improvise spiritual interventions or try to provide interventions for which they are not qualified.

CONCLUSION

Older adults with chronic or advanced illness approaching the end of life face numerous challenges in all domains of existence. As their physical conditions decline, they may continue to experience losses and difficulties in several areas, including the psychological, interpersonal, and spiritual. Additionally, older persons may have difficulty navigating the health-care system as a result of limited resources and financial stressors, lack of caregiver support or presence of caregivers who are unable to meet their needs. As a result, communication with medical providers may be negatively affected and create opportunity for misunderstandings and increased emotional sufferings. Cultural and spiritual variables have a strong impact on how older adults make sense of their personal struggles through illness and approaching death. Spirituality and meaning-making processes are deeply connected. Clinicians who make an effort to understand cultural and spiritual values and explore how those values guide older adults' lives will experience improved overall communication with them. This improved communication, stronger emotional connection, and the profound respect that comes from *knowing* who the person is from multiple perspectives may result in improved psychospiritual well-being for the ill person and, in turn, higher professional and personal satisfaction for the entire treating team.

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CHAPTER

4

Working With Family Caregivers of Persons With Terminal Illness

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In this chapter, we seek to provide mental health professionals with information that will allow them to work effectively with the family caregivers of terminally ill patients. We make two important assumptions—the first regarding the families with whom readers will be working, and the second about readers themselves. First, we assume that most families confronting the end of life are "normal." Although some families may exhibit individual or family psychopathology requiring specialized and intensive intervention, the vast majority are simply "normally dysfunctional." This chapter focuses on working with normal families (Walsh, 2002) facing an extraordinarily stressful set of circumstances. Second, we assume that readers are experienced clinicians with their own methods or styles of working with patients and families. As such, this chapter does not attempt to teach readers how to perform therapy, but rather introduces specific issues and information that will enable practitioners to use their skills more effectively with family caregivers of dying patients.

We divide the chapter into sections based on three issues that are important to address with many families: (1) end-of-life decision-making, (2) communication among caregivers and the dying patient, and (3) self-care and coping. Before discussing these issues, however, it may be worthwhile to explore the context in which families find themselves as a loved one approaches death.

THE CONTEXT

Dying was different 50 years ago than it is today. In the past, people were more likely to die unexpectedly, falling prey to accidents, heart attacks, pneumonias, and other conditions that took life quickly. Today, many once-deadly illnesses are more easily cured or prevented (see Kiernan, 2007, for an excellent discussion). Currently, longer-term chronic illnesses including cancer, chronic lung disease, and Alzheimer's disease are increasingly common causes of death in older adults (Heron, 2007). These progressive conditions have drawn out the time of death, creating a new stage or phase of life commonly referred to as "the end of life" (see Chapter 2 [Gabriel] for additional consideration of this topic). People may live for extended periods—months or even years—knowing that they have a condition that will ultimately take their lives. This last stage of life provides unique opportunities for individuals and their families to address such important tasks as setting practical affairs in order, making amends with estranged love ones, focusing on spiritual issues, and working toward closure with loved ones. In our experience, however, family members are rarely prepared to face this stage along with the stresses and caregiving responsibilities it can entail.

The Effects of End-of-Life Caregiving on Patients and Families

In their wide-ranging review of the literature, Higginson and Sen-Gupta (2000) found that a majority of the general public (between 51% and 91%, depending on the study) wishes to die at home. Nonetheless, about three-quarters of people in the United States actually die in hospitals or nursing homes (Teno, 2001). As mentioned, families are frequently underprepared to face the end of life and its difficult choices. Unfortunately, if a plan for the end of life is not made in advance or if the family is unable to make hard decisions, patients usually will receive "treatment as usual." This typically involves frequent or prolonged hospital stays, often with death occurring in the hospital. If other outcomes are preferred, it is important for patients to make their wishes known and for appointed family caregivers to be actively involved in care.

Families are systems, where individuals reciprocally influence one another. As such, caregiving affects both family members and patients. Most research has focused on the negative effects that caregiving can have on family caregivers. For instance, caregivers can experience decreased social and occupational functioning (Chentsova-Dutton et al., 2000). Perhaps connected to this decrement in functioning, caregivers are at increased risk of clinically significant depression in comparison to the general population (Haley, LaMonde, Han, Narramore, & Schonwetter, 2001). There is also evidence of decreased immune response in caregivers (Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, & Sheridan, 1996; Li et al., 2007) and poorer physical health (Haley et al., 2001). One study even identified caregivers as having an increased mortality rate in comparison to noncaregivers (Schulz & Beach, 1999). Despite the negative effects of caregiving, research suggests some positive effects. Though caregiver strain predicts higher levels of depression and anxiety, when caregivers perceive that they are successfully providing help, this predicts lower levels of anxiety and depression (Beach, Shulz, Yee, & Jackson, 2000) and higher sense of personal control (Krause, Herzog, & Baker, 1992). Moreover, caregivers who are more stressed may actually have an emotionally easier adjustment process postloss (Schulz et al., 2001).

Although research has found many negative effects for caregivers, the effects of caregiving on patients appear to be much more positive. In part, this disparity may stem from researchers not having studied the positive effects as extensively for caregivers as for patients. Nonetheless, patients tend to experience lower levels of depression due to the social support of caregivers and others (Gençóz & Aston, 2006). They also report lower pain levels (Steele, Mills, Hardin, & Hussey, 2005), perhaps due to the support and distraction afforded by those around them or by the better medical care that attentive caregiving may elicit. Patients also appear to enjoy better overall quality of life as a result of adequate support than those with less adequate support (Tang, Aaronson, & Forbes, 2004). Herbst-Damm and Kulik (2005) even found that terminally ill patients who were visited regularly by volunteer caregivers lived longer than those who were not.

A Definition of Adequate Caregiving

Obviously, adequate caregiving can have important mental and physical health benefits for patients. But, what constitutes adequate caregiving? Dakof and Taylor (1990) asked cancer patients to identify the most helpful and unhelpful actions performed by family caregivers and other individuals.

The most helpful action, cited by 37% of patients, involved expressions of concern from family caregivers. Other helpful actions cited by a large number of patients included: being physically present (32%), proving calm acceptance of the illness (22%), and providing physical assistance (22%). Note that three of the four helpful actions most commonly mentioned by patients do not require anything to be done; rather, they involve simply "being" with the patient in particular ways. Often, caregivers feel overwhelmed by not knowing what to do. According to the patients in this sample, caregivers don't necessarily need to "do" anything.

Patients also identified unhelpful actions performed by family caregivers and others (Dakof & Taylor, 1990). The most common of these, reported by 17% of patients, was criticism of the patient's response to the illness. In our experience, when patients talk about their illness or dying process, caregivers sometimes respond with statements such as, "Don't think like that," or "Think more positively." Although these well-meant statements are intended to be encouraging, patients can perceive them as critical. Other unhelpful actions included minimizing the impact of the illness (16%), expressing too much worry or pessimism (11%), and expressing little empathy or concern (10%). Another unhelpful action involved avoiding interactions with the patient altogether, a problem that these patients associated with friends (17%) but not with family (0%).

The positive effects of caregiving on patients, such as decreased depression and lowered pain levels, are based on the assumption that the caregiving received is adequate. When families are able to provide the best care possible, maximizing the number of helpful actions, the patient experiences improved quality of life. Mental health professionals can empower family members to perform helpful actions and avoid unhelpful ones by addressing their concerns and needs through accurate information and guidance.

Three common family concerns can be phrased as questions. The first major concern for families is, "How do I know what treatments are right?" Many family members find themselves in the position of making decisions for ill loved ones, faced with choosing among multiple care options. A second issue for many families is, "What should I be saying?" Many family members are unsure of how to speak with someone who is dying. A final question, "How should I be feeling?" is central for many families. When family members have never cared for someone who is dying, they may question whether their feelings are normal and wonder how to cope with the range of feelings. The following sections delve further into each of these issues.

HOW DO I KNOW WHAT TREATMENTS ARE RIGHT?

Physicians are less likely today than in the past to tell patients what the single "right" medical treatment is. In our experience, families often express anger, frustration, and despair because doctors will not tell them what to do as clearly as families would like. In one instance, an 85-year-old woman caring for her dying husband grabbed the first author's arms and shook him, exclaiming, "Why do I have to make the decisions? I'm not the doctor!" Doctors can guide families in their decision-making processes, but they cannot make the decisions.

Physicians may be reluctant to tell patients which care option is the "right" choice for at least two reasons. First, the field of medicine has become so vast that there frequently is more than one "right" choice. Second, physicians may be resistant to opine too strongly for a treatment for fear of lawsuit should this treatment fail. It is common practice for doctors to provide families with a menu of options, offering the pros and cons of several choices. In order to make a decision, families need to obtain accurate information and practice good decision-making skills. These are both tasks that mental health professionals can facilitate.

Obtaining Accurate Information

We recommend that mental health professionals play an active role in helping families obtain accurate and complete information about their loved one's illness and treatment options. Because family caregivers often find themselves feeling stressed and overwhelmed, they may be unlikely to take the time to seek out information on their own. As nonphysicians, we cannot provide specific medical information or advice; nonetheless, we can help families to locate helpful resources, communicate most effectively with physicians, and process medical information to make effective decisions.

One helpful source of information is books. We have found three books to be particularly useful for family caregivers, each of which addresses different informational needs. Generally, we recommend *The End-of-Life Handbook* to families and the *Handbook for Mortals* to patients. *The End-of-Life Handbook*

(Feldman & Lasher, 2007) is a guide written specifically for family caregivers, covering a balance of medical information (e.g., diseases and treatment options), practical concerns (e.g., advance directives, wills), and emotional issues (e.g., coping and self-care). The *Handbook for Mortals* (Lynn & Harrold, 2001), covers virtually the same ground, but was written more directly for patients themselves. A final book we frequently recommend is *How to Care for Aging Parents* (Morris, 2004). Virtually encyclopedic in scope, this book contains practical information about caring for older adults. If people are willing to read these or other books, they can quickly gain information about many aspects of the caregiving process. Clinicians may consider having copies of such books in their offices for families to borrow.

Another helpful resource is the Internet. Several sites provide a wealth of information for patients and families, including information about medical conditions, treatment options, and end-of-life care. We frequently recommend the AARP web site (www.aarp.org), which contains articles on housing options, life after loss, love and relationships, conditions and treatments, and doctors and hospitals. In addition, the site also contains message boards where families can post questions and read responses from others in similar situations. Another useful web site is WebMD (www.webmd.com). Although this is a for-profit site, making most of its revenue from advertising, it provides a plethora of useful articles on specific medical conditions and treatments. The Eldercare Locator (www.eldercare.gov), a public service of the U.S. Administration on Aging, helps locate resources for older adults across the country. The site connects families and patients with state and local community-based organizations that serve older adults and their caregivers. Caring Connections (www.caringinfo.org) is a web site run by the National Hospice and Palliative Care Organization (NHPCO). Along with a hospice locator service, it contains advance directive forms and free resources in both English and Spanish on a wide range of end-of-life topics. Finally, Growth House (www.growthhouse.org) is a site best used by professionals, containing articles about virtually all aspects of end-of-life care. We do not recommend giving every patient or family all of these web sites, but rather selecting those that apply to each family's particular situation.

Caregivers can also obtain information from family and friends. We always recommend that caregivers identify acquaintances who have confronted similar caregiving responsibilities, even if they were dealing with very different diseases or conditions. Although the specifics of the situations may differ, these individuals may be able to provide a wealth of information, including "I-wish-I-would-have-known" advice that could prevent missteps. They may be able to offer caregivers strategies on how to talk with doctors, knowledge of the best hospices in their area, tips for self-care, or helpful books and other sources of information. We encourage family caregivers to contact these untapped resources, noting that they often have knowledge that families don't even know they need. Of course, these individuals may not always offer good advice, which is why we frequently suggest to caregivers that relying on them (or any other single source) as the sole provider of information is not advisable.

Finally, an essential informational resource is the dying loved one's physician. In our experience, family caregivers often report that the physician is either the best or worst source of information. Physicians can be difficult to talk to, as they are often in a rush, facing limited time and many patients. Mental health professionals can provide families with training in particular skills that will aid in communicating with physicians and other health-care providers. In our experience, the following five pieces of information can greatly facilitate doctor–family communication (Feldman & Lasher, 2007).

First, families will benefit from realistic expectations regarding their meetings with physicians. Specifically, caregivers should expect physicians to be available for no more than 15 to 20 minutes at a time. Because people sometimes become angry or frustrated with physicians because of their limited time, it can be useful to discuss the reasons for this limit in advance. Although most physicians wish they could spend more time with each patient's loved ones, they also realize that every moment they spend with a family member is a moment that they are not spending with a patient who may need them. In an increasingly overloaded medical system, physicians often feel pulled in multiple directions—they want to spend time with the individuals in front of them, but also feel pressure to move on to the next patient or family in their care. We advise families to begin each meeting by saying something like, "I have a few items to discuss; it shouldn't take any longer than 15 or 20 minutes." Such statements help put physicians at ease, allowing them to focus more intently on the discussion at hand.

Second, we encourage family caregivers to make an appointment with the doctor. This is routine, of course, for outpatient visits. Even if the patient is being cared for as an inpatient, an appointment ensures dedicated time for questions and discussion. Appointments can sometimes be made through the physician's secretary. Alternatively, the nurse may know when the doctor makes rounds. Although rounds may not afford enough time for a sufficient conversation with the doctor, this is a good opportunity to request a later appointment. The nurse also frequently can answer the family's medical questions him- or herself, eliminating the need for an appointment with the physician.

Third, in preparation for the appointment, we advise caregivers to create a list of no more than two to three items to discuss and then to hand this list to the physician at the outset of the appointment. Such agendas not only enable family members to consider in advance what they wish to address, but research by Wells (2004) demonstrates that physicians find them helpful as well. Having a paper copy of the agenda allows doctors to see quickly what the family wants to know, as well as to infer what the family needs to know but isn't asking. Agendas allow everyone to remain on task and to utilize the short amount of time most efficiently. An important task for the mental health professional is to aid family caregivers in creating such a list prior to meeting the physician.

Fourth, we encourage families to take notes during the appointment. Research demonstrates that people only remember and understand part of what their doctor says (Lerner, Jehle, Janicke, & Moscati, 2000). Taking notes maximizes the caregiver's retention of what was discussed in the meeting, enabling more informed decision making. In addition, these notes can be reviewed with the physician at the conclusion of the meeting to check accuracy of understanding.

Finally, we recommend that caregivers bring someone along to the meeting. Although not absolutely necessary, a companion can aid in various ways. Most obviously, a companion can provide social support, which may be especially important if the physician is perceived as intimidating. Of equal importance, however, a companion can raise questions or concerns during the meeting that have been overlooked by the caregiver. After the meeting, a companion can also assist the caregiver in processing the information conveyed by the doctor.

Better communication with the physician ultimately will lead to better care for the patient. In addition to training family caregivers in the above communication skills, mental health professionals can mediate discussions between caregivers and physicians. When this is necessary, we generally suggest that health-care professionals approach the doctor first, asking for permission to attend the meeting. Throughout the meeting, they should attempt to aid in the communication process by clarifying confusing vocabulary, assisting the family caregiver in voicing his or her concerns and questions, and providing social support.

Good Decision-Making Skills

Once the information discussed earlier has been obtained, the next step is for families to make decisions. Unfortunately, the massive amounts of medical information that families encounter can feel overwhelming. Thus, an important role for mental health professionals is to help families process this information in order to ultimately make the best decisions possible.

One of the common pitfalls for many family caregivers is that, in the midst of processing the many necessary medical details, they lose sight of many equally (and perhaps more) important issues. If the patient truly is dying, moment-by-moment monitoring of lab tests, medication doses, oxygen saturation levels, and similar details cannot prevent the inevitable, only forestall it (and perhaps not even that). Nonetheless, in becoming consumed with such medical issues, families sometimes "miss the forest for the trees," failing to notice important opportunities to experience meaningful, loving connection. We refer to this process as the "medicalization" of the end of life. People tend see the end of life as a medical problem to be fixed rather than a genuine and unavoidable stage of life. Although the medical details are certainly important, they should not overshadow essential psychosocial factors.

Focusing on values can prevent families from unnecessarily medicalizing the end of life as well as assist them in making sound medical decisions. In short, good decisions are value-driven (Karel, Moye, Bank, & Azar, 2007). As such, it is important to help family caregivers to identify their own values, and more importantly, their loved one's values. Values to consider include religious values, values for home and family, and values about medical care. Many religions prescribe principles that may influence end-of-life decisions. In Christian Science, for example, believers generally do not take medications or even use hospitals; instead, prayer is viewed as the most important healing mechanism (Gazelle, Glover, & Stricklin, 2004). Other religious systems contain less extreme, but equally strong values. In addition, values regarding home and family can influence end-of-life decision making. Prior to being diagnosed with a terminal illness, many individuals already display consistent preferences in this regard, with some preferring to stay home and surround themselves with family, and others opting to spend evenings "out on the town." Finally, values regarding medical care differ widely from person to person. Whereas some individuals are extremely reluctant to see doctors or take medication, even when extremely uncomfortable, others are much more eager to utilize such options, even with the most minuscule discomfort. Facilitating a conversation with caregivers regarding their loved one's values can provide important clues about appropriate care options.

If patients are cognitively able to engage in direct discussions regarding values, mental health professionals should attempt to facilitate such conversations between these patients and their family caregivers. In cases where the patient has not yet written advance directives or appointed a Durable Power of Attorney for Health Care, this conversation can provide a good point of departure for drafting these invaluable documents (see Chapter 6 [Gabriel & Kennedy] for more information on advanced care planning). If the patient is incapable of participating, then the clinician should work with the family to help determine the values of their loved one as best possible. We routinely remind caregivers that their choices on behalf of the patient should be governed by their sense of the patient's own values and wishes.

WHAT SHOULD I BE SAYING?

Family caregivers frequently experience difficulty communicating with their dying loved ones. Although caregivers do not often directly ask mental health providers, "What should I be saying?" they may express this issue in various ways. Caregivers may lament the outcome of not knowing what to say—"We just don't talk anymore"—or comment that conversations are "awkward." Alternatively, caregivers may attribute the problem to the patient, stating that he or she does not wish to talk.

In our experience, the difficulty of communicating with a dying person often is driven by distorted beliefs. Caregivers sometimes believe that bringing up the illness will have dire consequences, possibly upsetting their loved ones to such a degree that they will never recover emotionally. Caregivers may believe that discussing the end of life will lead to irreparable rifts between themselves and their sick loved ones. They may fear that inviting discussion about end-of-life issues communicates that they are giving up hope for, or giving up on, their loved ones. Caregivers sometimes also fear the opposite, believing that they will offend their loved ones by talking about trivial things. They may fear that it is inappropriate to make small talk, that this is disrespectful given the gravity of the situation. It is also common for people to believe that, if conversation wanes, the silence will be "awful" or "unbearable." In situations where direct communication has not been part of the pre-morbid relationship, family caregivers may now criticize themselves unfairly for not being more communicative about intimate or "deep" topics. Mental health professionals should assess for such distorted beliefs that can dramatically affect the quality of relationships.

As an example, we recall Martin and his wife, Jennifer. Martin, a charming man with a wonderful sense of humor, was diagnosed with a brain tumor at 55 years of age. The tumor quickly took his ability to walk, though he remained cognitively intact for some time. Because Jennifer understandably found it difficult to care for him at home, she enrolled him in an inpatient hospice. For the first month after Martin entered hospice, Jennifer visited almost daily. But, as the tumor caused increasing memory difficulties and disorientation, Martin observed with great distress that she visited less and less. Because of his memory deficits, the psychologist wondered if Martin was forgetting that Jennifer had visited. With his permission, he decided to telephone Jennifer to reassure Martin that she had been there. After three days of unsuccessful attempts to reach one another, they finally made contact. During this call, Jennifer cried as she admitted that she had not visited in nearly a month, stating, "This must sound awful. I swear I keep meaning to visit, but I just can't bring myself to come." When asked what she thought was blocking her from visiting, she said, "I don't know what to say to him anymore, and the silence is terrible." Like many family members and friends of terminally ill patients, Jennifer was at a painful loss for words. As her husband's health declined, Jennifer was not sure how to communicate with him. Although she was afraid of confusing or upsetting him, she was even more frightened of the silence between them.

In such cases, it can be helpful to discuss gently with caregivers the previously cited survey of patients' caregiving preferences (i.e., Dakof & Taylor, 1990). As mentioned, three of the four most helpful caregiver behaviors cited by patients were not "behaviors" at all. Rather, they were simply "ways of being"—in other words, expressing concern, being physically present, and providing calm acceptance. This can be powerfully reassuring to caregivers who believe that they should be doing or saying something specific.

Suggested Topics of Conversation

Even when the family caregiver is not experiencing distorted thinking, communicating with a dying individual can be challenging. In our experience, it often is helpful to give family caregivers a "menu" of possible conversation topics. Below, we list several common topics of conversation.

Small Talk. Small talk constitutes a key foundation of relationships. Although deep and abiding relationships cannot be based on small talk alone, most of our hours with friends and family are spent discussing relatively superficial topics. For many, this remains the case at the end of life. Chatting about family gossip, the latest football game, or current events can be wonderful ways of establishing social and emotional connection.

Feelings. Asking how the patient is feeling is an effective method for both connecting socially with the patient and providing needed support. Many terminally ill patients feel emotionally isolated, wondering if family and friends could ever understand what they are experiencing. Family members who have the courage to ask how their loved ones are feeling provide them the opportunity to express their physical and emotional pain, as well as their loves and joys. This can be an emotional experience for patients and family alike, and may not be appropriate for all patients. In relation, asking the patient if he or she needs help can be both a gateway to conversation and an opportunity to do something concrete to bring comfort to the patient.

Life Review. Decades ago, Butler (1963) observed that older adults naturally engage in the normal and healthy process known as life review. Many seriously ill people cherish the opportunity to tell others about their lives. By recalling the events of their lives, dying people can feel a sense of closure and satisfaction with their experiences. In fact, life-review-based psychotherapy has been shown to be an effective treatment for depression in older adults (Serrano, Latorre, Gatz, & Montanes, 2004). We often suggest to family caregivers that they develop a list of open-ended questions about their loved one's life and use these to start conversation. With the patient's consent, many families choose to make a video or audio recording of their loved one's responses as a way of capturing them for posterity.

Spiritual Beliefs. For many patients and families, there is no more important topic than that of spirituality. Although conversations about faith may not be appropriate for all patients, they can be helpful for some. If family caregivers decide to broach this subject, they should be prepared for the patient's convictions not to match their own. We've seen many dying patients experience significant distress because of pressure from family members to change their spiritual beliefs or practices. Although it is appropriate for family members to share their own beliefs, they should not expect or demand agreement. It is most beneficial for patients if the conversation is focused on their own beliefs. If engaged in sensitively, a conversation about such beliefs can be immensely comforting for both families and patients.

Shutting Down and Opening Up Conversations

No matter the topic of conversation, talking with a dying individual requires a great deal of openness on the part of the family. When emotional topics arise, the initial impulse for many family members is to minimize or prevent strong feelings. As mental health professionals, we can coach families on how to avoid shutting down conversations.

Families shut down conversations in several ways. Such common phrases as, "Don't talk like that," "Think positive," and "Everything is going to be fine," are often intended to comfort dying patients by keeping conversation upbeat. Unfortunately, they can stop meaningful conversations from unfolding and prevent emotional connections within families at the end of life. As mental health professionals, we should listen for such phrases. If possible, it is valuable to spend time in the room with the caregiver and patient, monitoring their interactions. In one-on-one meetings with family members, we often ask them to recall what they have been talking about with their loved ones, including what words they used and the motivations behind those words. If we detect any of these statements, we gently engage the caregiver in a psychoeducational discussion, suggesting open alternative statements that encourage conversation rather than shut it down (see Figure 4.1).

As mental health professionals, having these conversations requires openness to accepting our own (countertransferencial) feelings of distress (additional consideration of this topic is in Chapter 5 [Kasl-Godley] of this volume). We should attempt to model being open and tolerating discomfort. When family caregivers raise these uncomfortable topics with us, it is important that we are open and fully present, even when the subject matter is difficult. We also can take a more active role in ensuring that these conversations are successful. We can perform role-plays with family caregivers, in which we play the role of the patient. We also can model conversations for caregivers, with the caregiver in the role of patient. Alternatively, we can engage in a conversation with the

Words That Shut Down Conversation	Words That Open Up Conversation
• "Don't talk like that."	• "This must be hard for you."
• "Everything is going to be fine."	• "I feel scared, too."
• "Think positive."	• "Nobody can stay positive all the time. What's on your mind?"
• "Keep fighting!"	• "What do you want to do? I'll respect whatever your wishes are."
• "Don't get upset."	• "I can tell this is upsetting."
• "I'm not going to talk about this with you."	• "I feel stressed right now, but this is important. Can I take a break and talk about this a little later?"
• "Be strong."	• "I'm here for you no matter what."

Figure 4.1 Conversation-Closing Statements and Conversation-Opening Alternatives

terminally ill patient in front of the caregiver, concretely demonstrating that conversations about difficult topics can occur without dire consequences. Finally, clinicians can mediate conversations between caregiver and patient, intervening when necessary to keep the conversation open.

HOW SHOULD I BE FEELING?

Caregiving is stressful. There are three kinds of stress associated with caregiving: emotional stress (Haley et al., 2001), physical stress (Haley et al., 2001), and social stress (Rokach, Matalon, Safarov, & Barcovick, 2007). Emotionally, it can be difficult for family caregivers to witness their loved ones' declines in heath. Physically, caregivers often must perform heavy lifting, such as assisting loved ones in and out of chairs or beds. It also may be necessary to stay up late at night or sleep in a chair beside the patient's bed. Perhaps partly for this reason, research discussed earlier in the chapter demonstrated that caregivers tend to have depressed immune responses (Li et al., 2007). Socially, caregivers may need to spend most of their days with their dying loved ones, dramatically reducing their ability to maintain a healthy social life. Of course, caregiving also can be meaningful and fulfilling. An important task of mental health professionals is to help family caregivers to manage the stress inherent in the role while maintaining the sense of meaning and fulfillment.

Normal Emotions

As a result of the stresses just mentioned, family caregivers experience a wide variety of normal emotions. Unfortunately, such feelings often trigger distorted, self-critical beliefs. Although these beliefs do not accurately reflect reality, they can add to caregivers' emotional distress.

For instance, people facing the loss of a loved one sometimes report feelings of anger or frustration. Family caregivers often feel angry because their loved one is leaving them or become frustrated by the immense time and effort involved in caregiving. As a result, caregivers sometimes criticize themselves for feeling angry, experiencing such beliefs as, "I am a terrible person for feeling this way."

Likewise, caregivers frequently encounter guilt stemming from the belief, "I should have done things differently." More specifically, caregivers often criticize themselves for not advocating more strongly for their loved ones' care, not picking up on symptoms earlier, or not having "forced" their loved ones to pursue a particular treatment option. They may even label themselves as "a terrible person" because of such perceived oversights. To gently challenge such thinking, we often ask family members, "If you really were a bad person, would you feel this guilty? Do you know of anyone who feels this guilty who actually is a bad person?" Although caregivers may feel guilty, it is important to remind them that experiencing the emotion of guilt does not mean that anything really is their fault. We frequently ask caregivers to carefully consider what information was available to them *at the time* they made the decisions about which they now feel guilty. Through such discussion, caregivers often realize that they made the best decisions possible given the available information.

Sometimes caregivers also experience moments of relief as their loved ones approach death. These feelings are normal when death means the end of suffering for the patient and the conclusion of a long and arduous caregiving process for the family member. Although caregivers sometimes believe that they are awful people for feeling this way, dying patients often comment that they, too, think fondly about their caregivers being relieved of their heavy duties.

Emotion	**Distorted Belief**
Anger	“I’m selfish for feeling this way.”
Sadness	“I need to be strong/not be a downer.”
Empathy	“I’m not upset enough.”
Guilt	“I should have done things differently.”
Happiness	“It’s sick/wrong to feel good.”
Relief	“I’m a monster for feeling this way.”
Numbness	“There’s something wrong with me.”

Figure 4.2 Feelings and Beliefs Experienced by Caregivers

See Figure 4.2 for a list of normal feelings experienced by caregivers and the distorted beliefs that can be associated with these feelings. All of these emotions in moderate amounts are normal. As mental health professionals, we should remind caregivers that these feelings are natural when experiencing a loss and gently challenge their resultant distorted thinking.

Coping With the Stresses of Caregiving

Although helping caregivers to identify the distorted thinking that may be contributing to their emotional distress is helpful, it often is not enough. Even when thoughts are not distorted, caregiving can lead to significant emotional distress. For this reason, caregivers may benefit from learning concrete ways to cope with emotions. There are two things we encourage nearly all caregivers to do: (1) ask for help when they need it, and (2) schedule concrete self-care activities (Feldman & Lasher, 2007).

Asking for help. We frequently have overheard family members and friends offer help to caregivers. Although caregivers almost always respond thankfully, they usually do not follow up on these offers. In our experience, this lack of accepting help, even when offered, is often driven by distorted beliefs. Common beliefs include, “I’ll bother people if I ask for help,” “They don’t really want to help, they’re just saying that to be nice,” and “They wouldn’t help even if I asked.” As mentioned previously, an important role of the mental health professional is to assess for and gently challenge such distorted thinking. Sometimes these beliefs are true, of course. In our experience, however, people generally will help as long as caregivers ask for something that the helper: (1) is capable of doing, and (2) is relatively easy to do.

An activity that many caregivers find useful involves creating a menu of helpers. On the left-hand side of a piece of paper, we ask caregivers to list all of the people that could possibly provide assistance. Then, in the right-hand column, we instruct caregivers to note the ways that each person could help. As we assist caregivers in brainstorming ways that each person might help, we refer to the two criteria just discussed. We also remind caregivers that there are many helpful behaviors that go beyond providing direct care to the patient, such as delivering a meal or lending a supportive, listening ear. The caregiver now has a menu of helpers that he or she can call on when needed. The next step is to contact one or more of these helpers to see if they are willing to provide the assistance listed. Although mental health providers should build realistic expectations by informing caregivers that not everyone on the list will agree to help, it is likely that most will, provided that the requested help conforms to the two criteria discussed.

Self-care. Family caregivers not only often have difficulty asking for help, but also can neglect taking care of themselves emotionally, physically, and socially. In such cases, mental health professionals should work with caregivers to arrange their schedules to include time for self-care activities. We are not suggesting overhauling caregivers' schedules, as is sometimes done in behavioral activation interventions with depressed clients (Martell & Addis, 2004). Instead, we encourage caregivers to allot a modest 2 or more hours a week for self-care. For many caregivers, it is key to schedule this ahead of time. If self-care activities are not scheduled or are promised only abstractly for "sometime this week," caregivers are unlikely to do them as the exigencies of caregiving take over.

Self-care consists of activities or pursuits that the caregiver enjoys. These can be as simple as going to a movie, cooking and eating a favorite meal, engaging in a hobby, or spending time with a friend. Such activities may be important for two reasons. First and foremost, they may help to mitigate some of the detrimental effects of care-giving cited earlier, including decreased social functioning (Chentsova-Dutton et al., 2000) and depressed affect (Haley et al., 2001). Second, self-care activities provide opportunities to pursue goals beyond those present in the caregiver role. Snyder (2000) suggests that individuals are aided in the grief process by embracing new life goals. Mental health professionals can prepare family members to transition from the role of caregiver in part by helping them to identify and participate in important long-standing goals or engage new ones.

Unfortunately, just as distorted beliefs hinder asking for help, they also can prevent caregivers from participating in self-care activities. Common distorted beliefs include, "I'm selfish for thinking about a movie when my loved one is suffering," "It would be irresponsible of me to take time away," "I should always be there in case my loved one needs me," and "My loved one would never forgive me if I left his or her side for even a minute."

We often respond to these distorted beliefs by citing the wisdom of two sources. The first is an unrelated one—flight attendants. Airline passengers are told that, should oxygen masks fall from the ceiling, they are to put on their own masks first and then assist children. Even airlines realize that someone cannot care for another's needs until his or her own needs are at least partially met. By extension, family caregivers cannot continue to be emotionally present and helpful to their loved ones if they are not seeing to their own emotional, physical, and social needs.

Dying patients often echo this sentiment. One patient that the first author cared for was a 78-year-old woman with chronic obstructive pulmonary disease (COPD). Her 52-year-old daughter, an extremely precise and controlling lawyer, was constantly stressed and overwhelmed. Despite her rigidness and stress, she was a loving and attentive caregiver. Unfortunately, caregiving began taking a toll on the daughter's health, as evidenced by constant fatigue, headaches, and the common cold. When it was suggested that she schedule time to practice self-care, she responded, "I could never do that. My mother would never forgive me." When the topic of self-care arose in a one-on-one meeting with the mother, however, she enthusiastically stated, "Will you please tell my daughter to take some time off? She's always sick. Besides, I wish she would leave me alone every once in a while; she's always hovering."

Mental health professionals will repeatedly encounter similar scenarios. Patients are concerned about their loved ones and want them to take care of themselves. An often-effective intervention involves bringing the caregiver and patient together. In the example above, the therapist facilitated a discussion in which the mother expressed her wish that her daughter take opportunities to care for herself. This enabled the daughter to take more time for herself, improving her mood and energy dramatically, which ultimately enriched the caregiving relationship.

CONCLUSION

Caring for a dying loved one can be a stressful and emotional process. When done adequately, however, it can lead to better quality of life for the patient and deep satisfaction for the family caregiver. In this chapter, we have discussed three important issues, phrased as questions, which often arise when working with family caregivers of terminally ill patients: How do I know what treatments are right? What should I be saying? How should I be feeling? If mental health professionals are able to address these questions in straightforward and practical ways, caregivers will be able to support their dying loved ones and themselves as effectively as possible.

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CHAPTER

5

Serious Mental Illness

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Being diagnosed with advanced, life-limiting, or terminal illness and living with the often concomitant uncertainty and unpredictability of the illness can be stressful for individuals, exacerbating existing or longstanding psychiatric symptoms or triggering a new onset disorder. In this chapter, we discuss the interrelationship between advanced physical disease and mental illness and then briefly review specific mental disorders and their clinical management at the end of life.

ADVANCED PHYSICAL DISEASE, PSYCHIATRIC SYMPTOMS, AND MENTAL DISORDERS

Association Between Physical Disease and Psychiatric Symptomology

Physical illness can be a risk factor for psychiatric problems. Elevated psychiatric symptoms and/or psychiatric disorders are common among individuals with life-limiting or terminal illness across multiple venues, including outpatient primary care (Lyness, Caine, King, Cox, & Yoediono, 1999; Van Hemert, Hengeveld, Bolk, Rooijman, & Vandenbroucke, 1993), cancer centers, general hospitals (Feldman, Mayou, Hawton, Ardern, & Smith, 1987), nursing homes (McCarthy, Blow, & Kales, 2004), and home care (Bruce et al., 2002; Kennedy, Polivka, & Steel, 1997; Miller & Rosenheck, 2007). Rates range from 15% to 50% in hospital settings, 20% in nursing homes, and nearly 40% in home care.

Unfortunately, psychiatric symptoms and psychiatric disorders in medically ill patients often are un- or undertreated with respect to both psychotherapy and psychopharmacotherapy (e.g., Wilson et al., 2007). For example, studies of individuals with advanced lung and heart disease have found that only one third of anxious/depressed individuals with chronic obstructive pulmonary disease (COPD) and one tenth of depressed individuals with heart failure receive treatment (Gottlieb et al., 2004; Kunik, et al., 2005). Another study of individuals with advanced cancer who also had a major psychiatric disorder found that only 45% received mental health services (Kadan-Lottick, Vanderwerker, Block, Zhang, & Prigerson, 2005).

Mental illness also can be a risk factor for physical illness. Individuals with serious mental illness (SMI), defined as a psychiatric disorder that substantially interferes with at least one major life activity over the past 12 months, are at higher risk for progressively debilitating medical disorders than patients without SMI, with rates ranging from 50% to 78% (Felker, Yazel, & Short, 1996; Jones et al., 2004; Kamara, Peterson, & Dennis, 1998). Furthermore, medical comorbidity is associated with more serious psychiatric symptoms and worsened health status and outcomes (McGrath & Holewa, 2004). Individuals with SMI have higher mortality as a result of death from cancer, cardiovascular and respiratory disease, diabetes and hypertension, as well as suicide and accidents (BarChana et al., 2008; Capasso, Lineberry, Bostwick, Decker, & St. Sauver, 2008; Ösby, Brandt, Correia, Ekbom, & Sparén, 2001; Parks, Svendsen, Singer, & Foti, 2006).

Individuals with SMI experience higher morbidity and mortality than individuals without SMI for several reasons. First, individuals with SMI may be more likely to engage in poor health-related behaviors such as smoking, chronic substance use, and poor diet and exercise, all of which are associated with increased risk for medical disorders such as heart disease, diabetes, hypertension, respiratory disease, and cancer. Second, individuals with SMI may be taking psychiatric medications that contribute to weight gain, or in some cases, medications that may promote cancer or reduce resistance to some tumors (Damjanovic, Ivkovic, Jasovic-Gasic, & Paunovic, 2006). Third, health care for individuals with SMI tends to be more complicated. Due to psychiatric symptoms (e.g., perceptual distortions or cognitive processing difficulties), persons with SMI may not be able to identify or describe their medical problems clearly, leading to missed or misdiagnosis and delays in treatment (Dembling, Chen, & Vachon, 1999; Druss, Bradford, Rosenheck, Radford, & Krumholtz, 2001; Rathore, Wang, Druss, Masoudi, & Krumholtz, 2008). They may be reluctant to seek medical treatment, in part from mistrust or fear of psychiatric hospitalization, or be unable to tolerate interventions or adhere to treatment as prescribed. Fourth, individuals with SMI may be poor advocates for themselves due to skill and knowledge deficits (e.g., how to use the health-care system or navigate relationships with medical providers) and have limited support available to advocate on their behalf (Emsley, Chiliza, & Schoeman, 2008; Goldenberg, Holland, & Schachter, 2000).

In addition, we as treatment providers may contribute to management complications. We may have difficulties ascertaining the underlying cause of psychiatric symptoms due to atypical presentations of medical problems or to symptom overlap. We may misattribute medical symptoms to the psychiatric illness or underestimate the ill persons' abilities to cope with their diagnosis and current circumstances because of their psychiatric conditions (Baker, 2005; Felker et al., 1996; Goldenberg et al., 2000).

Finally, individuals with SMI may have poor access to, or receive sporadic, preventive and/or illness-specific health care due to systems issues such as homelessness, incarceration, or even lack of routine, comprehensive physicals (Dickey, Normand, Weiss, Drake, & Azeni, 2002; Emsley et al., 2008; Goldenberg et al., 2000; Hahm & Segal, 2005; Mitchell & Malone, 2006). Medical management can be complicated simply by poorer quality medical care (Druss, Bradford, et al., 2001; Miller, Druss, Dombrowski, & Rosenheck, 2003) or poor continuity between mental and physical health care. Of note is that when psychiatric care for individuals with SMI is integrated into primary care medical settings, their emotional well-being and mental health improve, which presumably reduces the barriers to medical management posed by acute psychiatric symptoms (Druss, Rohrbaugh, et al., 2001).

Unfortunately, there is no coordinated system to care for people with SMI who are dying. Medical settings, particularly acute or long-term care settings, often are not well equipped to handle these individuals and psychiatric settings typically are not structured for seriously medically ill patients (Goldenberg et al., 2000). Ideally, for institutionalized individuals with SMI at the end of life, they would be able to remain where they have resided (e.g., state hospitals, residential care homes, board and care homes, or long-term care settings) but this outcome typically requires training for staff to increase their competence and comfort with end-of-life care (Foti, 2003). People who are homeless present even greater challenges, as they cannot be cared for at home and may not tolerate institutional care (Kushel & Miaskowski, 2006; Podymow, Turnbull, & Coyle, 2006).

Capacity to Participate in Advanced Care Conversations and Medical Treatment

Medical providers may be hesitant to initiate goals-of-care conversations for fear of worsening the psychiatric symptoms of individuals with SMI or even engendering psychiatric symptoms in people without a major mental illness. However, not only are individuals with SMI typically able to tolerate end-of-life discussions (Foti, Bartels, Merriman, Fletcher, & Van Citters, 2005; Foti, Bartels, Van Citters, Merriman, & Fletcher, 2005), they tend to express the same wishes and needs at end of life as individuals without SMI.

Individuals with SMI are receptive to, and able to participate in, advance care planning, though their capacity to formulate and communicate their treatment preferences and decisions may fluctuate (Candilis, Foti, & Holzer, 2004; Foti, Bartels, Merriman, et al., 2005; Foti et al., 2005). Thus, providers should try to discuss and document medical and psychiatric preferences, values and beliefs during the individuals' stable and competent periods. Conversations can be informed by proxy reports and supplemented by hypothetical scenarios, semi-structured interviews (e.g., HCPQ—Health Care Preferences Questionnaire), and formal assessment tools such as the MacCAT-T (Grisso & Applebaum, 1995) or Hopkins Competency Assessment Test (Janofsky, McCarthy, & Folstein, 1992). It is incumbent on providers to document all relevant issues and considerations that form the basis of their opinion. See Qualls and Smyer (2007) and the American Bar Association/American Psychological Association (2008) title, *Assessment of Older Adults With Diminished Capacity: A Handbook for Psychologists*, for more general resources on assessing capacity in older adults using principles and strategies that also apply to persons with SMI.

Unfortunately, often when individuals with SMI are hospitalized, they are presumed to lack capacity to make treatment decisions and are not involved in these discussions (Candilis et al., 2004). Often health-care providers incorrectly assume that because the person has fluctuating mental status and/or a serious psychiatric illness, the person lacks capacity and, therefore, the substitute decision makers (power of attorney, conservator, guardian) are evoked, with all subsequent treatment decisions made for the individual. Although this course of action may be appropriate, it is possible that at another point in the day or for a less complex decision, the individual may be capable of making decisions, as decisional capacity is a dynamic process and is decision-specific rather than global.

One particularly troubling decision for many health-care providers can be a medically ill person's decision to forgo life-sustaining treatments or not to pursue life-prolonging interventions in the context of depressed mood. Depression may influence some individuals either to seek or decline interventions. The specific impact of depression varies across individuals (Ganzini, Lee, Heintz, Bloom, & Fenn, 1994). Some individuals may continue to be rational in expressing a desire to terminate life-sustaining interventions but nevertheless be expressing a request that is driven by hopelessness and pessimism regarding the future; that is, depression can influence the type of decision a person makes but leave the ability to articulate or justify the decision relatively intact (Breden & Vollmann, 2004). Other individuals may have been clear about what they want for themselves prior to becoming depressed and these preferences do not change even in the context of depression. Thus, the presence of depression does not always mean that the medically ill person lacks decisional capacity, though it is a prevalent assumption even among mental health providers (Ganzini, Leong, Fenn, Silva, & Weinstock, 2000).

SPECIFIC MENTAL DISORDERS AND THEIR MANAGEMENT

Over the past decade, there has been increasing attention to the identification and management of psychological distress and mental disorders in individuals with advanced and terminal illness (Goy & Ganzini, 2003; Irwin et al., 2008; Kelly, McClement, & Chochinov, 2006; Miovic & Block, 2007; Pessin, Rosenfeld, & Breitbart, 2002), namely depression (Block, 2000; King, Heisel, & Lyness, 2005; Wilson, Chochinov, de Faye, & Breitbart, 2000) and anxiety (Jackson & Lipman, 1999; Roth & Massie, 2007) though even here, discourse tends not to discriminate between resent onset, chronic or comorbid conditions. However, there remains a paucity of information regarding Posttraumatic Stress Disorder, Schizophrenia and other Psychotic Disorders, Bipolar Disorders or Personality Disorders at the end of life (Woods, Willison, Kington, & Gavin, 2008). In this next section, we review some special considerations in the assessment and management of specific mental disorders present at the end of life.

Depression

Prevalence rates of depression vary widely depending on the patient population, type and severity of physical illness, and method and timing of assessment (e.g., Reeve, Lloyd-Willams, & Dowrick, 2008). Prevalence of Major Depressive Disorder among persons with advanced disease ranges from 5% to 15% (Derogatis, et al., 1983; Hotopf, Chidgey, Addington-Hall, & Ly, 2002; Kadan-Lottick et al., 2005; Wilson, et al., 2007). When including clinically significant depressive symptoms or Adjustment Disorders, the rates increase to 20% to 50% among patients in palliative and hospice settings (Derogatis et al., 1983; Lloyd-Williams & Riddleston, 2002; Razavi, Delvauz, Farvacques, & Robaye, 1990).

Low rates of identifiable depressive symptoms have been explained in multiple ways. Medically ill individuals may be reluctant to report depressive symptoms or may conceal them due to stigma or perceived weakness (e.g., Hinton, 1994). In addition, medical providers may avoid asking about or exploring depressive symptoms because of time constraints or fears of upsetting patients by inquiring about their emotional health (Block, 2000; Noorani & Montagnini, 2007). Providers may believe that depressive symptoms are a normal response to terminal illness and/or may believe there is little that can be done to alleviate symptoms (Block & Billings, 1994; Sharpe et al., 2004). Health-care providers may worry that patients will not be able to tolerate medication side effects or drug interactions associated with the addition of antidepressants and thus are conservative when prescribing antidepressants (Wilson et al., 2000).

Certain medical illnesses and/or complications of the disease and its treatment are associated with depression. These conditions include cancer—particularly pancreatic, oropharynx, breast cancer, and brain tumors or metastases—hypercalcemia, anemia, corticosteroids, chemotherapy, whole brain radiation, CNS complications, and thyroid disorders (Miovic & Block, 2007). Additional risk factors include functional dependence and loss of control, poor pain control, a diminished sense of meaning or purpose, a history of depression, perception of oneself as a burden, poor support, concurrent stressors such as financial strain (Wilson et al., 2000) and younger age (Lloyd-Williams & Friedman, 2001). Palliative care patients who meet criteria for both Major Depressive Disorder and Anxiety Disorder experience even greater difficulties than do patients with depression only (Wilson, et al., 2007). They likely will be unable to complete unfinished business, maintain meaningful relationships or experience pleasure. They may experience increases in pain, suicidal ideation, and requests for hastened death (Block, 2000).

Ideally, all individuals should be screened for depression (and other psychiatric disorders) at the time of referral to palliative care and/or hospice services. Assessment should include a comprehensive review of possible risk factors, behavioral observation, proxy reports when possible, and clinical interview/self-report screening measures such as the Geriatric Depression Scale or Hospital Anxiety and Depression Scale. Although a comprehensive review of the assessment and treatment of depression in advanced and terminal illness is beyond the scope of this chapter, we will highlight a few key issues. See Noorani and Montagnini (2007); King, Heisel, and Lyness (2005); Lloyd-Willams, Spiller, and Ward, (2003), and Thekkumpurath, Venkateswaran, Kumar, and Bennett, (2008) for excellent reviews.

One key issue to consider is the overlap of symptoms associated with advanced or terminal illness, medication and depression. For example, decreased appetite, weight loss, sleep disturbances and fatigue or decreased energy can be a function of depression, disease and/or medication. Furthermore, symptoms can represent Major Depression, Adjustment Disorder with Depressed Mood, grief and complicated bereavement, and/or subsyndromal symptoms. In one's differential diagnosis, it is useful to consider not only the severity, pervasiveness, and/or duration of symptoms but the presence of particular cognitive symptoms—namely dysphoria, anhedonia, hopelessness, negative self-image, guilt, helplessness, worthlessness, and goal-directed suicidal ideation.

Rosenfeld, Anderson, and Werth (2008) offer useful questions to ask to assess these core cognitive symptoms. Does the patient continue to derive enjoyment from normally pleasurable activities (with appropriate modifications for current functional status or substitute new activities)? Does the patient continue to set goals and possibly modify/shift these goals as the illness progresses (e.g., comfortable dying, meaningful interaction with family/friends)? Does the patient expect his or her team to be able to manage his or her symptoms and keep him or her comfortable? Is there anything the patient hopes to accomplish or is looking forward to? Alternatively, does the patient exhibit pervasive pessimism regarding most aspects of his or her future and feel powerless to affect change? Does the patient feel like he or she has nothing left to contribute? Has made no substantial contributions in his or her life? Sees his or her life as having amounted to nothing? That he or she has no value as a person and will not be remembered or missed? That he or she is a burden, a feeling that is disproportionate to the demands of the situation and does not reflect realistic struggles. Does the patient feel responsible for causing his or her illness despite no known or clear etiology? Is there existential suffering?

Another issue that is salient among terminally ill persons is normative thoughts of death as separate from goal-directed suicidal ideation (SI). Although terminally ill individuals may hope that death comes quickly and even desire hastening their dying process, most do not have plans to hasten their death nor exhibit goal-directed SI, which is more typical of severe depression and hopelessness. Typically, thoughts of death are transient and associated with feelings of loss of control and anxiety about the future. Some individuals may be afraid to share thoughts about wishing to die for fear that they will be seen as suicidal. If individuals endorse thoughts of death, providers will want to explore the persons' reasons for wanting to end life now and the meanings of the desire to die; the presence of physical symptoms and how effectively they are being managed, particularly pain; religious, spiritual, and existential concerns, and reasons for living. Risk for goal-directed SI increases in the presence of suffering, poor prognosis, fatigue and exhaustion, hopelessness, helplessness, substance use, personal and family history, lack of social support and diminished control.

Another salient area to consider when assessing mood symptoms at the end of life is the differentiation between depression and grief over current and anticipated losses in terminally ill patients, coined preparatory grief (Periyakoil & Hallenbeck, 2002). Grief often is experienced in waves, the intensity of which diminishes over time whereas depression is constant and unremitting. Individuals with advanced or terminal illness who are grieving normatively typically have a preserved self-image, though dependence and functional decline can threaten their self-worth. They often are able to experience pleasure and look forward to the future (Periyakoil & Hallenbeck, 2002) whereas depressed individuals enjoy few things and lack positive future expectancies. The Terminally Ill Grief or Depression Scale (TIGDS) has been designed and validated to differentiate between preparatory grief and depression in hospice inpatients (Periyakoil et al., 2005). In addition, patients may experience complicated grief as distinct from depression or preparatory grief, as older hospice and palliative care patients are likely to have experienced the death of family and friends. Their own situations may trigger or compound complications in bereavement.

Treatment of mood disorders at the end of life should include aggressive management of the underlying medical illness and associated physical symptoms as well as the mood disorder. The overarching goals are to improve quality of life, manage the psychiatric symptoms, strengthen coping with the disease and associated changes, reduce helplessness and hopelessness and, promote meaning-making. There are few studies examining the effectiveness of psychological treatment for depression in hospice and palliative care patients but the findings are encouraging. Cognitive-Behavioral Therapy (CBT) has been found to reduce depressive symptoms in patients with advanced cancer (Anderson, Watson, & Davidson, 2008; Greer et al., 1992; Holland et al., 1991; Moorey et al., 1994; Willams & Dale, 2006) as has Supportive-Expressive therapy (Kissane et al., 2007). Cognitive therapy also has been found to reduce depressive symptoms as well as fatigue, insomnia, and anxiety in women with metastatic breast cancer (Savard et al., 2006). Mindfulness-based stress reduction meditation seems to be a useful approach in managing depressive symptoms in people with cancer (Garland, Carlson, Cook, Lansdell, & Speca, 2007). Life review, which is an explicit focus of hospice and palliative care, is effective in treating depression in older adults (Serrano, Latorre, Gatz, & Montanes, 2004) but it has not been examined as a means of reducing depression in terminally ill patients. See Wilson, Lander, and Chochinov (2009) for a review of pharmacological treatment of depression at the end of life.

Anxiety

Prevalence of diagnosed anxiety disorders in individuals with advanced and terminal illness ranges from 2% to 30% (Derogatis et al., 1983; Kadan-Lottick et al., 2005; Miovic & Block, 2007; Periyakoil 2005; Roth & Massie, 2007). Individuals with chronic obstructive pulmonary disease (COPD) may be particularly vulnerable (Brenes, 2003), with Generalized Anxiety Disorder

(GAD) ranging from 10% to 15% (Yellowlees, Alpers, Bowden, Bryant, & Ruffin, 1987) and Panic Disorder ranging from 32% to 37% (Moore & Zebb, 1999; Yohannes, Baldwin, & Connolly, 2000). Most anxiety disorders seem to be associated with the physical illness rather than predating it.

Anxiety disorders can result from medical complications of the physical illness or its treatment. Risk factors include the underlying disease, particularly for those diseases that cause shortness of breath and hypoxia (e.g., pneumonia, pulmonary embolism, lung cancer, pleural effusion, COPD, and cardiac disease); endocrine disorders (diabetes, hyper/hypothyroidism), neurologic diseases (Parkinson's), metabolic disorders (hypo/hypercalcemia, hyperkalemia, dehydration, hyponatremia), sepsis, or impending cardiac or respiratory arrest. Anxiety also can be associated with medications (e.g., corticosteroids, stimulants, antiemetics, bronchodilators) and withdrawal from medications (e.g., opiods, benzodiazepines) or alcohol. Anxiety may represent a conditioned response to treatment (e.g., chemotherapy, radiation) or a reaction to poorly controlled symptoms such as pain. Procedures such as wound care or personal care that may exacerbate discomfort can result in conditioned anxiety (Jackson & Lipman, 1999; Roth & Massie, 2007). A prior history of anxiety disorder also may increase risk for anxiety at the end of life. In addition, being around someone who is highly anxious may increase the likelihood of becoming anxious oneself (Bambauer et al., 2006).

Medically ill individuals often experience anxiety in response to uncertainties and fears inherent in living with life-limiting or terminal illness. They may fear medical interventions, treatment or particular symptoms, and may worry about their capacity to cope with those symptoms. They may fear incapacity, dependency, or disfigurement and may have specific fears about dying, engendered in part from past experiences with the death of significant others. Individuals at the end of life may be fearful of falling asleep, worried that they may not wake up. They may fear past transgressions and being rejected or abandoned. They may be concerned about how their loved ones will cope after they are gone. They may worry about financial, legal, and practical matters and fear not having time to complete their affairs. They may fear nonexistence or the afterlife.

As in the case of depression, assessment of anxiety should include a comprehensive review of possible risk factors, behavioral observation, proxy reports when possible, and clinical interview/self-report screening measures such as the Geriatric Anxiety Inventory. Assessment of anxiety in individuals with advanced or terminal illness is complicated by the fact that physical causes of anxiety can be difficult to distinguish from psychological ones. Physical symptoms used to diagnosis anxiety and panic may be present as a part of the normal dying process. In addition, anxiety symptoms may reflect a diagnosable disorder, normative fears, or existential suffering and are likely to co-occur with depression and/or delirium. As with depression, it may be helpful to focus on cognitive symptoms such as derealization, depersonalization, and fears of going crazy, generalized worries or worries about future panic attack (Periyakoil, 2005). In addition, providers also will want to explore the nature of patients' and involved family members' fears. Common shared fears include that the medically ill person will suffer, that the caregiver will not be available when the person needs him or her, that the caregiver will not know what to do in the event of a medical crisis, and/or that the person's treatment preferences will not be honored (Bambauer et al., 2006).

Treatment of anxiety disorders includes aggressive management of symptoms associated with the underlying physical illness as well as anxiety. Few studies have examined the effectiveness of psychotherapeutic interventions for anxiety in hospice and palliative care patients. Supportive therapy and psychoeducation are effective in reducing anxiety symptoms. Being gravely ill can be highly stressful. Mental health providers can acknowledge and validate this fact and explore sources of anxiety and normalize, when appropriate. Providers can reassure medically ill individuals about good symptom management, provide information about the dying process, assist with end-of-life tasks, facilitate communication of needs, problem-solve concerns when appropriate, and bolster protective and resiliency factors such as meaning-making, sense of purpose, and values-based living.

CBT, namely cognitive restructuring, relaxation training, and coping skills rehearsal, has been associated with reduced anxiety and psychological distress in individuals with advanced cancer (Greer et al., 1992; Moorey et al., 1994; Moorey & Greer, 1989). In the studies by Moorey and colleagues, patients were taught to identify negative thoughts, rehearse impending stressful events such as a discussion of end-of-life issues with family, implement ways of handling these events effectively, plan and carry out practical activities that create a sense of mastery, express feelings openly to partners, and increase self-esteem by identifying and fostering personal strengths. This approach is notable given the focus on family in light of the finding of increased risk for anxiety in one member of a dyad if the other member has a diagnosed disorder (Bambauer et al., 2006). Relaxation strategies, particularly breathing retraining, have been found to reduce distress caused by breathlessness (Corner, Plant, A'Hern, & Bailey, 1996). See Roth and Massie (2007) for a discussion of pharmacological treatment of anxiety disorders at the end of life.

Post Traumatic Stress Disorder (PTSD) and Acute Stress Response

Individuals with a trauma history and PTSD may experience worse physical health problems than those without a history (Krause, Shaw & Cairney, 2004). Individuals diagnosed with a life-threatening illness may be at increased risk for developing acute stress responses and PTSD, with estimates ranging from 0% to 33% (Kangas, Henry, & Bryant, 2002; McGarvey et al., 1998). Risk factors include prior negative life stressors, female gender, younger age at diagnosis, avoidant coping (cognitive and behavioral), poor social support, reduced physical functioning, poor provider–patient communication, prior trauma history, and psychological problems and elevated distress subsequent to diagnosis (Butler, Koopman, Classen, & Spiegel, 1999; Green et al., 2000; Kangas, Henry, & Bryant, 2005; McGarvey et al., 1998). Recurrence of disease may be more traumatic than the initial diagnosis (Cella, Mahon, & Donovan, 1990). Factors that affect meaning of the illness/treatment and perceived life threat are potential mediators of distress (Gurevich, Devins, & Rodin, 2002).

To what extent the life-threatening or terminal illness is itself the instigating trauma versus a trigger for preexisting PTSD is unclear. Deterioration of health may create a sense of vulnerability or loss of control similar to that experienced during the original trauma (Buffum & Wolfe, 1995). The threat to life inherent in terminal illness, to both personal and physical integrity, may mimic the original trauma, exacerbating previous PTSD (Feldman & Periyakoil, 2006). Posttreatment scars, pain, or physical limitations can be persistent reminders of the disease and evoke perceived threat. Diagnostic tests, medical procedures, or even personal care also can trigger overwhelming anxiety if they reproduce the trauma experience (e.g., colonoscopy mimicking sexual abuse; cleaning of genitals during personal care). Tests and procedures that evoke prior trauma experiences may result in the individual with PTSD avoiding or ignoring problems or refusing care.

PTSD can impinge on factors important to hospice and palliative care—emotional and practical support, communication, life review, and unfinished business (Feldman, 2010). Many individuals with PTSD are used to being isolated and detached and are wary of interpersonal relationships, particularly those with people in positions of authority. They have a high need for control and are avoidant of trauma reminders. They may have difficulty communicating with care providers as direct, clear communication requires effective affect regulation and trust of others both of which are difficult for persons with PTSD. The normal process of life review and attending to unfinished business for persons with PTSD at the end of life may induce anxiety, guilt, regret, anger, or sadness when key memories are trauma related. Thus, individuals with PTSD may avoid the life review process in order to avoid or suppress reminders or feelings.

Standard treatments for PTSD have limitations for individuals at the end of life, particularly length of time both in terms of duration of treatment and length of individual sessions (e.g., prolonged exposure) and the likelihood of increasing distress in the short term when individuals may have only a relatively short time to live. Pilot studies of prolonged exposure with older adults look promising but they have not been replicated with individuals with advanced illness (Thorpe, 2009). A model proposed by Hyer and Woods (1998) for treatment of PTSD in older adults has potential application to the treatment of PTSD at the end of life. In a reformulation of this model by Feldman (2010), treatment begins by addressing short-term concerns, then proceeds to longer-range concerns should the medically ill persons live long enough to benefit from addressing such issues. In stage one, providers offer emotional support and address problems of immediate concern for the individuals, in order to quickly maximize quality of life, such as making funeral arrangements, reestablishing contact with estranged relatives, or paying bills. Active listening, validation, and reassurance are emphasized. In stage two, providers focus on medium-range goals of providing education about PTSD and skills training (e.g. communication, social, relaxation), which enable ill individuals to improve their quality of life. In stage three, the medically ill persons and provider focus on specific trauma-related issues. The provider encourages individuals to share stories about the trauma at their own pace. Stage three begins when individuals are open to speaking about the trauma and likely to live long enough to benefit from it. Ultimately, work at this stage encourages forgiveness of self and others.

A pilot study of life-review to treat PTSD in older adults (Maercker, 2002) also may be applicable to individuals with advanced disease and is consistent with stage three in the Hyer and Woods (1998) model. Trauma is discussed in the context of the life stage in which it occurred. Both undesirable and desirable changes engendered by the trauma are explored, weighing and valuing events of one's life and facilitating meaning-making. This approach is consistent with the view that prior trauma may serve as an organizer of preexisting and subsequent experiences that then filters the impact of a current stressful event.

Finally, progressive muscle relaxation and guided imagery have been found to reduce acute stress responses in individuals with cancer (Baider, Uziely, & Kaplan De-Nour, 1994). Supportive-expressive therapy in combination with psychoeducation has been associated with reductions in traumatic stress symptoms and mood disturbance in women with advanced breast cancer (Classen et al., 2001).

Schizophrenia and Other Psychotic Disorders

Prevalence rates of Schizophrenia or other Psychotic Disorders in individuals with advanced or terminal illness are unknown. However, nearly 50% of individuals with Schizophrenia have a comorbid medical condition, though these conditions are often misdiagnosed or underdiagnosed (Goldman, 1999). Common conditions include cardiovascular disease, respiratory disease, diabetes, and infectious diseases. In addition, when the medical illness is diagnosed, it often is quite advanced (Inagaki et al., 2006). This outcome occurs for a variety of reasons. Individuals with Schizophrenia may be reticent to seek health care. Individuals with Schizophrenia may be unable to clearly and accurately describe their physical symptoms or communicate their history (Bunce, Jones, Badger, & Jones, 1982) thereby complicating identification. Once a medical condition is identified, treatment providers may be reluctant to inform individuals of the details of their diagnosis for fear of aggravating their psychiatric symptoms. Furthermore, even after being diagnosed and informed about a medical condition, individuals with Schizophrenia may not be able to accurately describe their medical condition or grasp the meaning of the diagnosis (Pary & Barton, 1988). In addition, both individuals with Schizophrenia and providers may underestimate or ignore co-occurring medical illness, particularly when an individual exhibits more severe positive symptoms (Jeste, Gladsjo, Lindamer, & Lacro, 1996), as the individual's comorbid physical conditions may seem a relatively less important in the context of florid psychosis.

Individuals with Schizophrenia, particularly Paranoid Type, may be reticent to pursue treatment or be distressed by procedures and medications if they view treatment as an effort to manipulate or harm them. They also may have had prior negative experiences with providers such as being put on involuntary holds, forced to take medication, or reacted to with fear or trepidation. Individuals may have difficulty tolerating medical care due to the close interpersonal contact it requires. They may have difficulty identifying their feelings and may express them in a distorted way. They may need help to recognize that their feelings are normal and appropriate (Lanza, 1988). Individuals with severe negative symptoms may have difficulty understanding and cooperating with cancer treatments (Inagaki et al., 2006). In addition, their experience of pain may be described in less typical terms (e.g., tingling, itching, pressure, or heat and cold). Pain may be muted or highly tolerated due to difficulty interpreting sensory information accurately because of negative symptoms, for example, pain, or the believed source of the pain is incorporated into the delusional system (Dworkin, 1994; Karasu, Waltzman, Lindermayer, & Buckley, 1980; Talbott & Linn, 1978). Furthermore, some neuroleptics may enhance analgesia. Collectively, these factors may result in delays in detection of medical disease as pain often is a marker of illness.

Assessment of both current psychiatric and physical symptoms is important. A variety of medical conditions can exacerbate or even bring out schizophrenic symptoms (i.e., multiple sclerosis, acute intermittent porphyria—deficiencies of enzymes that produce heme, which is essential for the transport of oxygen to cells in the body—pheochromocytoma—typically benign tumors of the adrenal gland, systemic lupus, autoimmune disorders, or stimulant abuse) or other conditions can mimic Schizophrenia (e.g., neurologic syndromes, AIDS, encephalitis, autoimmune disorders, substance withdrawal, dementia) (Adler & Griffith, 1991). The Cumulative Illness Rating Scale for Geriatrics (CIRS-G) has been used effectively to assess comorbid physical diseases in individuals with Schizophrenia (Jeste, Gladsjo, Lindamer, & Lacro, 1996).

The overarching goal for treatment remains the same for those without a terminal illness—minimize vulnerability and stress, maximize adaptive capacity and function and, enhance social support, particularly involvement of family. Mental health providers will want to assess patients' beliefs about their psychiatric symptoms and identify specific triggers, including the advanced or terminal illness. Providers can explore how individuals typically cope with medical and psychiatric symptoms and reinforce adaptive coping responses while also gently guiding persons to more rational perspectives regarding their symptoms when they have misattributed the symptoms (e.g., using belief modification, focusing/reattribution, normalizing) (American Psychiatric Association Practice Guidelines, 2004b).

For example, with respect to auditory hallucinations, providers can ask "When do you hear voices and how do you cope with them?" "What do you say to yourself when the voices command you to do something and you ignore the voices?" If the voices interfere with medical management, providers can attempt to discuss with individuals the fact that it is not the voices themselves but their response to the voices that determines the outcome. Patients can experiment with various strategies. Individuals experiencing hallucinations can be encouraged to generate a list of thoughts that they can use to ignore the auditory hallucinations and have this written list close by so that it can be referred to as needed. They can read aloud, hum a song, make a telephone call, use relaxation strategies, or any other distracting activities. For individuals with visual hallucinations, providers can encourage them to examine the details of what they see, as often this process alone can make hallucinations disappear. Providers can inquire about what has happened to patients previously when they saw these visions and assure patients that while these visions are frightening, the visions have appeared before and have not hurt them. Of note, in advanced disease, providers will want to discriminate hallucinations associated with thought disorders from those associated with terminal delirium.

With respect to delusions, delusions often come on gradually, and for a period of time, individuals with Schizophrenia or other Psychotic Disorders may have doubted them. Rather than disputing the delusional beliefs, providers are encouraged to adopt an attitude of benevolent curiosity, which may give them some insight into the patients' thinking processes. Sometimes patients experience delusions that can be exacerbated because they lack real-world knowledge and providing accurate knowledge may help patients cope with delusions (American Psychiatric Association Practice Guidelines, 2004b).

One of the most critical issues when working with individuals with Schizophrenia or other Psychotic Disorders at the end of life is adherence to medical intervention in the service of symptom management. Adherence may be improved by providing structure, routine, consistency, and limiting contact, whenever possible, to one person with whom the individual has gotten to know and trust, in collaboration with any long-standing mental health providers with whom the patient has a good relationship. The mental health provider may have knowledge about how best to engage the individual or how the individual is likely to respond to treatment. If procedures or medical interventions are warranted, providers can walk the medically ill individual through what to expect, in clear, simple, repetitive language prior to the intervention and discuss who will follow the individual's care. The team will want to create a clear, consistent treatment plan, ideally agreed on by medical and psychiatry services and the medically ill individual and family in advance. Appropriate pharmacological management of psychiatric symptoms remains imperative, particularly given the finding that the odds of receiving antipsychotics decreases with increasing medical complexity (Chwastiak, Rosenheck, & Leslie, 2006). Social skills training also can be useful, particularly regarding how to express needs and negotiate medical and psychiatric care.

Bipolar Disorder

Prevalence rates of Bipolar Disorder in persons with advanced or terminal illness are unknown. However, there is some suggestion that psychiatric symptoms may worsen in response to treatment or medications. For example, interferon, corticosteroids, stimulants, and antidepressants can induce or exacerbate mania in persons with Bipolar Disorder (Greenberg et al., 2000). Physical illness disrupts social rhythms such as sleeping, eating, physical activity, and social and emotional functioning and these disruptions can trigger mood symptoms. Sleep problems can be particularly disruptive to individuals with Bipolar Disorder in that a disrupted sleep-wake cycle can trigger manic episodes; thus, good sleep hygiene is critical to managing their psychiatric symptoms. Psychosocial stressors also can trigger mood symptoms.

Overarching treatment goals include reducing distress, increasing function, and decreasing the likelihood and severity of future mood episodes. Mental health providers will want to promote individuals' awareness of the role of stress in precipitating or exacerbating their mood symptoms, highlighting stresses common at the end of life, particularly family conflict or dysfunction. Mental health providers can develop a plan with individuals with Bipolar Disorder for managing or minimizing stressors, developing skills for coping with stressors and ways to modulate daily activities to better regulate social rhythms and maintain structure, to the extent possible given the underlying physical disease (American Psychiatric Association Practice Guidelines, 2004a).

Comorbid substance abuse, which is common among persons with Bipolar Disorder (42% to 72%; Feinman & Dunner, 1996; Schuckit et al., 1997; Sonne & Brady, 1999; Tsuang, Cowley, Ries, Dunner, & Roy-Bryne, 1995), tends to worsen psychiatric symptoms and decrease effectiveness of palliative care interventions. Untreated substance abuse compromises palliative care interventions in that substance abuse can impede the diagnosis of psychiatric problems and increases patient suffering; complicate pain and symptom management, in part through poor treatment compliance and increased concerns about misuse of medication; and create tension among patients' support networks particularly when family members find themselves having to dispense medications and/or limit access to them (Passik & Theobald, 2000).

The high comorbidity between Bipolar Disorder and substance use calls for careful assessment of symptoms. Substance use can mimic the psychiatric disorder, may cause mood and anxiety syndromes, or may be an attempt to control mood and anxiety symptoms. For example, alcohol may cause anhedonia, decreased concentration, apathy, or insomnia. The CNS stimulants such as cocaine or amphetamines may cause euphoria, grandiosity, or paranoia (Quello, Brady, & Sonne, 2005). The exact relationship between mood symptoms and substance use can be ascertained after gaining better control over the substance use. As individuals gain control over their addiction, they also are more likely to be able to attend to and cope adaptively with their advanced or terminal disease.

Passik, Kirsh, and Portency, 2002; and Passik and Theobald, 2000 outline strategies for managing active substance use in the context of outpatient and inpatient palliative care. Outpatient providers are encouraged to discuss patients' drug use openly, to limit the amount of drug dispensed per prescription, and to make refills contingent on outpatient palliative care clinic attendance. Providers also may want to require participation in drug treatment or 12-step programs, involving sponsors, family and friends, and/or conduct spot urine toxicology screens. Inpatient providers will want to discuss patients' drug use openly and reassure patients that steps will be taken to avoid drug withdrawal. Providers are encouraged to provide close monitoring such as collecting daily urine samples and requiring visitors to check in with nursing staff before seeing the patient and discouraging passes to leave the hospital. Irrespective of the setting, it is critical to educate family and staff on the difference between dependence and addiction and to identify one's own biases and assumptions about addiction, particularly in the context of pain management.

Rigorous treatment of both the underlying affective and substance use disorder (SUD) is recommended (e.g., providing education on the relationship between SUD, and Bipolar Disorder and substance use as a way of self-medicating; promoting self-care strategies and coping with risky situations); but many palliative care settings typically are not well equipped for this level of psychiatric intervention. Of note, the goal of substance abuse treatment likely is not complete abstinence but harm reduction/controlled use with the hopes of minimizing interference with effective symptom management, particularly pain (Kirsh & Passik, 2006).

Personality Disorders

Prevalence rates of Personality Disorders in medically ill individuals are virtually unknown. One study of individuals with cancer found a 3% prevalence (Derogatis et al., 1983). Empirical data also is lacking on how individuals with Personality Disorders cope with or adapt to advanced or terminal illness but they likely are ill prepared to cope. They arrive at the end of life with lifelong coping deficits and often diminished self-esteem and worth due to a lifetime of problems and failures. They likely experience comorbid mental health problems such as substance use, anxiety and affective disorders, or eating disorders. Medical illness and treatment threatens their already vulnerable sense of physical attractiveness and performance, control, autonomy, independence and privacy (Geringer & Stern, 1986) and requires them to tolerate enormous uncertainty while maintaining collaborative relationships with care providers and family (Passik & Hay, 1998). The situation may be worsened when persons with Personality Disorders find themselves in institutional environments where they experience increased dependency on others, lack of privacy and disrupted routines.

Individuals with Personality Disorders often are challenging for medical providers (Crits-Christoph & Barber, 2002) and can be a drain on the health-care team. They may use a disproportionate share of services and medical resources (e.g., direct care, consultation time, or staff attention and emotional energy). The particular behavior manifest will be a function, in part, of the specific Personality Disorder. Furthermore, by identifying the specific function of behaviors, providers may be better able to meet the individuals' needs.

Persons with Odd-Eccentric features are likely to have difficulty enduring physical exams, medical procedures and treatment due to discomfort with physical closeness, intrusions in their personal space and/or general suspicion of the intention of others. They may give limited information in response to questions and appear eager for the visit to end. They may seem uncomfortable, agitated, or paranoid and respond best to a neutral, predictable, matter-of-fact style of communication.

Persons with Dramatic-Emotional features may be experienced as manipulative, demanding, noncompliant, and disruptive. Persons with Borderline Personality Disorder may have fragile, stormy, and inappropriate relationships with medical providers (Nowlis, 1990; Searight, 1992) in which appropriate boundaries are difficult to maintain. Individuals with Borderline Personality Disorder may be experienced as difficult to please, demanding, or needy (Passik & Hay, 1998). They are likely to be highly sensitive to a loss or change in health-care teams and referrals can elicit fears of abandonment and rejection. They may divide and polarize staff and split teams. Individuals with Narcissistic Personality Disorder may appear arrogant, patronizing, or grandiose. They may have difficulty admitting medical problems, seeking appropriate care or valuing physicians' perspectives as problems that are viewed as incompatible with the person's inflated sense of self and feelings of uniqueness.

Persons with Anxious-Fearful features are likely to present with comorbid anxiety and depression. They may seek medical help more frequently due to a prominence of worry, attempt to get physicians to make decisions for them, have endless questions that prolong visits, or conversely, may be afraid to ask questions and delay seeking medical attention. They may have difficulty tolerating being alone. Persons with Obsessive-Compulsive Personality Disorder may seek multiple opinions about diagnosis and may meticulously document symptoms.

Medical providers often feel frustrated, ineffectual, and overwhelmed when working with patients with Personality Disorders. Mental health professionals can assist medical providers in managing these reactions by more broadly conceptualizing patients' behaviors. When a patient or family member's behavior is attributed solely to the stress of advanced illness or the dying process, without an understanding or appreciation of the way in which the stress of dying may evoke long-standing interpersonal dynamics, staff may set unreasonable expectations for themselves or not feel comfortable setting limits, which can lead to burnout or avoidance. Providers will want to remain engaged, empathic, and available to patients while also protecting themselves through limit setting, assertive communication (patient and provider), maintenance of clear boundaries, behavioral contracting, and containment of behaviors that disrupt or interfere with functioning of the medical staff. Having all team members aware of all aspects of care also will help limit splitting and minimize its impact. These strategies will allow appropriate connection, which is particularly important to patients at the end of life who may experience a sense of abandonment of treatment providers when transitioning from curative to palliative approaches.

Keeping medically ill individuals with Personality Disorders focused on the here-and-now and short-term, specific tasks such as how to share a room or maintain an appropriate personal care schedule can be helpful. It also can be useful to develop the patient's sense of responsibility for change and elucidate the benefits to behavior change. Providers can draw on adaptive personality traits and use psychotherapy interventions as warranted (e.g., social skills training, graded exposure and behavioral rehearsal regarding negative self-evaluation). Finally, when patients are reluctant to adhere to necessary medical interventions, staff can try to appeal to an important personal relationship (staff or family member) or particular beliefs (Fogel & Martin, 1987). For example, "Dr. Smith, our esteemed Palliative Care consultant, reviewed your case and recommends a trial of Haldol for your nausea. I believe you can handle this medication just fine." See Rosowsky (2000); Rosowsky, Abrams, and Zweig (1999); and Segal, Coolidge, and Rosowsky (2006) for a more detailed discussion of treatment of personality disorders in older adults, which includes a focus on long-term care settings.

CONCLUSION

Although we may not be able to eliminate psychiatric symptoms or SMI at the end of life, we can ameliorate symptoms to improve quality of life when we take the time to understand the respective disorder in context, set appropriate expectations for ourselves and our patients, rely on the shared expertise of an interprofessional team, treat physical and psychiatric symptoms, monitor and process our own reactions, and practice good self-care.

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CHAPTER

6

Advance Care Planning

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This chapter explores the process of advance care planning and key issues that clinicians may face when discussing advance care planning with individuals and their families. Even though legislation has supported advance care planning since 1991 with the implementation of the Patient Self Determination Act (PSDA), actual completion of advance directives is still relatively low, less than 25% (Heyman, 2008). Advance care planning is a way to ensure that individuals' preferences for care at end of life are known and documented. Advance care planning is best thought of as a process, with concrete components that can be revisited throughout the course of someone's life and/or illness trajectory.

ADVANCE DIRECTIVES

Advance directives are defined as written instructions that provide direction for the provision of medical treatment when an individual is no longer able to make medical decisions. Advance directives are comprised of two types of legal documents: a living will and a durable power of attorney for health care. The *living will* portion of advance directives documents an individual's wishes and decisions about care ahead of a crisis should the individual be unable to speak for him or herself. Advance directives can be broad and basic (e.g., if a person were to have a terminal illness with no hope of meaningful recovery, he or she would opt for comfort and focus on symptom management) or very specific (e.g., would want a trial of intensive care, or ventilator support but no pressors). There are many forms of advance directives, ranging from Five Wishes (information available at www.agingwithdignity.org) to state-specific advance directive forms. In formalizing advance directives with individuals, the individual must complete the form correctly so that health-care providers can honor their wishes (i.e., needing witness signatures or notarization).

An advance directive is a tool that individuals and their families use in advance care planning to discuss wishes for care at the end of life and that empowers individuals to have an active role in their care, even if they come to a point where they are unable to make medical decisions. Advance care planning is not a static task that, once completed, holds for the rest of a person's life. Instead, advance care planning is a process, especially because people's goals and values change across their lives and disease trajectories. Advance care planning as a process takes into account the fluidity and uncertainty that life presents, and by being a process, continues to involve the individual along the illness trajectory to help ensure that the person's wishes can be known and honored.

In completing an advance directive, clinicians help individuals think about their values and priorities, especially in the context of their current situation or illness. Language, formats, and examples included in advance directives help to facilitate this process. When dealing with chronic illnesses, it is difficult to imagine ahead of time the different potential crises or complications that may arise over the course of the illness. That is why advance care planning is a process. As an individual experiences life and as the illness progresses, what a person values and hopes for may change. For example, a woman with early onset dementia may function fairly well with minimal modifications in lifestyle or assistance from others. In the early stage of the illness, she may opt to continue to have routine screenings such as cholesterol screenings or breast cancer screenings, because her overall quality of life is good. However, it is important to begin discussions with this individual about how she would define good quality of life, because as the disease progresses, her quality of life may decline as she defines it. If this same individual values the ability to converse with family, it is important to talk about how she would want care when the time comes where she no longer recognizes family members. If she states that her life would lose meaning when she could no longer recognize her family, that could be defined as the point when routine screenings or an emergency cardiac catheterization should she develop chest pain would no longer be appropriate. Instead, the focus should switch to keeping her comfortable until some final event happens that causes her death. It could be a heart attack, a stroke, or even cancer—the proximal cause is less important than ensuring her comfort. What is important is that she is able to define for her family and providers when she would no longer want to pursue treatment in the context of her illness and dying trajectory.

Clinicians need to be aware of some of the barriers that prevent individuals from advance care planning and completing an advance directive. These include the patient's knowledge about advance directives, discomfort about the topic, and fear of death. Clinicians themselves who assist patients in addressing advance care planning issues and completing advance directives need to have their own understanding and comfort level with death and dying to better facilitate these discussions with patients who may be struggling with these decisions.

CONVERSATIONS ABOUT ADVANCE DIRECTIVES

Ideally, these advance care planning conversations and documentation of wishes should occur before individuals get ill or develop terminal conditions. However, that is not often the case. Difficult decisions are made every day across the healthcare continuum. Often, these conversations regarding goals of care happen while someone is in the acute hospital, having been admitted for yet another exacerbation or complication. In supporting individuals and families during difficult conversations, the GOOD acronym is a useful tool (Hallenbeck, 2003).

The GOOD acronym stands for G—Goals, O—Options, O—Opinion, and D—Document. Table 6.1 shows a summary of the GOOD acronym. A provider initiates a conversation by eliciting from the individual and other key family members their current understanding of the illness, using an open-ended question such as "What is your understanding of your illness?" Once it is clear that the individual and family members have a correct understanding of the situation, the provider then asks about the individual's *goals* and/or hopes. Where one person may hope for a cure, another may hope for pain relief, or to live to a certain key event. When goals are realistic, the provider then discusses the *options* that exist to help the individual achieve his or her goals. Without realistic goals in the context of the illness, informed discussions cannot occur. This helps to narrow

Table 6.1 GOOD Acronym

G—Goals	• Identify stakeholders • Clarify stakeholders' understandings • Clarify big picture goals first • Assess values that guide big picture goals • Identify option-specific goals
O—Options	• Make a mental list of relevant options to consider • Inquire if stakeholders are considering options other than those on your list • Discuss benefits and burdens • Consider probability • Honor values
O—Opinion	• Offer your opinion • Separate data from opinion • Explain your opinion, incorporating data from earlier discussions
D—Document	• A list of participants in the discussion and decision • A brief account of the essence of the discussion, with attention to the final decision • With regard to advance care planning, pay attention to both what the patients want now, and what they may want if certain things happen • Make sense of the decision

Source: Hallenbeck (2003).

down the field of choices that exist; it would not be necessary to review all medical interventions available if the individual no longer wants to be subjected to invasive therapies. After reviewing all of the options, the provider then can offer an *opinion* as to which option may best help the individual achieve his or her goals. Last, the individual makes a decision based on the discussion, and the provider *documents* the discussion. (For a more detailed description by the author, go to: www.mywhatever.com/cifwriter/library/70/4977.html)

Some parts of this framework apply more directly to the medical provider, who can present the medical situation and address specific concerns regarding probability of certain outcomes or risks and benefits of certain interventions. However, other health-care providers often take part in these conversations and aid the person and family in thinking through or coping with the situation.

A 45-year-old gentleman had been hospitalized for weeks for treatment of a cancer and then the ensuing complications. It became clearer to the health-care providers that he would not survive the hospitalization; however, no conversations about his prognosis had taken place recently. After he had expressed his desire to go home and asked about the possibility with the care that he required, the health-care team held a family meeting. When the team informed the patient of his terminal prognosis, he was then able to express his *goals* of being with his family and switching the focus of his care to comfort. Based on his goals, the team gave him the *options* to discontinue cardiac monitoring and unnecessary interventions, such as monitoring and treating his blood sugars. It was the *opinion* of the team that switching the focus of his care was appropriate in light of his prognosis, and they were able to move him to a larger room so that his family could stay with him in his final days. The health-care team *documented* the conversation, resulting in medical decisions.

DURABLE POWER OF ATTORNEY FOR HEALTH CARE

Advance directives contain both a living will component and a durable power of attorney component. The individual identifies a *durable power of attorney for health care* (DPOA), who is the individual's appointed spokesperson should that individual lose decision-making capacity. This loss of capacity may be temporary or permanent, depending on the underlying condition. There is also the possibility for individuals to direct the DPOA to have active authority even while they have decision-making capacity.

Capacity in the context of advance care planning refers to *medical* decision-making capacity. Patients are presumed to have capacity, defined as the ability to comprehend information, consider options, evaluate risks, make a decision, and communicate that decision, unless proven otherwise (Beauchamp & Childress, 1994). Appelbaum (2007) lists the four criteria of decision-making capacity as the abilities to: communicate a choice; understand the relevant information; appreciate the medical consequences of the situation; and reason about treatment choices. "Decision-making capacity" should not be confused with the legal concept of "competence." Incompetence is a legal determination made by a court of law. Someone may be deemed legally incompetent to handle their own finances but still retain decision-making capacity to make decisions about medical treatments.

During the illness trajectory, capacity does not always remain stable, and providers must continually assess a person's capacity to make informed medical decisions. Although a provider may deem an individual not to have capacity for a specific decision, he needs to continually evaluate the individual's capacity for subsequent decisions, as the loss of capacity may only be temporary. Causes of loss of capacity include the disease itself (i.e., stroke or brain cancer), delirium, side effects of medications, or medical intervention (i.e., someone who is sedated in order to be placed on ventilatory support). Physicians often make an initial assessment of capacity but can ask for the input of other providers involved with the patient. The Mini-Mental State Examination (MMSE) and the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) can be helpful in assessing capacity. The MMSE identifies patients at the high- and low-end range of capacity. The MacCAT-T incorporates information specific to a given patient's decision-making situation (Grisso & Appelbaum, 1998).

The role of the DPOA is to direct care and make medical decisions for the patient, representing the individual's wishes and values. This means that the DPOA should not act on his own interests, but on the interests of the patient. Sometimes, DPOA's feel as if the burden of the decision rests with them. Do I make the decision to "pull the plug," and then have to live with that decision for the rest of my days?

One way to help with this challenge is to reframe the questions asked of the DPOA. Instead of providers asking, "Do you want to stop life support?" Or, "Do you want to transition to comfort care?" providers could ask, "What would your loved one want were he able to be part of this discussion?" or "How would your loved one have wanted his care to proceed if he could speak to us right now?"

Optimally, the individual completing the document for a DPOA notifies the person she or he has appointed and discusses with the DPOA his or her wishes. Not every circumstance can be identified ahead of time, which is why advance directives are often more general versus specific. However, the more aware the DPOA is of a person's values and wishes, the easier it is for the DPOA to then make specific medical decisions should the need arise.

PRACTICAL ISSUES IN ADVANCE CARE PLANNING

Advance care planning addresses various common scenarios that patients and their families can experience in advance chronic illness and at the end of life. These scenarios include: the withdrawal or withholding of life-sustaining treatments; refusing escalation of care; and refusing medical tests and procedures.

The decision to withdraw or withhold life-sustaining treatments is less difficult if individuals and their families have been involved in advance care planning discussions all along the illness trajectory. With chronic progressive illness, cure is not an option. Whether the medical team should initiate certain life-sustaining therapies depends on the individual's goals, values, and beliefs, and quality of life as determined in previous discussions. If these discussions have not taken place previously, the health-care team needs to initiate these discussions to best honor an individual's wishes. For example, a woman in the early stages of dementia who still has good quality of life may choose to undergo chemotherapy for breast cancer. However, the same woman with advanced dementia, who is bed-bound and does not recognize her family, may have discussed with her family that she would not want to aggressively treat conditions such as a cancer or a pneumonia at this point in her illness.

Withdrawal or withholding of life-sustaining treatments such as ventilatory support, artificial nutrition and hydration, and dialysis should not be viewed as giving up, especially in the context of advanced or terminal illness, as these treatments do not guarantee extending a person's life or adding to the quality of life. Whether life-sustaining treatments are appropriate to initiate or to discontinue depends on continuously evaluating a person's goals in the context of the illness. Legally, there is no difference between withdrawing interventions and withholding interventions, although in practice it is often more difficult to withdraw a therapy once initiated compared to not starting a therapy (e.g., withdrawing ventilatory support versus not starting ventilatory support).

A 65-year-old gentleman was admitted from a skilled nursing facility to an intensive care unit after he was found unconscious and required life support. He was placed on ventilatory support and medications to support his heart function while the medical team conducted various tests to determine the cause of his neurological status changes. After several days of testing, the team had not yet determined the cause of his condition, and he remained in a critical status. The nursing staff shared with the palliative care team that the children had mentioned the possibility of their father not wanting all these interventions. The team then met with the family. In that discussion, the children shared that their father had lost his wife and grandchild a year earlier in an automobile accident. Since then, he was cared for in a skilled nursing facility because he had a spinal cord injury and was a quadriplegic. Prior to this admission, the children felt that their father had not had good quality of life, and relayed that their father had often mentioned that he missed his wife. When the team discussed with the family the unlikelihood of their father returning back to his baseline after this admission, the children determined that their father would not have wanted to pursue aggressive interventions to reverse the cause of his current illness, and would have preferred to "let nature take its course." Based on their father's values, the children made the decision a few days later to withdraw all life support and to let their father die, focusing on his comfort.

Health-care teams often present another option of *not escalating care*. For people who are critically ill with advanced illness, such as a woman with end-stage lung disease admitted with respiratory distress, the choice to not escalate care may be completely appropriate. Discussions about these possibilities, if they have taken place ahead of the crisis, will help individuals make decisions about the appropriateness of escalating care. In the previous example, if the woman's physician discussed the risks and benefits of placing her on ventilatory support, she would have the time to make an informed decision. In people with advanced illness, escalating care does not guarantee better outcomes. In the case listed, one of the risks of placing the woman on ventilatory support would be the inability to wean her off of it, which would then force her family to decide to withdraw support.

A gentleman with stage IV lung cancer required ventilatory support in order to breathe. He had a tracheostomy placed but needed to remain in the intermediate intensive care unit for ventilation. His disease was not curable, and the tumor that was causing his breathing difficulty could not be removed surgically. Early discussions with the patient and his brother took place, and the patient verbalized his desire for continued ventilation while he could still interact with his loved ones. Several weeks later, the gentleman experienced more complications, and became less interactive and responsive. At that time, his brother, whom the gentleman had identified as his DPOA, decided not to conduct further workup or escalate his care to the intensive care unit, as the patient had understood that at some point complications would arise that would impact his mentation, and he knew that escalating care would not improve his quality of life. The brother then made the decision to remove ventilatory support and had the team focus on administering medications that would relieve his brother's shortness of breath while allowing a natural death.

Another practical issue in advance care planning is deciding whether to refuse or forgo medical tests and/or interventions. Although in most cases there is "always something more that can be done," it does not mean that tests or interventions should be done. Again, these decisions are informed by advance care planning discussions that personalize the decision to the person's situation. For example, although it is standard practice to screen for colon cancer or breast cancer periodically over a woman's life, if she has advanced dementia, and would not have wanted interventions to treat those conditions, then she can opt to refuse these tests (either by documenting these wishes in a living will, or having her DPOA relay her wishes). In a different situation, a man with end-stage cardiac disease has the option to refuse treatment for pneumonia, even if it is treatable, if he deems his quality of life to be so poor that he would prefer to die from the pneumonia at this point versus some other cause at a later date.

When the person is able and deemed to have capacity, she or he can make the decision to withdraw or withhold any life-sustaining treatment not desired. Health-care providers have the responsibility to ensure that the decision is informed, and to present all the options that support the goals, but the final decision rests with the individual. Advance directives assist the DPOA in making the decision to withdraw or withhold life-sustaining therapies when the individual is unable to make the decision. The decision is made by the DPOA, and involves discussions with the health-care team. At times, the health care team will approach DPOA when decisions need to be made (e.g., a terminally ill patient is admitted to a medical floor for an infection, and the team needs to know whether to move him to the ICU when he begins to have more difficulty breathing). The health-care team also reviews advance directives when someone is admitted to the hospital to help determine the care plan. Based on the content of an individual's advance directive, the team then proceeds with the care that honors the individual's wishes.

The providers must read the advance directive, not just document the one that has been completed. At times providers may incorrectly assume that because a person has completed an advance directive, then he or she is an automatic do not resuscitate (DNR).

CHALLENGES WITH ADVANCE CARE PLANNING

Challenges arise with the difficult decisions that need to be made at end of life. Although a person can outline his or her wishes through an advance directive, providers tend to rely on the expressed wishes by the DPOA when it comes to actually making the medical decisions. In part, this may be due to the uncertainty of prognosis and when the advance directive should be implemented or it could be due to the interpretation of what is meant by parts of the advance directive. For example "no extraordinary means" is very vague. To one person, that may mean no stay in the ICU, but still could entail artificial nutrition and hydration. It is important, in the context of the individual's overall goals and situation, to anticipate some of the specific complications that may arise, or interventions that may be offered; preparation of the patient and DPOA will help them to make informed decisions.

Without an identified agent or an advance directive, the team then turns to the family to be the surrogate decision maker. Traditionally, next of kin surrogates are often considered in the following priority: spouse, adult children, parents, siblings, and then other relatives (ABA Commission on Law and Aging, 2007). A close friend may also be considered as a health care surrogate for a patient in some health-care settings. There usually needs to be documentation that describes their relationship and familiarity with the patient and verification by appropriate staff in the medical record. Surrogate decision makers may not feel comfortable in this role, especially if they never discussed with the patient his or her wishes regarding end-of-life care. There may be disagreement among surrogate decision makers about what type of care their loved one should receive. In these types of situations, the role of the health-care provider is to facilitate these difficult conversations and provide professional opinions with regard to the options available. A family meeting may be necessary to help the family members better understand the need for their involvement in making medical decisions on behalf of their loved one. If the family is unable or unwilling to accept the responsibility of making a decision for the family member, or if there is conflict among the family about decisions, court action may be required. It is also during this time that providers may need to involve the hospital ethics committee.

A different type of problem exists with trying to honor advance care directives across health-care systems. Most health-care systems are not integrated and accessing an advance directive can be difficult, especially in times of crisis (e.g., transfer from a community nursing home to the local hospital). The burden of providing copies of advance directives lies with the individual and his or her family. When admitted to the hospital or when admitted to a skilled nursing facility, people and their families often have to present this document over and over again, as health-care systems have not all adopted an electronic method of retaining copies of advance directives. Even for those institutions that keep electronic records, providers still need to confirm that the most recent advance directive is indeed current and correctly expresses the wishes of the individual. These documents do not travel with the person either, so when discharged from an acute care setting, individuals usually have to present the same directive to the next facility. Sometimes health-care providers help with this process and fax along the information, but that practice is not consistent.

To address some of these challenges, states have begun to adopt POLST—Physician's Orders for Life Sustaining Treatment—or some similar version (http://www.ohsu.edu/polst). The POLST paradigm program was developed with the intent of helping to address the system challenges that exist in trying to honor patient wishes. At this writing, eight states have already adopted this program, with at least 14 additional states developing programs. The form takes the advance directive one more step, by turning treatment wishes of an individual into actionable medical orders that are legal across all types of facilities within that state. POLST is printed on single brightly colored sheet (color determined by the state), documenting medical orders of an individual specific to end of life. In states where the POLST paradigm has been adopted, the POLST document travels with the individual. In this way, providers readily see the wishes of an individual and the corresponding orders that honor those wishes. A medical provider, as defined by state regulation, must sign this form in order for it to be valid.

CONCLUSION

Advance care planning is a process. Even though there may not be an advance directive, providers cannot assume that the individual would want heroic measures or extraordinary means of treatment, which is currently the default in our health-care system. Also, having a living will does not always mean that a patient would want to forgo treatment. Advance directives are tools to assist individuals and providers in advance care planning and help to ensure that the individual's wishes be followed throughout the illness trajectory. As our population ages, more people will live with chronic illnesses for many of their final years. As health-care providers, it is imperative that we help facilitate difficult conversations about wishes and hopes as people face their mortality. By doing so, we empower people to be part of the decision-making process until the very end.

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CHAPTER

7

Pharmacologic Management of Pain

W. Nat Timmins

This chapter reviews the basics of pharmacologic management of pain especially as it pertains to the elderly patient population. We first understand and utilize the palliative perspective to pain management. After reviewing the scope of the problem of pain in the elderly and the general approaches to developing a pharmacologic treatment plan, we investigate the basics of pain physiology to understand current and future targets for treatment. The goal of this chapter is not to teach you how to prescribe pain medication. Rather, the goal is to prepare you to participate in a health-care team by knowing what different treatment modalities are used, what side effects may be encountered, and how medications will affect your patients and their overall plans of care.

PALLIATIVE PERSPECTIVE

Physical pain is an (almost) universal human experience. Physicians have been therefore aware of pain since the beginning of medical history. At the same time, an understanding of pain and its treatments has been remarkably thin even into modern times. Almost all physicians encounter this symptom of pain in patients but are often poorly equipped to understand, assess, and adequately treat pain. Up until the last 20 to 30 years, pain was the "domain" of all physicians, and the specialty of none. The last 30 years have spawned increased understanding, research, and recognition of pain in its many forms. With this understanding have come increased interest among physicians, and, consequently, some physician specialization in pain management.

No single medical specialty focuses on pain although pain specialization is more visible in health care. Although there is an organization dedicated to training and accreditation for pain medicine in the United States (American Board of Pain Medicine with 2,200 certified physicians as of February 2008), there are also subspecializations among many medical specialties that address pain. There also exists an unintentional dichotomy in the world of pain management between noninterventional pain management (management that uses primarily medications, and therapies to manage pain) and interventional pain management (management focused more on injections, nerve blocks, and devices such as nerve stimulators). Interventional pain management is more likely to be provided by anesthesiologists and often does not address longitudinal chronic pain management, especially with chronic pain requiring medication management. Pain management in university and research hospital settings is more likely to be provided by neurologists.

Physicians practicing in the emerging field of palliative medicine (like the author) also frequently address pain (as part of a larger spectrum of symptoms) as specialists focused on people with advanced, progressive, life-limiting disease. Because of the nature of the elderly population, palliative medicine is frequently the watershed between pain medicine and geriatric medicine.

Hospice and palliative medicine, too, is emerging as a distinct medical specialty. The Academy of Hospice Physicians, formed in 1988 with 250 founding members, has grown into the American Academy of Hospice and Palliative Medicine with 2,600 members in 2006. Also in 2006, the subspecialty of hospice and palliative medicine within the American Board of Medical Specialties (ABMS) and the Accreditation Council for Graduate Medical Education (ACGME) was born.

Physicians with expertise in chronic pain management can manage much of the physical pain common to end of life, but there are often times when a palliative approach is necessary. Pain at the end of life usually has more than just physical roots. There are usually social, psychological, and spiritual components of this pain that must not be overlooked. Treating only the physical pain may not adequately manage the patient's suffering. Patients at the end of life also tend to be more medically frail with higher risk of medication side effects and fewer tolerable routes of medication administration. With this frailty comes greater likelihood that the patient will not be able to leave the home to come to the clinic. Palliative medicine specialists assess the whole patient as a person, recognize risk of side effects with the physiology of the dying body, and reach out to homebound patients with house calls.

SCOPE OF THE PROBLEM

As suggested earlier, physical pain is an almost universal human experience. Although there are a few unique individuals who have had various degrees of pathological insensitivity to pain as described in the clinical literature, the vast majority of people experience some level of pain on a daily basis. Although there continues to be some debate about the true biological role of pain, the scope of the problem of the experience of pain is fairly well documented. Indeed, the chief complaint of pain remains second only to the common cold as a reason to see primary care practitioners in the United States. Among the elderly, studies have suggested that the prevalence of significant pain in community-dwelling patients may be as high as 25% to 56%. In the nursing home population, pain is even more prevalent and is estimated that 45% to 80% of residents experience substantial pain.

VISUAL MODEL FOR PAIN

Like an onion, pain has multiple layers, and an onion model for pain has been suggested (Loeser, 1982). The innermost layer is termed nociception (physical transducers in the body transmit the detection of tissue damage or even potential tissue damage). The next level is the response to nociception, or "pain." A sensation of pain is generated in the spinal cord and brain. The next layer of the onion is suffering or the negative affective response generated in the brain by pain and its associated emotions and psychological states. The outermost layer is the individual behaviors that arise as a response to suffering. The focus of this chapter is on the innermost layers of nociception and pain. At the same time, we must acknowledge how the pain behaviors affect assessment and treatment. Indeed, these pain behaviors significantly contribute to many of the hurdles that must be overcome in the health system and in society as a whole. Addiction, and more importantly, fears of addiction by the patient, family, provider, and society, often negatively influence reporting of pain and treatment of pain.

GENERAL PRESCRIBING STRATEGIES

The medical management of pain has progressed in the past decades. Sophistication and elegance now begin to characterize treatment regimens for pain. There persists, however, a bit of "if all you have is a hammer, everything looks like a nail" mentality. Many physicians unfortunately use the same analgesic for all types of pain. In addition, as discussed previously, the perspective and training of a physician is quite likely to influence recommended treatments for the same condition. An interventional pain specialist is more likely to jump to nerve blocks, epidural spinal injections, and so forth, when medical management might be equally appropriate. Conversely, some practitioners continue to prescribe oral medications when an interventional technique from another provider might be more suitable.

A basic tenet of medical treatment is the need to balance risks and benefits. This applies to medications and interventional techniques equally. In the elderly, there are added dimensions. Because of age and accumulation of diseases, the elderly are particularly likely to experience polypharmacy from their multiple medical providers. There may or may not be care coordination among multiple specialists putting the elderly patient at added risk because they are often, by virtue of aging physiology, even more susceptible to risks from single medications and medications in combination. These risks increase further in the elderly dying patient as the physiology of dying usually involves even more decreased function of the kidney and liver. Much lower doses of medication than usual may be tolerated and effective. Though there may be more risk of side effects during the dying process, the patient may accept certain side effects such as somnolence more than the nondying patient would.

A related risk derives from the cost of medications and consequently cost of polypharmacy. The price tag for multiple medications can quickly consume a large proportion of a fixed income. Fortunately, many of the medications that are most useful for the management of pain have become more affordable. Many are now available generically. One must acknowledge, however, the influence of pharmaceutical marketing on physician prescribing. Patients and families, and other members of the treatment team, must still advocate and proactively discuss incremental benefit versus risk (counting excess cost of the medication as an element of risk) with their prescribing providers.

An associated prescribing principle in palliative medicine that takes some of the above commentary a step further is "maximizing bang for the buck." In this case, the "buck" is pharmacological as well as financial. We look for medications that may have benefits across a range of symptoms and with a range of routes of administration. For example, steroids, such as dexamethasone or prednisone, are a key tool in the palliative toolbox. Steroids are given orally, sublingually, through feeding tubes, intravenously, subcutaneously, intramuscularly, or rectally. They are useful for management of pain—especially bone pain and neuropathic pain—nausea, shortness of breath, malaise, lack of appetite, and fatigue. One treatment can therefore be used for multiple symptoms and can be given by different routes as a patient's health declines and previous routes of administration become unavailable. This inexpensive treatment minimizes polypharmacy. Why are not more people on steroids? This is where balancing risks and benefits come into play. Steroids typically have greater long-term risks than short-term risks and greater short-term benefits than long-term benefits. A patient with a prognosis of several weeks will therefore be more likely to experience greater benefit than risk, where a patient with a prognosis of years may well experience the opposite balance with greater risk than benefit.

BASIC PAIN PHYSIOLOGY

Let us now return to an overview of the physiology of pain in preparation for understanding how to target therapy pharmacologically. The details of the "pain pathway" are quite complex; the anatomy and neurobiology are beyond the scope of this chapter. For a good, older review of pain psychiology, see Cross (1994). *Scientific American* also has a series of excellent articles on pain for the non-physician reader (http:// www.scientific american.com/topic.cfm?id=pain). The essence, however, is seen in Figure 7.1.

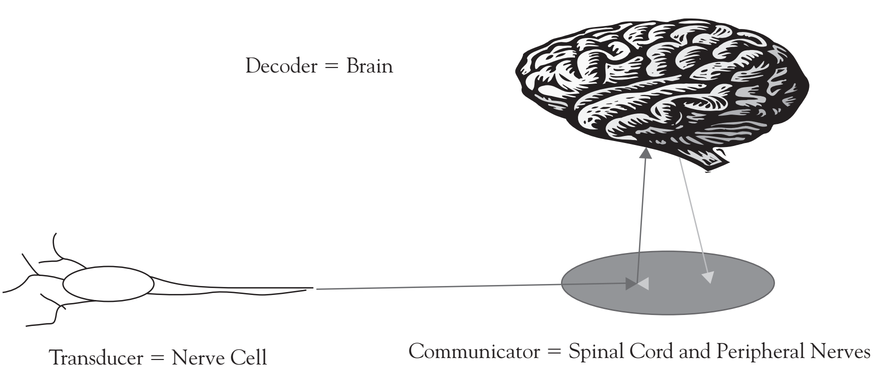

Figure 7.1 Simplified Pain Pathway

The transducer in the figure is the specialized cell that begins the process of nociception, or the perception of pain. These cells detect actual or potential tissue damage due to pressure, cold, heat, and so on, and generate neurochemical signals to notify the rest of the organism.

Transducer signals must reach the decoder for action and do so via the communicator pathways. Communication begins in peripheral nerves and extends through the spinal cord to the thalamus and cortex in the brain. Several known peripheral nerve types transmit specific pain sensations. A-Delta fibers communicate sharp pain quickly while C fibers transmit dull, aching pain more slowly. The spinal cord also appears to have multiple pathways for pain signal communication. Two ascending pathways carry information from the peripheral nerves to the brain, and one (or more) pathways carry information from the pain back through the cord. Sharp pain signals travel through one anatomically specific tract while dull pain travels through another tract.

Descending pathway(s) from the brain allow modulation and feedback from the brain/decoder. Within the brain, initial processing begins in the thalamus, which serves as a relay center to the somatosensory cortex for sensation, frontal cortex for “thinking” and planning, and the limbic system for emotional response. Although the brain is an important component of the pain system, it is not the endpoint. Signals regarding pain also leave the brain to return to the communicating spinal cord to modulate the pain experience.

The descending pain attenuation pathway in the spinal cord was a key discovery that led to the Melzack-Wall gate hypothesis that was published in *Science* (Mezlack & Wall, 1965). The gate control hypothesis of pain explains the curious everyday phenomenon—why do you shake your hand after you bang your thumb with a hammer? Shaking your hand activates other receptors that cause transmission of a signal through sensory pathways in the peripheral nerves and spinal cord that can cause a neurological traffic jam in the spine and attenuate how much of the pain signal is communicated through to the brain detector. In essence, your brain’s perception of your shaking hands partially drowns out your brain’s perception of the pain due to the smashed thumb.

Another part of the gate control theory addresses the descending pathways in the spine that allow the brain to attenuate incoming pain signals. The presence of descending pathways appears to be responsible in large part for the success of many of the behavioral treatments that are effective for pain management. In addition, the descending pathways provide a route for outgoing emotional signals from the brain to have their effects on incoming pain sensation, thus, in part, explaining why two patients with similar incoming pain signals will have differing pain experiences when one patient is depressed and another patient is euthymic.

The damage to the pain transmission system itself, anywhere along the path from the transducer to the detector, will generate a pain experience. The pain experienced by damage to the system can be different in many respects from the pain experienced by direct activation of the system. For example, activation of a “sharp pain” transducer-communicator-detector pathway causes sharp pain that may last only minutes, or for days. Conversely, damage to the same transducer-communicator-detector pathway by disease, infection, and so forth, may well generate burning pain, aching pain that can last from months to years. In addition, damage to that pathway may induce signal transmission along the other pathways in the spine and detector system over time.

This difference in the quality and timing of the pain experience leads the clinician from understanding to assessment, diagnosis, and treatment. Indeed, the clinical assessment of pain focuses on characterizing the timing (acute versus chronic) and other characteristics of pain to pinpoint likely causes that allow directed treatment.

CLASSIFICATION OF PAIN

Pain is classified along two typical axes: duration of pain (acute versus chronic) and physiological origin (nociceptive versus neuropathic). Most patients experience pain somewhere along these axes (e.g., acute nociceptive pain, chronic neuropathic pain). In addition, patients, especially those patients with advancing age and/or end-stage illnesses, commonly have multiple pain etiologies simultaneously. Unfortunately, the gate-control theory of pain does not apply in these situations: Having chronic neuropathic pain does not preclude or protect a patient from having acute nociceptive pain.

Nociceptive Pain

This type of pain is experienced when transducers transmit their signals through the intact communicators of the ascending spinal pathways to the brain. Nociceptive pain is often subcategorized into somatic pain and visceral pain. Somatic pain is the pain of the smashed thumb: it is well-localized (you know it is your thumb and not just somewhere on your arm) and it is often described as throbbing or aching. Visceral pain, in contrast, is the pain referred from deeper structures, such as the intestines or urogenital tract. It is poorly localized ("it hurts somewhere down there") and is typically described as "dull" or "cramping."

Neuropathic Pain

Neuropathic pain arises from injury to peripheral nerves, the spinal cord, or the brain itself. It is thus more of an injury to the pain or sensory system itself rather than a report of nociception. Patients often have a more difficult time describing neuropathic pain. They may describe electrical shocks, burning, shooting, buzzing, tingling, or even itching that is severe enough to be called painful. Because the nervous system is damaged, there is often accompanying alteration of normal sensation. There may be decreased sensation of light touch or temperature. Alternately, usually nonpainful stimuli may be perceived as painful or paradoxical: cold is perceived as hot, sharp is perceived as dull, and so forth.

Inflammatory Pain

Inflammatory pain is more difficult to characterize. Some clinicians do not separately classify inflammatory pain and instead group this type of pain with neuropathic pain while others may group it with nociceptive pain. The challenge rests in its mixed etiology. The pain that results from nearly normal transducers and communicators—nearly normal because the inflammation that triggers the transducers is also affecting the communicators in such a way that pain is potentiated through altered signal transmission. Thus, most inflammatory pain might be viewed as pain that exists in the continuum between nociceptive and neuropathic pain.

Acute Pain

Acute pain is the more commonly experienced and understood end of the pain duration axis. Acute pain is generated by immediate tissue-injury or potential injury and communicated through nociception. With acute pain the sympathetic nervous system is usually triggered with its attendant changes in vital signs such as elevated heart rate, elevated blood pressure, and so on. By definition, acute pain is typically of limited duration and generally resolves with the healing of injury. Acute pain is usually more responsive to pharmacologic treatment.

Chronic Pain

By definition, albeit somewhat arbitrarily, chronic pain is pain that has persisted for more than six months. Chronic pain perpetuates after real or potential tissue injury is resolved or healed. Chronic pain involves central sensitization and permanent structure abnormalities of the central nervous system, typically using the anatomically specific pathways in the spinal cord as previously discussed. Because of physiologic adaption, changes in vital signs are not usually seen. Clinically, chronic pain proves more resistant to simple pharmacologic management and often best managed with a combination of behavioral and pharmacologic modalities.

PHARMACOLOGIC THERAPY

We group pharmacologic therapy for pain management into two classes of medication. The analgesics were designed specifically to treat pain. Adjunctive medications usually come from different therapeutic classes but have been found to attenuate the communication of the pain experience and thereby also act to relieve pain.

Analgesic Medications

The first treatment class we explore is the analgesics. Analgesics are medications whose primary therapeutic function is to manage pain of all types without inducing unconsciousness (to differentiate from anesthetics). There are essentially three groups of analgesics: acetaminophen, nonsteroidal anti-inflammatory drugs (NSAIDs), and opioids.

Acetaminophen is a useful medication in common use and available over the counter. Its mechanism of action for analgesia is not clear. In addition to pain management, it is a fever-reducer. Patients generally tolerate acetaminophen well. The biggest risk with this medication is liver damage. Risk increases as dosage exceeds 4,000 mg per day, and by concomitant liver disease or intake of three or more alcoholic drinks per day.

The NSAID is a therapeutic group with multiple members and subclasses. The original member of this class was aspirin. Newer members range from over the counter to medications available by prescription only, all of which represent attempts to maximize benefits while minimizing risks. The pharmacodynamic action of NSAIDs focuses on the enzyme cyclooxygenase to affect the prostaglandin cascade. In theory, NSAIDs invoke analgesia by reducing activation and sensitization of transducers when inflammation is involved. In addition, NSAIDS reduce potentiating effects of inflammation on communicators at the peripheral nerve and spinal cord levels. Unfortunately, NSAIDs benefits come at a somewhat greater price than acetaminophen. Because cyclooxygenase and the prostaglandin cascade are also involved in protecting the lining of the stomach, platelet clotting, and kidney function, NSAID actions have side effects. Different NSAIDs have variable risks of peptic stomach ulcers, increased risk of bleeding, and potential to worsen kidney failure and high blood pressure.

Opioids refer to any substance that binds to opioid receptors in the central nervous system. This includes synthetic substances as well as the opiates that are substances derived from alkaloids extracted from the opium poppy (*Papaver Somniferum*). In the world of clinical pain management, the even broader term of narcotic is generally avoided because narcotic is in many ways more of a regulatory and drug enforcement term than an accurate medical term. From a regulatory standpoint, all opioids are narcotics, and the legal classification of narcotic includes many other substances such as marijuana and cocaine (a misnomer as narcotic refers to substances that induce sleep).

Our understanding of the mechanism of action of opioids is imperfect but increasing. First, we recognize that opioids exert their effects by binding to receptors in our nervous system. These receptors exist as part of the endogenous opioid system—a "homegrown" physiologic system that allows compounds manufactured by our body (e.g., endorphins, enkaphalins, and dynorphins) to regulate pain. Opioid analgesics mimic these naturally occurring, body-produced substances. To simplify a complicated system: Opioid analgesics exert their actions at μ-receptors. These receptors, when triggered by an opioid, lead to decreased neurophysiologic transmission of pain via at least two mechanisms. Across the synapse (the interface space between two neurons), pain transmission is decreased on the transmitting end by blockage of calcium channels and decreased release of neurotransmitters that signal pain. On the receiving end, μ-receptors dampen pain signal transmission through increased potassium conductance and hyperpolarization of the neuron. Historically, researchers thought μ-receptors were primarily in the brain. Over time, however, research showed that μ-receptors are also in the spinal cord. More recently, μ-receptors have been found in the peripheral nervous system and even in peripheral nerves at the level of the skin.

Although this model provides a starting point for understanding how medications like morphine work, it obviously leaves out many of the complicated nuances that contribute to the clinical experience with opioids. For example, side effects are explained by opioid binding at other, non μ–receptors. We will not go into the details of these receptors at this time. All opioids share similar side effects to varying degrees.

Common side effects with opioids include constipation, nausea, sedation, dry mouth, and sweats. Less common side effects are dysphoria (even to point of delirium), myoclonus (brief, involuntary twitching of muscles), pruritus (itching), urinary retention, and respiratory depression. With the exception of constipation, most side effects are transitory and occur primarily when opioids are initiated or the dose is increased. A person starting opioids for the first time or increasing opioid dose may experience somnolence or mental fogginess for one to several days before these side effects resolve, but constipation must be managed with laxatives indefinitely. Respiratory depression (the inhibition of breathing) deserves special comment because it is a greatly (and probably an overly) feared side effect of opioids. With careful management of opioids, respiratory depression is rarely seen. Indeed, pain itself is a powerful antagonist of respiratory depression. Respiratory depression is a greater risk for recreational opioid users than for clinically appropriate patients.

Tolerance

Tolerance is the pharmacodynamic concept that the dose of a medication must be increased over time to maintain the same effect. For the purpose of incidence of side effects, tolerance means that with fixed medication dose, the effect (e.g., nausea) will decrease over time. In addition, tolerance also explains why exaggerated physiologic responses (typically opposite to the side effects seen with the medication) occur when the medication is suddenly stopped. Why tolerance occurs with some side effects and not others is not completely understood. In addition, how tolerance occurs at the cellular level is not understood. A third mystery is why animals develop tolerance to analgesia with opioids in experiments; but in clinical practice, humans do not consistently develop tolerance. For example, many patients with stable pain may receive good analgesia with stable doses of opioids for years.

Another interesting feature of the concept of tolerance is incomplete cross-tolerance. Clinically some patients reach a point in their treatment where increased doses of a given opioid result in increased side effects without increased analgesia. Changing from one opioid to another (e.g., changing from morphine to hydromorphone) can result in greater analgesia with fewer side effects at a lower than expected opioid conversion ratio (see later in the chapter).

An important aside is to address the misconception that tolerance is the same as addiction. Tolerance occurs in the inner, physiologic layers of the onion where nociception and pain occur, and tolerance is seen with many medications besides opioids. Indeed, there are many medications (e.g., blood pressure medications, diabetes medications) that require increased dosages over time and when stopped, are more life-threatening than opioids. Addiction behaviors occur at the outer psychological and social layers, suffering and pain behaviors, of the onion model.

The potency of opioids varies based on several drug characteristics. Clinically known opioid analgesics include morphine, codeine, tramadol, oxycodone, hydromorphone, hydrocodone, fentanyl, and methadone. Though they all act at the μ–receptor, they do so in varying degrees. In addition, each opioid has slightly different properties that affect absorption, distribution, and so on. All of these differences account for the clinically apparent differences in potency and the less clinically useful concept of "strength." Morphine, given its long history, is the reference point for understanding the relative potency of various opioids, and we commonly refer to "oral morphine equivalents" as reference units. Morphine has such word recognition among patients (and most physicians) that it is commonly assumed that it is the "strongest" of the opioids. Perceived strength or effectiveness really depends on the dose of the opioid. The dose of one opioid compared to another depends on the relative potency of the two opioids. Thus, equianalgesia (equal pain relief) is often experienced whether a patient takes orally 5 mg of morphine, 5 mg of hydrocodone, 2.5 mg to 5 mg of oxycodone, 1 mg of hydromorphone, or 0.5 mg of methadone. Other pharmacodynamic properties come in to play when comparing opioid potencies across different routes of administration. Here, for example, 1 mg of hydromophone given intravenously equals a dose of 20 mg of morphine given orally. Alas, the complexities in prescribing caused by the different potencies across routes of administration and between different opioids can commonly lead to errors. These errors perpetuate resistance and fear of prescribing by both patients and physicians.

Adjunctive Medications

Driven in part by the understanding of the different types of pain (nociceptive versus neuropathic and acute versus chronic) and in part by the challenges (pharmacologic and societal) of opioid prescribing, interest in adjunctive medications continues to increase. Simplistically, adjunctive medications attempt to modify pain experience by modulating the pain pathway at receptors and sites separate from the μ–receptor. Clinically adjunctive medications are more commonly used in therapy for neuropathic and chronic pain. Historically, adjunctive medications have a different primary therapeutic intent (i.e., they were originally intended for depression but were found to have secondary benefit for pain). There are six different groups of adjunctive medications. The first five groups are primarily used in the management of neuropathic pain.

1. *Antidepressants*. The analgesic effect of antidepressants exists beyond any antidepressant effects. Tricyclic antidepressants have the most research and clinical backing with amitriptyline being a prototype. Selective serotonin reuptake inhibitors have varied effects on analgesia. Serotonin-norepinephrine reuptake inhibitors have shown greater promise. Choice of antidepressants, as is often the case in management of depression, depends on choice of tolerable side effects. Dosing often depends on presence of comorbid depression. When patients do not have depression, providers often prescribe lower doses of antidepressants because lower doses are all that is required for analgesia. This dose differential supports the theory that there is a difference between the analgesic and antidepressant effects of these medications.
2. *Anticonvulsants*. These medications are believed to provide analgesia at the cellular level by stabilizing membranes through calcium channels, sodium channels, or GAGA activity. Commonly used anticonvulsants for adjunctive analgesia include gabapentin, pregabalin, valproic acid, and carbamazepine. Gabapentin is commonly used as a first-line anticonvulsant primarily because it is generally well-tolerated, available generically, does not require monitoring of serum levels, and has few drug interactions.
3. *NMDA Receptor Antagonists*. These medications are felt to act at NMDA receptors in the spine to influence the aforementioned ascending and descending pain communication pathways in the spinal cord. The NMDA receptors act almost as physiological amplifiers by

making neurons more sensitive to other inputs, and NMDA receptor antagonists block this amplification to make neurons less sensitive to pain inputs. The most commonly used NMDA Receptor Antagonists in clinical practice are methadone and ketamine. Methadone is the more commonly used of the two. It is a unique medication because it is felt to work at both the μ–receptor and the NMDA receptor. Methadone is one of the least expensive of the prescription analgesics. Power comes with a price, however. Methadone can interact with many medications, can affect heart rhythm, and has a higher propensity for nausea as a side effect than morphine. In addition, methadone has complex pharmacodynamics that make its effective use more problematic at times (e.g., when first started, it is short acting but becomes both short acting and long acting over the course of a week or so). Ketamine, though also quite powerful (i.e., it can provide analgesia when many other opioids or combinations have provided inadequate analgesia), is infrequently used because of higher rates of side effects of dysphoria, hallucinations.

4. *Sodium Channel Blockers*. Intravenous or subcutaneous lidocaine is used in special situations when first- or second-line analgesics and adjunctive medications prove inadequate. Lidocaine acts on sodium channels and is thought to affect damaged nerves. This class of medication is not first line because of a greater risk of cardiac side effects (heart rhythm disturbances).
5. *A2-Agonists*. Clonidine is the clinically most commonly used α2–agonist. This older drug is more frequently used for hypertension than for adjunctive analgesia, and it is more commonly given in spinal infusions than orally because of significant incidence of side effects (somnolence, low blood pressure, confusion), especially in the older population.
6. *Corticosteroids*. Among the corticosteroids, prednisone and dexamethasone are the ones most commonly used in practice for analgesia. The primary role for corticosteroids is in the management of bone pain due to cancer metastases. Their mode of action is thought to be several fold. First, corticosteroids reduce inflammation and may therefore reduce the inflammatory component of many pain states. Second, these drugs may reduce pain by reducing swelling, which may be pressing on nerves and causing pain secondarily. Last, they may even have direct effects on nerve discharge through action at sodium channels. Unfortunately, these

useful drugs have increasing rates of side effects the longer (often more than several weeks) they are used. They can suppress the body's own steroid system, cause cataracts, cause or exacerbate diabetes, affect cholesterol, and cause stomach ulcers. In addition to physical side effects, steroids can cause or exacerbate depression, mania, or cycling between the two states. Steroids may have their greatest value in the final weeks to months of life when short-term benefits are not outweighed by long-term risks. Palliative radiation therapy (XRT) provides analgesia for pain due to cancer metastases by mechanisms much like the corticosteroids.

RATIONAL COMBINATIONS

Pain management typically involves combinations of medications that fall into three principle categories. The physician will choose appropriate combinations based on decisions involving etiology of pain, duration of pain, other medical and psychological comorbidities, and patient goals of care. Standardized algorithms for managing pain are emerging but must be individualized for each patient's circumstances.

First, we often combine long-acting preparations and short-acting preparations, often of the same medication. For example, cancer pain is often present throughout the day with the possibility of exacerbations due to disease activity or physical activity. We have learned that anticipatory prescribing is better than reactive prescribing. That is, we can achieve better analgesia (often with fewer side effects and lower overall doses of medications) by "around the clock" dosing that provides a continuous level of medication that produces analgesia throughout a 24-hour period. Long-acting preparations of morphine or oxycodone use delayed, sustained release of medication to allow every 8- or 12-hour dosing. At the same time, a rapid-onset (and usually, as a consequence, also short lasting) "breakthrough" dose of morphine can then be used when additional pain develops and the long-acting preparation has already been given.

Second, we may combine two analgesics from different analgesic classes. These medications are the much more commonly encountered combinations experienced by most people. The most commonly combined analgesics are opioid-acetaminophen or opioid-NSAID. Examples include hydrocodone/acetaminophen (commonly known by the brand name of Vicodin), oxycodone/acetaminophen (Percocet). There are numerous dose combinations that vary the dose of both the opioid and the acetaminophen or NSAID. These medications are most helpful for mild-moderate severities of pain. The primary downside to these combinations is the dose ceiling that occurs due to the nonopioid coanalgesic. For example, more than 8 tablets of a hydrocodone/acetaminophen combination (with 5 mg of hydrocodone and 500 mg of acetaminophen in each tablet) in a 24-hour period will exceed the recommended limit of 4,000 mg of acetaminophen and run the risk of liver damage.

Third, we are learning to combine analgesics and one or more adjunctive medications. The most common pain type requiring this type of combination is neuropathic pain. With neuropathic pain a patient may require low (or high) doses of an opioid combined with a Tricyclic antidepressant, for example. The goal is often to maximize analgesia while minimizing side effects. Thus, we may combine low doses of two agents with the hope of obtaining synergistic effects. The alternative is using a single class of medication and increasing until adequate analgesia is achieved or intolerable side effects or toxicity occur. With neuropathic pain, all too often the single medication class approach results in the side effects or toxicity before adequate analgesia occurs—the "cocktail" approach with two or more medications chosen to combine their effects.

ROUTES OF ADMINISTRATION

The number and location of possible targets for medication administration has grown as research has demonstrated over time that opioids and adjunctive medications act not just in the brain but in the spinal cord and even peripherally at the site of injury. In addition, as we learn more about side effects and how they can be minimized, we are often choosing routes of administration other than "by mouth"—the historically preferred route of administration for morphine.

Oral (by mouth), sublingual (under the tongue), buccal (between the teeth and the mucous membranes of the cheek), intranasal (sprayed up the nose), rectal (by rectum): Most opioids are absorbed to variable degrees and rates across mucous membranes (which line the nose, mouth, and rectum). They can be given as tablets, capsules, liquids, or even specially created lozenges. Depending on the opioid, absorption and onset of action occurs within 15 to 30 minutes and will last 1 to 4 hours.

Intravenous and subcutaneous administration produces rapid impact, with most intravenously administered opioids taking effect within 5 to 15 minutes and lasting 30 to 60 minutes. Opioids will act within 15 to 30 minutes when given subcutaneously and last approximately 60 minutes. The subcutaneous route is often used in the hospice setting as needles are quite small, do not require an "IV" that can be quite difficult to obtain in dying patients, and are easily replaced if dislodged.

Transdermal administration relies on special properties of certain opioids like fentanyl or special "vehicles" prepared by compounding pharmacists to allow medications to be delivered through the skin to the bloodstream. Advantages include an alternative to the oral route, a minimally invasive mechanism, and in the case of the fentanyl patch, a depot effect that can allow the patch to need replacing only every three days with continuous medication release during that time.

Topical administration differs from transdermal administration because with topical administration you are applying the medication to a specific site in or around the skin surface to achieve medication effects locally (within inches). The key advantage to this route is that when pain is caused by localized tissue injury (or potential injury), topical medication administration allows more focal pain relief with less potential for side effects because the medication reaches the rest of the body in much smaller amounts (if at all). Pressure sores and cancer breaking through the skin are optimal situations for topical medications. Morphine (and other opioids or even opioid-adjunctive medication cocktails) can be compounded into sterile gels to place on the wound. This often results in analgesia without nausea, constipation, or other potential side effects previously discussed.

Spinal analgesia administers opioids and/or adjunctive medications into several possible locations around the spinal cord. This provides regional analgesia with the goal of maximizing analgesia and minimizing side effects. Because the drugs avoid much of the rest of the body, certain side effects can be decreased or avoided altogether. In addition, smaller doses of medication are often required because there is more direct targeting of pain receptors in the central nervous system. Other advantages include reservoirs that can be implanted under the skin to allow weeks to even months of medication delivery. In addition, because the medication is in an isolated reservoir, there may be decreased potential for medication abuse behaviors. Disadvantages of spinal analgesia include somewhat more limited availability—typically only specially trained anesthesiologists or neurosurgeons are able to insert spinal catheters and/or surgically insert the medication reservoir. In addition, complete systems often cost thousands to tens of thousands of dollars. Because this route of delivery is rather invasive, there is higher risk of infections.

Case Example

J. B. is a 79-year-old man who has been healthy for much of his life. He has smoked a pack a day for many years, however. Over the past few months, he has unintentionally begun losing weight and he becomes easily fatigued on the golf course. When he develops a cough and seeks medical care for possible pneumonia, a chest x-ray reveals a large lung mass. Biopsy confirms Non-Small Cell Lung Cancer. He pursues treatment and receives several rounds of chemotherapy. Despite treatment, his cancer progresses and he learns that he has metastatic disease to his liver and adrenal glands. He begins to develop pain on his right side.

A palliative medicine consultation is requested to assist with symptom management. J. B. is assessed to have cancer-related nociceptive pain due to tumor effects. Goals of care and advance care planning are also assessed during the consultation. As further questioning reveals that the pain is intermittent and mild-moderate in intensity, he is started on hydrocodone/acetaminophen combination tablets and instructed to use one tablet every 4 hours as needed for pain. The consultant also discusses the side effects of the medication. An over-the-counter laxative containing senosides is recommended to counteract the constipating effects of the hydrocodone.

J. B. is seen in follow up several weeks later. He reports generally good pain control but uses his medication nearly every four hours around the clock to control pain. He is started on long-acting morphine tablets twice daily and continued on the hydrocodone/acetaminophen, increased to 2 tablets every 4 hours as needed for breakthrough pain (pain that "breaks through" the relief provided by the long-acting pain medication).

This regimen works for several weeks until the pain increases again. His long-acting morphine is increased and hydrocodone/acetaminophen discontinued. Morphine sulfate immediate-release tablets are started for breakthrough pain.

He develops upper back pain that shoots down his arm. He is found to have metastatic disease near his spine. Options for care are discussed and he chooses to pursue radiation therapy to the disease near his spine. Because the pain relief from radiation may take up to two weeks to take effect, the palliative medicine consultant starts J. B. on a two-week course of the corticosteroid dexamethasone by mouth. Within two days of starting the steroid, the shooting pain abates significantly. He receives a dose of radiation therapy and the dexamethasone is stopped after a two-week course. He continues to have some residual burning pain in his arm and he is started on gabapentin by mouth. With the combination of morphine and gabapentin, his symptoms are well controlled for several months while he receives chemotherapy. His function status begins to change and because of fatigue he is now spending about half of the day in bed. At about this time, he develops significant nausea with a new type of chemotherapy that was initiated after finding more metastases.

J. B. is hospitalized with dehydration. Palliative medicine follows him at the hospital and his advance care plan and goals of care are revisited, but the patient's symptoms are severe enough that he cannot begin to discuss his understanding of his disease and his treatment options. Palliative medicine assists the attending oncologist with medications to control his nausea. He and his family are having ongoing discussions about goals of care when he develops further exacerbation of his pain. Significant increases in his oral morphine doses are required and he begins to develop hallucinations. Palliative medicine stops the morphine and prescribes a different opioid, hydromorphone. His hallucinations resolve and his pain improves. Once his symptoms are better controlled, the interdisciplinary health-care team arranges a family meeting to discuss prognosis and treatment options. The team helps the patient to clarify and describe his definition of quality of life. Once the patient learns that he has many comfort options, but few acceptable (to him) curative options, he is then able to clearly discuss with his family his desire to discontinue active, aggressive cancer treatment and he elects to return home with hospice care under the guidance of palliative medicine.

With hospice support, he is cared for by his family at home for several more weeks. His pain remains well controlled with minimal changes in his hydromorphone infusion. He develops a painful ulceration of the skin on his front chest wall that is due to a cancerous ulcer. Despite the hydromorphone infusion and good control of his other pain, he reports that dressing changes on the ulcer are very painful. A topical preparation of morphine in a gel is prepared by the hospice and applied to the wound with great symptom relief. With his symptom relief, he is able to continue to work on life closure and he dies peacefully at home with his family at his bedside two weeks later.

CONCLUSION

Though pain at the end of life is certainly not new, health care has improved the person's experience of this pain. Research advances and increased physician awareness and specialization have brought better understanding of the biological basis of pain and increased sophistication in the pharmacologic management of the pain experience. As part of the interdisciplinary approach to pain and suffering at the end of life, physicians can now prescribe rational treatments to manage the physical component of pain.

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CHAPTER

8

Nonpharmacological Approaches to Pain and Symptom Management

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For patients near the end of life, and their families, control of pain and other common physical symptoms (e.g., fatigue, nausea, and dyspnea) often assume extreme importance. These symptoms can sometimes be challenging to control, but often, until they are reasonably well-managed, patients and their families have difficulty focusing on the psychosocial-spiritual tasks associated with the dying process. The most effective interventions for these symptoms are pharmaceutical. Medications used for end-of-life symptom control have been the subjects of many volumes of scientific papers and many dollars spent on research. For most patients, skillful use of appropriate medications will be adequate in controlling end-of-life symptoms.

Although it is indeed fortunate that pharmaceutical interventions usually work, the process often still leaves patients feeling as if someone else is doing something *to* them in order to control their symptoms, rather than working *with* them. Families, too, can be left with a bit of this feeling, but also frequently feel helpless and powerless to help relieve the symptoms of their loved one. These feelings of helplessness and powerlessness may be partially alleviated if the treatment team is skillful in applying nonpharmacological interventions as adjuncts to the medications. In most cases, some aspects of these treatments can be administered by the family caregivers of patients, giving them the gratification of helping control their loved one's symptoms, while providing additive or synergistic benefits in terms of symptom control. Note that these interventions are rarely sufficient to provide adequate symptom control in the absence of pharmacological interventions, but they may indeed be effective in adding to the degree of symptom control provided by medications.

In this chapter, we review some of the most common nonpharmacological techniques used to control pain and other symptoms. By far, the greatest focus in the nonpharmacological symptom control literature relates to pain management; this is the primary focus of the discussion. Where these interventions may benefit other symptoms, we make mention of this fact. Where specialized training is required for application of these interventions, we also discuss this. This is not intended to be an exhaustive review of all available nonpharmacological treatments, but merely an overview of those most commonly used.

BRIEF OVERVIEW OF PAIN AND SUFFERING

Pain is a complex, often poorly understood phenomenon. Health-care professionals working with patients who have pain frequently find themselves mystified about patients' descriptions of their pain experiences and may not have easy explanations for a given patient's pain. Perhaps the definition of pain offered by the International Association for the Study of Pain illustrates some of the reasons for this: "Pain is an unpleasant sensory and emotional experience, associated with actual or potential tissue damage, or described in terms of such damage" (Merskey & Bogduk, 1994). First, pain is stated to be *both* a sensory *and* emotional experience. As we examine the neurophysiology of pain, we begin to see that these sensory and emotional experiences are tightly bound in the central nervous system, and may be inseparable. Whatever the etiology of the pain, the patient experiences both sensory and emotional changes, and optimal treatment addresses both.

A second factor that is troublesome with respect to pain is reflected in the clause ". . ., associated with actual or potential tissue damage, . . ." Often health-care professionals know exactly what is causing a patient's pain, as they can see either directly (e.g., a surgical wound) or through imaging (e.g., a pancreatic tumor) pathology (tissue damage) that is known to be painful. However, there are many cases, especially in patients with chronic noncancer pain syndromes, where this is not possible. For those patients, the pain is truly idiopathic (meaning that the cause is not known). Unfortunately, healthcare professionals often leap to the assumption that, in the absence of a documented physical cause for the pain, the cause must be psychological, generating a referral to a mental health provider for treatment of "psychogenic pain." As mental health providers, we accept these referrals and work to understand and treat the emotional (suffering) components of the patient's pain experience, but we also advocate for appropriate pharmacological and nonpharmacological interventions. We also may choose to educate our medical colleagues about that the fact that "idiopathic" does not equal "psychogenic," so that they can come to a more complete understanding of their patients' experiences.

GOALS AND BENEFITS OF NONPHARMACOLOGICAL INTERVENTIONS

The goal of nonpharmacological interventions for pain is to decrease the patient's perceptions of pain by reducing pain intensity and increasing pain tolerance, increasing adaptive pain behavior, and decreasing maladaptive pain behavior (e.g., excessive use of medications, attention seeking, social isolation; Gatlin & Schulmeister, 2007). These interventions have numerous benefits, including empowering patients through providing them with tools to manage their pain, thereby decreasing anxiety.

Considerations in Selecting Nonpharmacological Methods

In choosing specific nonpharmacological interventions, several factors must be considered. For some of these interventions (see Table 8.1 for examples that are discussed in this chapter), the patient's own physical and mental status capabilities need to be considered. For instance, patients who are self-applying heat and cold need to be cognizant of the dangers associated with prolonged exposure, and have the wherewithal to remove the heat or cold before reaching that point. Patients receiving massage need to have adequate platelet counts and function, lest they develop hematomas from the massage intervention. Patients utilizing guided imagery, meditation, and relaxation exercises need to have adequate ability to attend, concentrate, and remember the specifics of the exercise. Generally, though, most patients can find at least one of these interventions that will work for them.

Table 8.1 Nonpharmacological Interventions for Pain Management

Approach	Examples
Physical therapies	Hydrotherapy Heat and cold Electrical stimulation Exercise and positioning Massage
Cognitive therapies	Education Relaxation Guided imagery Biofeedback Meditation Music therapy Pet therapy Humor therapy
Other therapies	Aromatherapy Acupuncture Acupressure Chiropractic treatment Therapeutic touch/energy healing

Additionally, the patient's preferences, previous experiences with interventions, and coping styles should be considered. Patients who have had positive responses to some of these interventions previously will likely be more receptive to trying those interventions again and less likely to try those previously found to be ineffective. Patients who are more modest may balk at some of the more physical interventions, like massage, due to a sense of embarrassment, while being more interested in cognitive interventions such as relaxation or guided imagery. A thorough assessment of the patient's previous experience and preferred modes of coping will prove helpful in selecting specific interventions that will be accepted and utilized successfully.

Although the patient's characteristics are important in selecting interventions, it is also wise to remember the earlier discussion about the role of family members and other caregivers in applying these techniques. To the extent that these individuals can be involved in providing the treatment, both they and the patient may benefit, as they feel they are doing something important and helpful, while being allowed (or even encouraged) to spend more time in close contact with the patient.

Finally, providing support materials and education is quite important. Some of these interventions can be not only ineffective, but actually harmful, if applied in the wrong manner. The patient or the caregiver need to be adequately prepared to apply the interventions. This preparation can often be given in a quick demonstration, but adding some printed materials that can be left behind, or even video demonstrations of the use of these techniques, can increase the comfort of the person applying the treatment and the symptom relief experienced by the patient.

TYPES OF PAIN MANAGEMENT INTERVENTIONS

The remainder of this chapter will focus on some of the most common nonpharmacological interventions used in treating pain and related symptoms. For each, we give a brief description of the technique, references that demonstrate its effectiveness, and any specific notes or cautions that may apply.

Physical Therapies

Hydrotherapy. Hydrotherapy utilizes water to promote healing, improve symptoms, including pain, and facilitate other therapies such as exercise. Physical therapy or exercise in the water reduces stress on joints, increases mobility, and can reduce pain through thermotherapy (see "Heat and Cold," following). Stationary treatment in a whirlpool can also provide the benefits of thermotherapy and massage. In research studies, hydrotherapy has been demonstrated to reduce pain, primarily for patients with musculoskeletal pain related to osteoarthritis, rheumatoid arthritis, low back pain, or fibromyalgia (see Geytenbeek, 2002, for a review). Hydrotherapy is also used to promote wound healing and can be utilized following joint surgery. Caution should be used when utilizing or recommending hydrotherapy because water temperature and pressure can affect vascular functioning. Consultation with a physical therapist trained in the use of hydrotherapy may be necessary if extensive hydrotherapy is to be undertaken.

Heat and Cold. The use of heat and cold therapy can reduce pain and increase patient comfort. Heat therapy promotes healing through dilating blood vessels, increasing blood flow to the skin, and increasing the delivery of oxygen and nutrients to tissues. Heat can also increase muscle elasticity, which can decrease joint pain and minimize muscle spasms. Heat therapy is theorized to reduce pain through several possible mechanisms, including vascular dilation, as described earlier, counterirritation (i.e., masking or inhibiting pain with another sensation), and the direct influence of heat on neuromuscular tissue interrupting the cycle of pain and muscle spasms.

Patients can apply heat either locally to a specific area or more globally through use of a warmed blanket. Heat application can be used several times per day for 15 to 20 minutes each application. Caution should be used to avoid burns when using heat therapy; heat should be used only if the patient can feel the sensation of heat.

Cold therapy is often used to numb areas affected by local and acute pain. It is also useful for reducing inflammation. Cold therapy is effective through constricting blood vessels and decreasing the temperature of superficial tissues. Cold can also serve as a counterirritant, and may be applied through cold packs, ice massage, or vapocoolant sprays.

Similar to heat therapy, cold therapy can be applied several times per day, 15 to 20 minutes per application. To prevent tissue damage, a cloth or towel should be placed between the cold pack and skin. Caution should be used if recommending cold therapy to patients with tissue damage or reduced circulation. Cold therapy also may not be tolerated well by patients with particular types of pain, particularly neuropathic pain.

Although the application of heat and cold to painful areas is common, studies of systematic use of thermotherapy are limited. Research results about the effectiveness of applying heat or cold, specifically to painful joints, have been mixed (e.g., Brosseau et al., 2003a; Welch et al., 2002).

Electrical Stimulation. Transcutaneous electrical nerve stimulation (TENS) involves the application of small amounts of electrical current to painful areas in an attempt to relieve the pain. The current being delivered can be varied in terms of its intensity and wavelength, and often several adjustments must be made to find the optimal settings. The TENS may be contraindicated in patients with uncontrolled hypertension, cardiac pacemakers, and implanted intrathecal pumps or spinal cord stimulators, and application to the face or areas where there are documented tumors is not advised. The TENS may be covered by patients' health insurances, and typically requires a physician's order and initiation by a physical therapist.

Two mechanisms of action for TENS have been proposed. One involves selective stimulation of A-β fibers, which effectively blocks input from A-δ and C fibers at the spinal cord, as predicted by the gate control theory (Garrison & Foreman, 1994; Hollman & Morgan, 1997;

Kumar & Redford, 1982; Melzack & Wall, 1965). The other proposed mechanism involves production of endogenous opioids in response to electrical stimulation (Sjölund & Eriksson, 1979; Sluka, Deacon, Stibal, Strissel, & Terpstra, 1999). Sluka et al. (1999) also suggest that perhaps high-frequency TENS works through the gate control mechanism, while low frequency TENS increases endogenous opioid production. High-quality meta-analyses find generally poor quality studies and conflicting findings among those studies whose quality is sufficient for their inclusion in the analyses, both with chronic and cancer pain syndromes (Brosseau et al., 2003b; Khadilkar, Odebiyi, Brosseau, & Wells, 2008; Nnoaham & Kumbang, 2008; Robb, Bennett, Johnson, Simpson, & Oxberry, 2008) and with acute pain (Dowswell, Bedwell, Lavender, & Neilson, 2009). Nonetheless, some patients may perceive a benefit from TENS, and given the low likelihood of adverse effects, it may well be worth trying.

Exercise and Positioning. Exercise can assist in reducing pain by encouraging stretching, strengthening, and increasing range of motion. Through exercise, patients can prevent muscle atrophy and optimize muscle tone. Physical and occupational therapists can provide evaluation, instruction, and encouragement for patient exercise. When used appropriately, exercise can also improve other symptoms including fatigue and depression. Various forms of exercise (aerobic, strength-building use of weights, and flexibility-focused) may be useful for specific types of symptoms; again, proper evaluation of the patient's symptoms and recommendations for proper treatment by physical and/or occupational therapy is often useful.

Proper patient positioning serves numerous functions, including ensuring proper body alignment, preventing and alleviating pain, preventing pressure ulcers, and providing sensory stimulation. Positioning can also be used to assist with symptoms; for example, elevating a patient's limbs to decrease edema, or elevating the head of the bed to reduce dyspnea. Frequent assessment and adjustments in positioning is particularly important for patients confined to bed but also for outpatients receiving extended treatments or painful procedures. Frequent turning is essential for patients confined to bed, in order to increase comfort and prevent pressure ulcers. Other strategies for positioning include adjustment of the treatment chair, use of pillows, and ensuring proper alignment of the body and extremities.

Massage. Massage therapy utilizes various techniques, but is defined by manipulation of the soft tissues (e.g., muscles, tendons, ligaments, fascia) of the body with the hands or a mechanical device. It can serve to increase range of motion, improve circulation, and relax muscles, as well as having biochemical effects. In addition, receiving massages may help patients become more aware of their bodies and more knowledgeable about and familiar with the pain they experience. Massage therapy generally does not require effort on the part of the patient and may be ideal for patients who are not able to actively engage in other interventions. It can provide comfort and potentially be a source of acceptable touch for patients who have limited physical contact with others. Simple hand or foot massage can be used to provide comfort and convey presence and attention to a patient. As an intervention, it can be used alone or in conjunction with other treatments, including exercise, thermotherapy, hydrotherapy, relaxation, music therapy, or aromatherapy.

Massage therapy has been associated with improvements in a variety of physical and psychological outcomes. Research has suggested that massage therapy is effective for decreasing low back pain and headache pain (Cherkin et al., 2001; Furlan, Imamura, Dryden, & Irvin, 2008; Quinn, Chandler, & Moraska, 2002). Multiple studies have demonstrated that massage therapy can decrease pain intensity, promote relaxation, and decrease anxiety among cancer patients (Ferrell-Torry & Glick, 1993; Smith, Kemp, Hemphill, & Vojir, 2002). In addition, massage has been shown to decrease pain, anxiety, and need for pain medication in postoperative patients (Post-White et al., 2003). Massage therapy can be provided in the hospital as a complementary therapy or outpatients can seek out a licensed massage therapist. The risks of massage therapy are generally low; caution should be used if the patient has a history of problems with lymph nodes or thromboses.

Cognitive Therapies

Education. Patient education is a key component of pain management. Education can serve to decrease patients' anxieties related to unknown causes of their pain or fear of uncontrolled pain. In addition, education can enhance patient adherence to pain management strategies through a better understanding of the mechanisms or reasons for the interventions. Other common barriers to adequate pain management can also be addressed through education, including the beliefs that pain is inevitable or that nothing can be done about pain.

Research studies support that patient education can contribute to reduced anxiety and depression and improved pain control (Centanni et al., 2000;

Lechtzin et al., 2000). Education can be provided to patients both in person and through written materials. Considerations when preparing educational information include patients' educational levels and possible cognitive impairments. Providing education to patients' family members and other health care providers is also important because these individuals can assist by providing encouragement to utilize pain management strategies.

Relaxation. Relaxation is a broad category of techniques used to decrease anxiety, relieve muscle tension, decrease physiological responses to stress (e.g., respiratory rate, blood pressure), and regain a sense of control. A relaxation response can be achieved through a variety of purposeful techniques or indirectly through several of the other interventions described in this chapter (e.g., music therapy, pet therapy, meditation). Specific relaxation exercises can also be used in conjunction with other interventions. Relaxation training may be particularly helpful for patients experiencing increased anxiety, insomnia, or muscle tension or aching. Specific relaxation exercises include diaphragmatic (abdominal) breathing and progressive muscle relaxation (PMR), a technique that alternates between tensing and relaxing muscle groups.

Relaxation exercises can be self-led or guided by a practitioner or audio recording. When used for acute pain, relaxation exercises should be brief and simple. For chronic pain, relaxation techniques can be more involved, incorporating guided imagery (see later in the chapter) or other strategies, to increase the length of relaxation and offer variety over time. For maximum effect, relaxation exercises should be practiced in a quiet environment with minimal distractions. Patients should be positioned comfortably and should make an effort to clear their minds of other thoughts or concerns. Frequent practice with relaxation exercises allows patients to be more successful in achieving a relaxation response, particularly across a variety of situations.

Relaxation has been widely researched as a method for pain control. Review of the research literature suggests that relaxation exercises are more effective for managing acute or procedural pain compared to chronic pain (Redd, Montgomery, & DuHamel, 2001). Relaxation exercises are low cost, easy to teach and implement, and low risk for patients. They have the added benefit of providing patients with something concrete they can do to help themselves, increasing their sense of internal control.

Guided Imagery. Guided imagery is the process of utilizing visualization and imagination to elicit a desired response, generally relaxation. Guided imagery can also be used to provide distraction from either chronic or acute/procedural pain. Through use of clinician guidance or other aids (e.g., written or auditory scripts), patients are encouraged to imagine the sights, sounds, smells, tastes, and/or feel of a particular scene or experience. Guided imagery aims to be effective through having the mind and body respond to this imagined experience (e.g., the patient feels as if she or he is lying on a warm beach or attending a classical music concert).

Common imagery scripts (e.g., beach or mountain scenes) are widely available. Patients can also create their own scripts by identifying a scene that induces positive feelings and developing a full description of the experience. Research on the effects of imagery is limited but results suggest that use of imagery can improve patient comfort (Roffe, Schmidt, & Ernst, 2005). As with all relaxation techniques, frequent practice of guided imagery will increase the ease with which patients can focus on the exercise and experience relaxation benefits.

Biofeedback. Biofeedback aims to develop the patient's ability to control specific physiological responses through providing them with information about the response they are attempting to control. Common types of biofeedback are electromyograph (EMG) for muscle tension, thermography for skin temperature, electroencephalograph (EEG) for brain wave activity, and electrodermal response (EDR) for sweat gland activity. Multiple biofeedback modalities can be used with patients. Biofeedback allows patients to develop a sense of self-control to overcome pain or stress. Often, patients receive instruction in relaxation techniques, utilizing another intervention, and are given feedback about their relaxation response through special monitoring equipment. This sets up an opportunity for operant conditioning of these responses.

Biofeedback is most often used and studied with pain resulting from muscle tension (e.g., headache, myofascial pain). A review of recent research suggests that biofeedback can be effective for reducing pain for patients with tension/muscle contraction headaches, back pain, or temporomandibular disorders (TMD; Gatchel, 2004). Biofeedback is generally most effective when used in conjunction with other pain management techniques. Biofeedback involves little risk for the patient. Drawbacks of biofeedback include the need for special equipment and time and training necessary to result in positive effects.

Meditation. Meditation encompasses numerous strategies from traditional Eastern systems. One component of meditation, mindfulness, encourages awareness of the present moment. Meditation develops cognitive skills, including focus on the breath and repetitive words or phrases. Mindfulness-based stress reduction (MBSR) utilizes meditative strategies and has been shown to benefit patients with a wide variety of medical conditions, including chronic pain (Kabat-Zinn, Lipworth, & Burney, 1985). Patients using MBSR learn to develop awareness of their minds and bodies and respond with nonjudgmental, accepting thoughts. Use of meditation or MBSR generally results in relaxation and associated physiological changes (e.g., reduced heart rate, respiratory rate, and blood pressure). Meditation or MBSR has been demonstrated to improve immune functioning (Carlson & Speca, 2003), coping (Coker, 1999), and mood (Carlson, Ursuliak, Goodey, Angen, & Speca, 2001) in patients with cancer. Patients utilizing these techniques may benefit through developing a greater awareness of their bodies and pain, developing acceptance of their pain, and reducing psychological consequences resulting from living with pain. Meditative strategies can also be used in combination with other interventions, including exercise or music therapy.

Music Therapy. Listening to music is generally a positive experience, and it can serve to decrease pain by assisting with relaxation and by providing distraction. Music can be used alone or in conjunction with other interventions (e.g., massage therapy, relaxation, and aromatherapy). Listening to music is low cost, easy to implement, can be utilized in a variety of situations, and low risk. It is important to encourage patients to select music they prefer as preferences can vary widely among individuals.

A review of the research on the effect of music on pain across patient groups and disorders found that music reduced pain, increased the number of patients who reported at least 50% pain relief, and reduced the need for analgesics (Cepeda, Carr, Lau, & Alvarez, 2006). Music has been demonstrated to have a positive effect for both pain and mood on acute, procedural pain (e.g., Voss, et al. 2004) and chronic pain (e.g., Schorr, 1993).

Pet Therapy. The health benefits of pet ownership are well-known. According to the Centers for Disease Control and Prevention, pets can decrease blood pressure and cholesterol levels, decrease feelings of loneliness through companionship and unconditional support, and increase opportunities for exercise and socialization (CDC, 2009). Pets can also provide specific therapeutic benefit; for example, improved range of motion for the patient gained through activities such as grooming the pet.

In addition to pet ownership, animal-assisted activities or therapy can provide numerous benefits to both hospitalized patients and outpatients. A growing literature suggests health benefits to patients with a variety of medical conditions, including reduced pain, decreased respiratory rate, improved mood, and increased perceived energy (see Coakley & Mahoney, 2009). Animals can also serve to decrease procedural pain primarily through providing distraction. Many health-care settings have formal arrangements with pet therapy providers, who have been trained, along with their animals, to provide these services in a safe and effective manner.

Humor Therapy. Research has long shown a variety of positive effects of humor and laughter. For instance, laughter can reduce stress hormones, boost the immune system, and reduce blood pressure. Laughter has also been thought to trigger the release of pain-killing endorphins, though research has not demonstrated an increased endorphin level after laughter. Research has demonstrated that humor and laughter stimulate the reward centers of the brain that are also activated by cocaine, amphetamines, and alcohol (Mobbs, Greicius, Abdel-Azim, Menon, & Reiss, 2003). In laboratory studies, exposure to humor and laughter have been shown to raise discomfort thresholds and tolerance of pain (e.g., Cogan, Cogan, Waltz, & McCue, 1987; Zillmann, Rockwell, Schweitzer, & Sundar, 1993). In addition to the physiological routes mentioned earlier, humor and related laughter may work to decrease pain through relaxation and distraction. Patients who have a strong sense of humor may experience the greatest benefits with use of humor. As humor is subjective, it is important that patients find the stimulus (e.g., movie, stand-up comedy) funny; patients can be encouraged to explore finding sources that result in laughter.

Other Therapies

Aromatherapy. Though multiple definitions exist, aromatherapy is most simply the use of essential aromatic oils for therapeutic or medical purposes. It is currently the fastest growing of all complementary therapies. Whether used alone or in conjunction with other therapies, aromatherapy can produce a mild, temporary relaxation effect (Cooke & Ernest, 2000) and is believed to be effective through stimulating production of endorphins and norepinephrine (N. Perry & Perry, 2006). Aromatherapy is most often used in conjunction with massage therapy; although mixed evidence exists about whether aromatherapy enhances the effects of massage (see Wilcock et al., 2004), patients generally tolerate it well and request the ongoing use of aromatherapy.

Routes for absorption in aromatherapy include topical, internal, oral, and inhalation; olfactory inhalation is the most common method of absorption. Commonly used aromas include lavender, chamomile, and menthol (e.g., Vicks VapoRub). Products containing lavender or chamomile, which are believed to promote sleep or relaxation, are widely available. Considerations when using or recommending aromatherapy include the presence of nausea or other symptoms, which may be exacerbated through strong scents and the possibility of skin irritation if essential oils are applied topically. The National Association for Holistic Aromatherapy (2009) provides information on educational standards, qualified schools, and a scope of practice for aromatherapy.

Acupuncture. Acupuncture is one of the most widely accepted alternative medicine techniques in the Western world. A technique of Traditional Chinese Medicine (TCM), the theoretical basis of acupuncture is that energy (qi) flows through the body in patterns (e.g., meridians) and illness results when these patterns flow incorrectly or are blocked. TCM techniques address manifestations of illness (e.g., joint pain) through releasing energy and correcting imbalances. Pressure is applied to meridian points through insertion of small-gauge needles (acupuncture), a combination of needles and low-frequency electric current or ultrasonic waves (electroacupuncture), or by manual pressure with a finger (acupressure, see next section).

Some evidence suggests that acupuncture is effective because of releases of multiple endogenous substances (e.g., oxytocin, steroids, endorphins) that could not be produced by any single drug treatment (Filshie & Thompson, 2004). In addition, acupuncture may activate the hypothalamus and pituitary gland, resulting in systemic effects, including regulation of blood flow centrally and peripherally (Cho et al., 2006). Numerous research studies have suggested that acupuncture can be effective for reducing pain and increasing function either alone or in addition to more traditional interventions for conditions including low back pain (Furlan et al., 2005), neck pain (Trinh et al., 2006), and headache (Linde et al., 2009). Patients receiving acupuncture may experience a tingling sensation or minor bruising or irritation at the point of needle insertion. Patients' other medical conditions (e.g., swelling of the extremities, blood disorders) must be taken into consideration before initiating acupuncture.

Acupressure. As described earlier, acupressure is an ancient healing art based on the belief that physical pressure applied to various energy points and channels in the body can relieve pain and promote good health. Firm, gentle pressure is applied to "acupoints" on meridians in order to unblock the flow of "qi" and restore healthy energy flow.

Acupuncture and acupressure are most commonly used to address the same conditions or symptoms (e.g., fibromyalgia, headache, muscle cramps, osteoarthritis, arthritic pain, back pain, carpal tunnel pain). Similar to acupuncture, research suggests that acupressure can be effective for reducing pain and disability in conditions such as low back pain (Hsieh et al., 2006). These techniques can also be used to promote good health by assisting with weight loss and smoking cessation. Patients receiving acupressure may experience mild bruising at the points of pressure.

There are now a number of medical acupuncture training programs in the United States, but many experienced practitioners may not have completed a formal training program. As with many complementary and alternative therapies, the quality of practitioners can vary, and obtaining referrals from multiple sources can help identify those who are most effective.

Chiropractic Treatment. Chiropractic treatment is guided by the theory that the structure of the spine is related to functioning of the nervous system; reduced movement in the spine can result in increased pain and decreased function. Chiropractors primarily use spinal manipulation, pressure applied to the spinal joints, to increase mobility. They can also use other therapies, including massage, ultrasound, or electrical stimulation to relax muscles and increase movement. Chiropractic treatment is often used to treat low back pain, headaches, neck pain, and leg pain. Once considered an alternative treatment, chiropractic treatment is widely available and may be covered by insurance; in addition, chiropractors often serve on multidisciplinary treatment teams. Research evidence that chiropractic treatment is effective for back, neck, or headache pain is limited; in fact, one systematic review concluded that the efficacy of chiropractic manipulation was not supported by the literature (Ernst, 2004). Chiropractic treatment should be avoided or used with caution if the patient has a history of osteoporosis, symptoms of nerve damage, spinal metastases, or a history of spine surgery.

Therapeutic Touch/Energy Healing. Therapeutic touch, defined as the use of hands near the body with the intention to help or heal, may be of benefit, in addition to or as an alternative to massage therapy. Energy healing is similar to therapeutic touch in its concepts and practice. Practitioners using these techniques use their hands and their own energy stores and fields to assess and balance patients' energies and direct energy toward healing. More high-quality research studies on therapeutic touch are needed and current research results about the effectiveness of therapeutic touch are mixed. Therapeutic touch has been shown to decrease pain and fatigue among cancer patients (Aghabati, Mohammadi, & Pour Esmaiel, 2008) and pain and anxiety among burn patients (Turner, Clark, Gauthier, & Williams, 1998).

CONCLUSION

In the care of patients near the end of life, nonpharmacological pain management techniques can be helpful adjuncts to primary management with medications. Through combined use of these modalities, patients may experience greater relief of pain and other symptoms. More important than the degree of added symptom control, patients and their caregivers can experience significant psychological benefits from using these techniques. Nonpharmacological interventions can provide a sense of internal control over symptoms and help alleviate the feelings of helplessness that frequently accompany the end-of-life experience.

Application of many of these techniques can be carried out without the use of specially trained practitioners, but others (e.g., acupuncture, therapeutic touch, TENS) may require consultation with other health professionals with expertise in these modalities. Wherever possible, it is helpful to provide a number of options for patients and their caregivers, educating them thoroughly on how to properly apply these techniques and what to expect as a result. This will allow them to experiment and find the best match between interventions and the abilities and interests of patients and their caregivers.

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CHAPTER

9

Grief and Bereavement Care

Shirley Otis-Green

OVERVIEW OF GRIEF AND AGING

To be bereaved is to have experienced a loss of something of value. Grief is the normal response to that loss. The loss can be of a meaningful relationship, an important belief, or a treasured pet or possession (DeSpelder & Strickland, 2004). Grief is a multidimensional phenomenon with physical, psychosocial, spiritual, and social manifestations (Corless, 2006). Mourning is the process through which individuals adapt to a loss and is strongly influenced by culture and rituals (Ashenburg, 2002). Despite the universality of the experience, each person's grief experience is uniquely his or her own, though it impacts the entire bereaved person's social network (Hollingsworth, 1977; Holtslander, 2008). As we age, we experience multiple losses and the resultant accumulation of grief. The expression of grief is determined by many factors—our developmental stage, the circumstances of the loss, our social mores and religious and spiritual perspectives, as well as our personal loss history (Saunders, 1989).

Vast archaeological evidence shows that mourners have commemorated significant deaths from our earliest hominid prehistory. Throughout every culture, artists, poets, philosophers and spiritual leaders have explored the dynamic experience of grief, yet only recently has Western science begun the systematic study of death, dying, grief, and bereavement (the developing field of thanatology) and its impact upon individuals, families, and their social network (Irish, Lundquist, & Nelsen, 1993). Our understanding of what is a “normal” grief reaction has evolved as our sophistication in this field has increased (Parkes, Laungani, & Young, 1996).

GRIEF PROCESS

The process of grief begins with an awareness of a threat of loss (“anticipatory grief”), through the experience of the loss and continues through the integration of that loss into a “new normal.” Researchers are seeking to better understand how individuals cope with acute loss and integrate the legacy of the relationship to recreate a healthy, functioning life without the presence of the departed loved one (Klass, Silverman, & Nickman, 1996; Knight & Emanuel, 2007). This process is not orderly or predictable nor does it follow an expected time frame. Even under the best of circumstances, the grief process provides significant psychological challenges; at worst, it can become completely disabling (see Chapter 10 on complicated bereavement for a more in-depth discussion of this concept).

CONCEPTUALIZATIONS OF GRIEF

Early in the twentieth century there was a narrow view of what constituted an appropriate grief response (Canine, 1996). Walsh-Burke (2006) provides an overview of early literature that encouraged the mourner to “complete” their grieving as quickly as possible so that they might “get on” with their life. In the 1950s, Elisabeth Kubler-Ross (1969) began interviewing dying patients and composed a highly influential stage-theory of anticipatory grief (Maciejewski, Zhang, & Block, 2007). This concept was later modified by Bowlby (1961, 1973–1982) and Parkes (1970, 2001) who proposed a phase-based theory of grief.

Worden popularized a task-centered approach to understanding bereavement that focused on the need for the individual to accept the reality of the loss, process the pain of the grief, and ultimately, internally and externally adjust to a life without the deceased while creating an enduring connection with the loved one (Worden, 2008). Increasingly, researchers are now recognizing that grief is more of a process with great variances in how individuals adapt to a loss (Genevero, Marshall, & Miller, 2004; Stroebe, Hansson, Stroebe, & Schut, 2001). The field is attempting to understand how the nuances of gender and ethnicity, religion and culture impact the grief experience while thanatologists grapple with how best to identify and measure the outcomes of grief (Corr, Nabe, & Corr, 2003; Prigerson et al., 1995).

Older adults have been exposed to an accumulation of losses over their lifetimes and most have learned to adapt to grief. But compounded losses test the resilience of even the hardiest of individuals and heighten the risk for serious physical, social, existential, spiritual, and psychological ramifications (Christakis & Lund, 1992; Neimeyer, 2001) making those with limited resources and fragile support systems especially vulnerable for complications with grief (Sprang & McNeil, 1995).

A significant loss can trigger an existential crisis when an individual's long-standing beliefs about meaning and purpose in life are threatened. The death of a loved one can make life suddenly seem much less "fair" ("*Mary didn't deserve to die like that*") and the future far less predictable ("*If this can happen then anything can happen*"). This heightened sense of vulnerability creates panic. Deaths that occur without adequate preparation, that are sudden, unexpected, or especially violent and traumatic (such as suicides and homicides) increase the risk that the mourner will experience complications in their grief experience (Prigerson & Jacobs, 2001). Losses of relationships that are not socially sanctioned, such as still-births, terminated pregnancies, the death of an "illicit" partner or ex-spouse can result in disenfranchised grief that may go unexpressed or if expressed may be labeled by others as "exaggerated" grief (Doka, 1989). Ambiguous losses (such as with missing persons from war or disaster situations) are especially difficult for families to process (Boss, 1999).

Importantly, professionals can also minimize the probability of complicated grief by being involved prior to the death in efforts to provide a better dying experience (Berry & Griffie, 2006; Field & Cassel, 1997). Advocacy for quality end-of-life care will help to minimize regrets and better prepare survivors for what to expect following the death (Rolland, 2004). Even in situations where the death is sudden and traumatic skilled health-care providers can normalize feelings, educate and offer anticipatory guidance to help the family more effectively cope with the situation (Billings & Kolton, 1999). End-of-life experiences where families perceive that their loved one's needs were met and where they indicate that they felt that there had been adequate support and communication with health professionals prior to the death report healthier bereavement adjustment following the death

(Wright et al., 2008). Steps that we can take to minimize regret prior to death by addressing unfinished business can be a powerful intervention that also may minimize the risk of complicated bereavement (Byock, 2004).

Individuals' grief experiences are mediated by their relationship to the deceased, the nature of their attachment, the circumstances surrounding the death, historic antecedents and personal loss history, personality mediators, social factors, and concurrent stressors (Worden, 2008). Grieving is more turbulent when loved ones perceive the death to have been especially difficult or traumatic (such as associated with homicides or suicides), when end-of-life decision making is not well supported, when the death is associated with regret or when the bereaved feel a lack of permission to openly grieve. Additional risk factors occur when the relationship with the deceased was particularly complicated or ambivalent, when there is a lack of adequate social support, when an accumulation of losses overwhelm the bereaved's ability to cope or if the bereaved's resilience is impacted due to serious mental health comorbidities (Currow et al., 2008; Ellifritt, Nelson, & Walsh, 2003; Goodkin et al., 2005–2006; Horowitz et al., 1997; Jacobs, 1999).

MULTIDIMENSIONAL IMPACT OF GRIEF

The experience and expression of grief varies and is highly subjective, with manifestations throughout every aspect of an individual's life. The bereaved person may experience a range of sensations that include sleep disturbances, tears, shortness of breath, fatigue, nausea, aches, and muscle tension. Psychological symptoms may include loss of interest in things that had previously brought joy, sadness, helplessness, anxiety, guilt, shame, generalized anger, yearning, disbelief, difficulty concentrating, and impaired decision making. Grieving individuals may neglect personal hygiene. The bereaved may report vivid experiences of encounters with the deceased, which others may interpret as hallucinations or a sign of mental illness. The bereaved may struggle to return to work or to participate in social functions. Religious, spiritual, and existential concerns may surface during this tumultuous time with some people finding comfort in their faith traditions while others distance themselves from traditions that no longer seem to meet their needs. Given this litany of possible disturbances, it is not surprising that bereaved caregivers are at increased risk for illness in the months following the death of a loved one (Christakis & Iwashyna, 2003). Personal reminders from trusted professionals to attend to his or her health are especially useful for this vulnerable population (Rabow, Hauser, & Adams, 2004). Periodic assessments regarding the bereaved's level of exercise, frequent monitoring for changes in weight and sleep as well as other affects are especially important.

ASSESSMENT AND SCREENING

As outlined before, grief is a stressful process with implications throughout every domain of an individual's experience. It is not uncommon for these normal reactions to grief to be misinterpreted as indicators of dysfunction. Health-care providers need to careful not to prematurely pathologize an individual's reaction to grief. We need to be especially vigilant regarding the possibility that what we are witnessing is a culturally appropriate grief response (Lipson & Dibble, 2005). Certainly, professionals do need to be alert to signs that the bereaved may have a comorbid psychiatric condition or be considering self-harm and intervene accordingly (Barry, Kasl, & Prigerson, 2002), as it can be difficult to determine if the bereaved individual is suffering from generalized anxiety disorder, clinical depression, or posttraumatic stress disorder.

Various types of bereavement assessments exist, all of which attempt to discern the nature of the individual's grief reaction, understand the influencing factors associated with the loss, identify the risk-portrait for complicated grief and assist with determining a valid differential diagnosis (Aranda & Milne, 2000; Carmichael, 2005; Colorado Bereavement Services Project, 2003; Mystakidou, Tsilika, Parpa, Galanos, & Vlahos 2008; Pomeroy & Garcia, 2009). Ideally, the selection of an assessment instrument would be based on a review of the literature to find the least burdensome and most reliable, effective, valid, culturally compatible tool for the population being served. Following an intensive review of the literature, researchers at Brown University have developed a Web site (http://www.chcr.brown.edu/pcoc/toolkit.htm) listing a variety of bereavement assessment tools to address the needs of differing populations; however, the evidence base is still emerging to adequately guide the field in this regard. Instruments are therefore typically selected to complement the theoretical grief perspective adopted by the health professional or are based on the organization standard within which one works.

EDUCATION AND INTERVENTION

The experience of grief can be overwhelming so even individuals at minimal risk will benefit from education and support to normalize the range of symptoms associated with the loss and offer anticipatory guidance regarding what to expect during the bereavement process (Cook & Dworkin, 1992; Forte, Hill, Pazder, & Feudtner, 2004; Jensen, 2002). Although death is a universal life event, most individuals report feeling poorly prepared to cope with it (Rando, 2007). Professionals offer bereavement support not because grief is pathological, but because the experience of grief is more difficult to cope with when we are ill-prepared for it.

Until recently, most deaths occurred in a family setting shortly after an injury or following a brief illness. Improvements in sanitation and health care in developed nations have extended average life spans, allowing more individuals to survive longer with chronic conditions. As a result, the process of dying has become lengthier and more institutionalized, with a majority of deaths occurring in hospitals and in long-term care facilities. This has resulted in increasing numbers of people living longer without an intimate experience of death. This lack of exposure to the dying process leaves us without adequate role models for grief.

It is compelling to be offered a prescription for what to do when you are in a situation you've never before experienced. Grieving individuals may find spiritual traditions and rituals especially comforting immediately following a death as they offer guidance and support at times of confusion and crisis (Spiro, Wandel, & Curnen, 1998). For example, the Jewish tradition of sitting Shiva offers the newly bereaved community support in the first chaotic days following a death (Johnson & McGee, 1998). The bereaved seek confirmation that the seemingly "abnormal" experiences that they are having is indeed within the wide range of "normal" (Hedtke & Winslade, 2004; Rando, 2000).

Developing a comprehensive listing of community referral options is vital, for even specialized geriatric professionals will be periodically confronted with situations for which an outside resource will be useful (Field, Reid, Payne, & Relf, 2004). Identify bereavement support programs available in your local area and through the Internet as well as colleagues with an expertise in this field who are familiar with the cultural nuances of the diverse populations of individuals represented in your community. Local hospices may be an excellent source for sophisticated bereavement expertise

(Foliart, Clausen, & Siljestrom, 2001). Because having services available in a bereaved individual's primary language is important, support programs facilitated by bicultural and bilingual staff are especially appreciated during times of heightened vulnerability and stress (Otis-Green, 2006). Professionals can learn about and advocate for culturally relevant rituals, rites and traditions to aid in the expression of grief (Reid, Field, Payne & Relf, 2006).

NARRATIVE

Maria G. was a 67-year-old Latina woman whose husband of nearly 40 years had recently died following a long history of prostate cancer. She and her sister, Eva, have been attending the hospital's bereavement support group for several weeks when she reported concern that she hadn't cried since the funeral. Maria said that she has wanted to "remain strong" and then reluctantly admitted that she feared that if she allowed herself to cry she "wouldn't be able to stop." She identified herself as being interested in processing her grief, but was unsure of where to begin. The group facilitator explored with Maria her fears regarding the expression of grief and provided information and education regarding bereavement to normalize her concerns and then explained an activity that may allow her to begin to experience her grief with a built-in "safety net." Maria was asked to select a time frame where she would have a few hours to devote to this exercise and to identify a support person who she would feel comfortable with to assist her with this activity. Maria selected Eva to be her confidant for this activity because Eva had lost a son some years back in a car accident and she felt that Eva would understand her tears and sadness.

The facilitator then invited Maria to brainstorm regarding various strategies that might work for her to elicit a grief response. Maria agreed that on the designated Saturday, she would go into her husband's closet and pull out some of his favorite clothes, allowing herself time to reflect on when he had worn these items and consciously letting herself experience his scent. She would then go to the living room and put on some music that she and her husband had enjoyed together and look through a scrapbook or photo album and a few other treasures from important shared life events (such as from a vacation or honeymoon). Maria agreed to give herself at least an hour during which she would seek to experience with all her senses the loss of this person who was so important in her life.

The facilitator also encouraged Maria to set an agreed-upon time for Eva to come by the house to be with Maria to process this experience. Maria asked that Eva join her for a long walk in a nearby park where they could have a private picnic lunch. During the group session Eva clarified that she understood that her role would be to let Maria set the tone and the pace of their time together. She committed to let Maria talk or not as she chose, and agreed not to try to distract her from her feelings.

At the following group session, Maria reported that she had found this exercise to be very helpful. She said that she and Eva had openly shared their personal experiences of grief and found comfort in the intimacy that they felt during this time of intense mutual vulnerability. Maria said that she was finally able to "let her guard down" and cry. She reported that she felt stronger after she realized that she could experience intense grief and still recover from it to have a pleasant afternoon with someone she cared about. She expressed awareness that her grief would be ongoing, yet felt a sense of hopefulness in her ability to cope with this loss. Others in the group offered support and encouragement to Maria and Eva, further validating their courage in addressing their grief.

CONCLUSION

Establishing rapport and providing a safe and supportive presence is the single most important element of bereavement care. It takes courage to authentically and compassionately "be with" those who are grieving as they struggle with existential issues that few of us comfortably are willing to face. It is the prepared professional, however, who considers this invitation to reflect on their own values and beliefs (Walsh & McGoldrick, 2004) because sitting with those who are grieving reminds us that we too are vulnerable to grief and will someday face our own mortality.

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Additional Bereavement Care Resources

American Association of Retired Persons: http://www.aarp.org/family/lifeafterloss/

American Hospice Foundation: http://www.americanhospice.org/index.php?option=com_content&task=view&id=30&Itemid=45

Grief Net: http://www.griefnet.org/

Growth House: http://www.growthhouse.org/

National Hospice and Palliative Care Organization: http://www.nhpco.org/i4a/links/?pageid=3287&showTitle=1#Grief and Healing

National Library for Health—Palliative and Supportive Care Specialist Library: http://www.library.nhs.uk/palliative/ViewResource.aspx?resID=126800

Toolkit of Instruments to Measure End-of-Life Care: http://www.chcr.brown.edu/pcoc/Griefa.htm

CHAPTER

10

Complicated Grief

E. Alessandra Strada

INTRODUCTION

> Loss of a loved person is one of the most intensely painful experiences any human being can suffer.
>
> —John Bowlby

Grief is a natural reaction to any experience of loss. Perhaps we could conceptualize the essence of loss as any experience that "restricts" us by taking away possibilities and potential. Losing a loved one to death does not only mean losing the physical person, it means losing the sense of life as we knew it. It means losing important parts of our identities. Essentially, it means temporarily losing the sense of how to be in the world. When a loved one dies, the world changes and will never be the same.

Bereavement is usually referred to as the process of recovering from the grief of loss. "Grief work" is a term commonly used to refer to the process of bereavement. Bereaved individuals can easily relate to the concept that processing grief is hard work. Learning to live after the loss of a loved one is probably the most difficult type of work human beings have to learn.

Grief is the normal response to loss. The term grief can be used to indicate the constellation of symptoms that can be experienced after a loss. The loss of a loved one affects every domain of existence; grief affects the ability to think, physical health, psychological well-being, and personal relationships with religion and spirituality. The nature and type of loss impacts the experience and manifestation of grief. Although it is true that there is no right way to grieve, it is also true that the consequences of bereavement place a significant burden on us individually and on our whole society. After the loss of a loved one we may symbolically find ourselves in unfamiliar territory, where the landscape appears dark and threatening. We may not know which path we should follow in order to walk through the "land of grief" and come out the other end. Several metaphors have been used to represent grief and bereavement.

One of the images that often comes to my mind during my clinical work with bereaved patients is from Dante Alighieri's *The Divine Comedy*. Dante's metaphor of the dark forest has been used to indicate several types of psycho-spiritual and existential crises and can appropriately be applied to bereavement, for its power to precipitate profound psychological, spiritual, and existential crises. In the midst of acute grief, individuals may fear that they will never be able to come out on the other side of the "dark forest." In the *Divine Comedy*, Dante was able to walk through Hell, Purgatory, and ultimately reach Heaven, thanks to the help of Virgil, his guide. Similarly, our work with people who are bereaved involves guiding them through the dangerous land of grief, making sure that they will "make it" to the other side. This goal is often accomplished by first educating about grief and its manifestations, facilitating grief work, and allowing adaptation and integration to occur.

In some cases, however, people can symbolically "get lost" in the dark forest and lose sense of direction. Or, they can get "stuck" on a particular part of the journey and be unable to move forward. These two descriptions can be used to represent complicated grief, which is a condition where the grieving process may symbolically become "stuck," preventing a person from processing grief and integrating the loss. As we accompany people along their journey through grief and bereavement, we need to continually assess their ability to continue on the bereavement journey not only gently accompanying, but also intervening in meaningful and therapeutic ways when needed.

The goal of this chapter is to provide the reader with an understanding of the clinical manifestations of complicated grief. Nonpathological, individual grieving styles are described in this chapter because of their potential to become risk factors when grievers are not allowed to express and process their pain in a modality that feels natural and familiar to them. Risk factors and protective factors for complicated grief are also reviewed. Finally, this chapter describes integrative and evidence-based treatment modalities.

Individual Grieving Styles

Although the experience of an existential abyss created by the loss of a loved one may be a common experience for many people, the ways we approach the journey are individual and unique. No two people experience grief the same way. Grieving styles account for individual variability in the ways we approach grief work and bereavement.

Grief is not a disease, but it can become one. Therefore, before discussing maladaptive manifestations of grief it is important to explore and understand the unique grieving style each person develops and expresses after a loss. How do we learn to grieve? We typically learn it from our first exposure to loss and death. We learn how to grieve from our families, from our communities, and from our cultural milieu. We learn what are considered appropriate ways to display affect from the people who are closest to us when we experience the first loss. As already mentioned, individual grieving styles do not represent expressions of pathology. However, if grieving styles are not acknowledged, recognized, and allowed expression, they may easily become risk factors because they may cause grief to become suppressed or repressed As a result, the natural grieving process may literally get "stuck" and continue to be experienced with severe symptoms, which significantly affect the person's ability to integrate the loss and continue on with life.

Identifying individual grieving styles is important not only for personal psychological well-being, it is also crucial from a professional standpoint. Being aware of grieving styles allows clinicians to understand and recognize individual grieving styles in patients or clients and family members, and thus allows for a more thorough bereavement assessment, follow-up, and treatment plan. Clinicians experienced in the recognition of nonpathological grieving styles will be less likely to evaluate in negative terms grievers who express severe distress and will therefore model adequate and professional bereavement assessment and treatment for the rest of the palliative care and hospice team.

A simple exercise can help us identify our own grieving style. This exercise does not involve meditation, or visualization. It is an exercise in remembrance, reflection, and contemplation. It is an invitation.

For easier flow, you could read the entire set of questions and use a tape recorder. You could subsequently listen to the instructions and pause the tape recorder after each question.

Grieving Style Exercise

Sit in a comfortable chair, in an environment that will not interfere with your ability to reflect and remember. It could be a coffee shop, your house, your office. It would be better to turn off pagers and phones for the duration of this exercise. You may want to take three deep breaths, fully releasing any holding patterns in the out breath. Try to fully breathe out all the air in your lungs. And then, try to answer the following questions. Try to stay with each question long enough to allow memories and sensations related to the experience to emerge. Write down the answer if you can. Then, move to the next question when you feel satisfied.

1. What is the first death of a loved one you can remember?
2. Who died? The loved one could have been a pet, a friend, a family member.
3. How old were you?
4. What were the circumstances of the death? (sudden, or prolonged; from illness, or accident)
5. How did your family react to the loss? Did everyone react the same way, or differently?
6. What type of message did you receive from your family about what behavior is appropriate or not appropriate after a loss? How did people around you express their feelings?
7. If you were a child, were you involved in the rituals surrounding the funeral? Did you ask any questions? Were you given any explanations about the death? Or, did your family hold the belief that children should be protected from the experience of death and bereavement?
8. How did you express your feelings? Were you aware of your feelings at the time? Did you cry a lot, every day, for several days and weeks?
9. Did you feel held by the grieving style exhibited by your family and community at the time?
10. Would you have liked people to treat you differently or behave differently? If so, how?

And now, fast-forward to the most recent loss you have experienced. If you are acutely bereaved, you may want to wait to do the exercise until the most intense part of your grief has subsided. But really, you should do what feels right to you. If you can think about the most recent loss you have experienced, please answer the following questions.

1. Are you aware of your grieving style now?
2. Are you still grieving the way you did or learned to do after your first loss?

3. If your grieving style has changed over the years do you feel it is supportive of your personal journey now?
4. How comfortable do you feel addressing patients' and caregivers' grief in your professional capacity?
5. In what ways are you particularly gifted in recognizing and addressing grief?
6. How do you manage countertransference when working with bereaved patients?

Grieving Styles in the Literature and in Clinical Practice

The identification of grieving patterns is based on the seminal work of Martin and Doka (2000). They described three basic patterns: intuitive, pragmatic, and dissonant. I personally think these patterns represent predominant grieving styles; however, in clinical practice I have observed that most patients and caregivers have a "blended" grieving style. Accurate and professional grief and bereavement assessment should not be focused on labeling people according to one of the three grieving styles described later. Rather, clinicians can use the idea of a predominant grieving style as a general map or anchor point, with the goal of understanding the complexity of each individual's way of experiencing and expressing grief. The descriptions that follow represent my understanding of the three general grieving styles, combined with elements of my clinical experience.

Intuitive. Grievers described as intuitive may experience grief as "waves" of feelings and may easily feel overwhelmed by the pain of grief. Using the metaphor of ocean waves can resonate with bereaved individuals who often describe feeling as if they are literally drowning in pain. Grievers who predominantly grieve in this modality may display disorganized thinking, uncontrollable crying, and may benefit from being allowed to ventilate their emotions. I often use the ocean metaphor mentioned above validating the feeling of being in the middle of the ocean and unable to see the shore. However, I constantly remind my patients that I know that the shore is there and I can actually see it. I keep reminding them that we are moving toward the shore, even though sometimes the process may be so slow that it feels like nothing is happening. I also often remind my patients that at times they may feel hit by a wave of pain of unusual violence, but even the worst pang of pain will subside. I remind them that they will survive and will continue their grief work. I may become the holder of the hope that the pain will ultimately become less intense. I become the holder of the hope that they will learn to live even in the face of the most devastating loss.

Pragmatic. Pragmatic grievers are focused on problem solving and control over the environment. They may experience grief as a thought and be generally reluctant to talk about feelings. The ability to exhibit mastery of oneself and the environment is a core value. In terms of intervention, they may benefit from problem-solving approaches to grieving and bereavement. In terms of symptoms, they may exhibit and experience confusion, forgetfulness, and obsessiveness. Paradoxically they may experience more energy level than usual and engage in various activities. As a result, they may appear more productive and their internal grief may go unnoticed. I often find that grievers who predominantly utilize this modality may be perceived by the medical team as a bit detached and somehow disconnected from their grief. My role, then, as a psychologist, becomes that of "bereavement translator," facilitating communication between the bereaved individual and others, who may misunderstand or negatively perceive what may actually be perfectly adaptive grieving behaviors.

Dissonant. Grievers who function primarily in this style experience grief in one pattern but are inhibited from finding ways to express grief that is compatible with their experience. From a clinical standpoint, I have often observed this pattern in patients and caregivers who are immigrants with limited levels of acculturation and integration. Patients may describe a cultural background where, for example, public manifestations of intense affect are perfectly acceptable and may involve incontrollable crying, yelling, self-beating, and refusal to sleep, eat, or perform usual routines of self-care. These behaviors may, in some instances, have ritualistic value, are voluntarily stopped by the griever after what is considered an acceptable amount of time, and may not be the expression of psychopathology. These grievers soon find out that these behaviors are not considered acceptable by mainstream medical culture and will raise significant concern in providers, who will probably request a psychiatric consult to evaluate the patient's mental health. The discrepancy between what is perceived by the griever as appropriate and helpful behavior and what is considered acceptable by the host culture can cause distress for the bereaved individual and a sense of "being trapped" and feeling unsafe.

Because grief is such a unique and individual process it is not uncommon for members of the same family to express grief in different ways.

Sometimes grieving styles within a family or a couple are so different that communication difficulties and misunderstandings can occur. The potential "grieving mismatch" in couples and families represents another important area of interventions for clinicians with adequate training.

COMPLICATED GRIEF

The last decade has seen a significant amount of research aimed at understanding the nature of grief and its manifestations, distinguishing what is commonly referred to as normative grief, from pathological forms of grief. This investigation has been motivated by the clinical observation that even though the majority of bereaved individuals are able to integrate the loss of a loved one after a variable period of time, in 15% to 25% of cases, bereaved individuals continue to experience maladaptive reactions and psychiatric symptoms that significantly impair their level of functioning (Dillen, Fontaine, & Verhofstadt-Deneve, 2008; Prigerson et al., 1995; Simon, Thomson, Pollack, & Shear, 2007).

Horowitz et al. (2003) first offered a diagnostic algorithm differentiating complicated grief from Major Depressive Disorder. Subsequently, Prigerson and collaborators (1995) demonstrated that symptoms of pathologic grief form a cluster that is different from depression and anxiety. As a result, complicated grief was proposed as a newly recognized disorder and diagnostic entity different from major depression and anxiety (Zhang, El-Jawahri, & Prigerson, 2006).

In the most recent conceptualization, Prigerson and colleagues have revised the diagnostic criteria for complicated grief renaming the disorder Prolonged Grief (Boelen & Prigerson, 2007). In order to be diagnosed with Prolonged Grief Disorder (PGD), bereaved individuals must experience 1 of 3 symptoms in the "Separation distress" category, and 5 of 9 symptoms in the "Cognitive, Emotional, and Behavioral symptoms" category. Prolonged Grief Disorder has been proposed for inclusion in the DSM-5.

Clinical Manifestations of Complicated Grief

The literature shows evidence that complicated grief exposes bereaved individuals to significantly higher levels of morbidity and mortality in the physical, psychological, and social domain. It has been associated with disability and decline in overall level of function. A diagnosis of complicated grief increases the risk for major depressive disorder, anxiety disorders, suicidal ideation, self-destructive behavior, and suicidal behavior. In a study of 149 patients meeting criteria for complicated grief, 65% expressed the desire to die, 38% engaged in self-destructive behavior, and 9% made an actual suicide attempt. Severity of complicated grief and history of suicide attempt were the two variables associated with suicidal behavior after the loss (Szanto et al., 2006). Other negative health outcomes include increased risk for high blood pressure and cardiac events. Additionally, bereaved individuals with complicated grief have shown significant change in behavioral patterns related to alcohol and tobacco use.

Risk Factors for Complicated Grief

Presence of risk factors does not mean the bereaved will necessarily develop complicated grief. Rather, risk factors represent individual psychological, physical, and social vulnerability that ideally would be identified and addressed to prevent a protracted and complicated bereavement process. The main categories of risk factors that have been identified pertain to characteristics of the relationship between the bereaved and the deceased; characteristics of the bereaved; and circumstance of the death. As far as relationship variables go, insecure attachment patterns and dependent and close relationships between bereaved and deceased have been associated with complicated grief. However, it is crucial that clinicians do not interpret the results of these co-relational studies as an indication that close and dependent relationships are inherently "unhealthy." The construct of dependency is culturally determined and what may be described as "dependent" in U.S. mainstream culture may be considered simply the norm in other cultures.

Individual history of psychiatric illness, including depression and anxiety, as well as a history of prior losses, also represents a risk factor. A history of childhood separation anxiety, as well as a history of abuse and neglect has also been associated with complicated grief. Factors described in the literature as exposing bereaved individuals to a higher risk for bereavement include a childhood history of separation anxiety, overly controlling parent, parental abuse, early parental death, and insecure attachment styles. Additionally, a history of mental illness prior to the loss and an ambivalent relationship with the deceased increase the risk for developing prolonged grief disorder and may seriously undermine patients' and families' abilities to cope with the progression of illness and impending death.

Circumstances of the death may also play a significant impact on the bereaved adjustment. Long and prolonged deaths, especially when the bereaved individual has been the primary caregiver are a risk factor. Sudden and traumatic deaths and deaths of children are also risk factors. Lack of preparation and psychological support prior to the death are important categories of risk factors that are receiving increasing attention in palliative and end-of-life care because of the potential role for clinicians.

Complex relationships with the deceased that include presence of positive and also intense negative affect are considered a risk factor. Many bereaved individuals report experiencing contrasting emotions that may reflect ambivalences and conflicts in the relationship with the loved one who died. Death eliminates the possibility of working through conflict with the loved one, leaving the bereaved individual dealing with complex sets of memories and emotions. As a result, symptoms of acute grief can be difficult to tolerate, especially if one does not have adequate support. Therefore, many individuals can start self-medicating using food, alcohol, or other drugs, to calm the pain. Maladaptive patterns of addressing the physical and emotional pain caused by bereavement can become chronic if not addressed, and result in complicated grief.

A significant decrease in the ability to concentrate and focus is a common experience after a loss. People may report that their memory is impaired, they "cannot seem to get a hold on things," and they may feel that their lives are getting out of control. Some of the more dramatic cognitive symptoms are visual and auditory hallucinations. People may hear the voice of the loved one calling out in pain, or may see the image of the loved one lying in the hospital bed. Most of the times, visual or auditory hallucinations are transitory and reflect real events and circumstances related to the actual death. In people without a history of psychotic disorders or other mental illness, these perceptual disturbances can be disturbing. They need to be, however, monitored and normalized, because they can represent a normative manifestation of grief in the early stages of bereavement, but can lead to complicated grief if appropriate support is not provided.

The death of a loved one can also represent a difficult test for one's spiritual or religious beliefs. Spiritual symptoms may include conflicts in faith beliefs and loss of meaning and purpose. Religiosity and spirituality have been associated with both positive and negative coping. In many cases, bereaved individuals can rely on spiritual or religious beliefs to cope with grief and bereavement. However, the loss of a loved one can also create fertile ground for conflicts in faith beliefs and loss of meaning. Faith, as spirituality, is a dynamic concept that can sometimes evolve according to life circumstances. For some individuals, faith can be domain-specific and its beneficial effects may not automatically translate to bereavement. Individuals have reported the experience of "losing their faith," or being angry at God, after major bereavement. For those who belong to a religious organization, the God-Image is usually a reflection of the qualities attributed to God by the religious teachings. Some basic qualities of love, compassion, forgiveness, and justice are shared by most theistic religions. Religious individuals are likely to develop an image of God that embodies those positive qualities. The distress created by the loss of a loved one may create a rupture in the bereaved individual's image of God. The pain of the loss may alter the God image, which may become a judgmental and punishing presence. The awareness of the discrepancy between different God images can create significant spiritual distress, and would warrant more exploration in order to help relieve the patient's suffering and development of complicated grief.

COMPLICATED GRIEF IN THE PALLIATIVE CARE SETTING

Grief assessment and bereavement care should begin at the first contact between the patients and family and the palliative care or hospice team. As mentioned earlier, research has shown that complicated grief (aka PGD) is associated with physical and psychiatric morbidity, including increased suicidal ideation, and overall reduced quality of life (Zhang, El-Jawahri, & Prigerson, 2006). Therefore, identifying individuals at risk for developing complicated grief should be a particular focus of the palliative care team.

The Experience of Grief in Patients With Advanced Illness

The grief experience of patients who are dying should also be carefully understood, assessed, and treated, because it presents unique features that warrant an individualized approach. The term "complicated grief" is typically used in relation to the bereavement process experienced by caregivers after the patient's death. However, palliative care and hospice patients may be experiencing complicated grief at the time of admission, due to unprocessed losses occurred prior or during the course of their illness. Not uncommonly, patients will experience complicated grieving (grief about loss of loved ones) in addition to preparatory grief (grief about the imminent loss of his or her own life). The occurrence of this sort of "double bereavement" process can cause severe emotional distress in patients and generate a feeling of helplessness in caregivers. It is crucial that clinicians assess every patient for the presence of complicated grief and preparatory on admission.

The term "preparatory grief" has been used in the literature to indicate a normative grieving process that may be experienced by patients with advanced illness as they approach death (Mystakidou, Tsilika, Parpa, Galanos, & Lambros, 2008; Mystakidou, Parpa, et al., 2007; Ventafridda, Ripamonti, De Conno, Tamburini, & Cassileth, 1990). It has been described as a natural element of the life cycle (Periyakoil & Hallenbeck, 2002), with the potential to create significant suffering for the patient and the family system. Kubler-Ross' description of anticipatory grief as the grief that "the terminally ill patient has to undergo to prepare himself for his final separation from this world" (Kubler-Ross, 1997) has been frequently utilized to indicate this unique process. The patient's grieving process has a multidimensional nature that involves the physical, emotional, and spiritual domains. The patient's preparatory grief parallels the anticipatory grief experienced by family members. Spiritual orientation and religious affiliations modulate the extent to which the patient's own death is perceived as an absolute loss of self, or a transition to another existence of self that is primarily spiritual. In this sense, patients with advanced illnesses who are grieving their own deaths may be faced with the same tasks involved in grieving the loss of a loved one.

Applying Worden's task model of grief (Worden, 2002) to a dying patient's preparatory grief may allow providers to understand the nature and manifestations of preparatory grief and identifying areas that may require specific interventions to minimize distress for the patient. According to the original model, the tasks of grief work involved in processing the loss of a loved one are: (1) accepting the reality of the loss, (2) working through the pain of grief, (3) adjusting to a world without the loved one, and (4) emotionally relocating the loved one and continuing on with life.

When applied to patients, the first task involves dealing with the awareness of a limited prognosis and impending death. Although this task involves a pragmatic and cognitive process for family members, it allows room for various shades of gray when it comes to dying patients. In other words, bereaved family members are faced with the task of accepting that the loved one is, in fact, dead, and no longer living. Patients may, however, experience various degrees of awareness and acceptance of the fact that their death is near. Their willingness to openly acknowledge that they are dying should not necessarily be interpreted as a sign of benign acceptance and "better" adjustment to the dying process, the same way that unwillingness to openly acknowledge that death is near is not necessarily a sign of unhealthy denial. Open awareness of dying does not automatically translate into acceptance or peace. Similarly, although patients may choose not to openly acknowledge they are dying, they may still be internally engaged in processing this reality. Death awareness is a complex construct, initially explored in Glaser and Straus' landmark study *Awareness of Dying* (Glaser & Straus, 1965), which described possible scenarios reflective of awareness contexts between patients and caregivers. The types of awareness described in their study are (1) open, (2) suspected, (3) mutual pretense, and (4) closed. In open awareness both patient and caregiver are aware that the patient is dying and are open to talk about it. In closed awareness the caregiver is aware that the patient is dying, but this awareness is hidden from the patient. In suspected awareness the patient suspects, but the topic is not openly discussed. In mutual pretense, one or both parties in the patient-caregiver dyad pretend that they do not know the patient is dying. Many factors impact how awareness of dying is conceptualized by patients and caregivers. Cultural, spiritual, and religious beliefs, and family history, including perceived ability of patient or caregiver's ability to cope with the impending death, are some of the factors that add to the complexity of the issue.

The second task of Worden's model involves working through the pain of grief. For dying patients, this task may become a major source of distress as their care transitions from a curative to a palliative mode. For many patients with advanced illness, the moment they first hear about hospice care may mean getting in touch with the fact that their illness will not improve and they will probably die soon. This moment of awareness is not experienced by all patients, nor do patients who have awareness of their impending death experience the same level of emotional distress as a result of it. However, whatever resources can be mobilized by the palliative care team should be used to relieve suffering for the patient and the family.

The third task involves adjusting to a world without the loved one. For dying patients, this task may involve progressively withdrawing from a world that will be soon without them. It is possible that the progressive emotional withdrawal that many patients experience as they are entering the terminal stage may be caused not only by the physical decline, but also by a progressive grieving process that facilitates patients' symbolic disinvestments of emotional energies from the outside world.

The fourth task applied to bereaved individuals involves "emotionally relocating" the loved one and continuing on with life. For patients who are dying, this task may involve emotionally relocating loved ones, family members, and other sources of emotional attachment, in order to find some form of peace with their own death and dying process. For the palliative care team, the task is to understand and facilitate the dying patient's grieving process, as well as guiding and supporting the family.

TREATMENT APPROACHES FOR COMPLICATED GRIEF

Most of the interventions developed for the treatment of complicated grief have been tested on bereaved individuals, after the loss of a loved one. However, as mentioned before, in the palliative care and hospice setting it is not uncommon to find that patients with advanced or terminal illness are already suffering from complicated grief. Bereavement assessment performed by the palliative care team should include patients and their caregivers. It should explore history of loss and especially focus on deaths that occurred in the family in the year prior to the first contact with the palliative care team. The initial psychological, spiritual, and bereavement-related assessment should attempt to differentiate the various dimensions of grief experienced by patients and caregivers. It should not be assumed that patients exclusively experience preparatory grief related to the progression of illness and their approaching death. Patients who have lost a loved one prior to their admission to the palliative care or hospice unit may experience symptoms of complicated grief that may become superimposed on preparatory grief related to their dying process. Therefore, part of the psychosocial interventions provided to patients should include complicated grief as possible diagnoses.

Clinicians working in the palliative care and hospice setting need to become familiar with the clinical manifestations of grief, including sociocultural norms related to individual grieving styles, and normative grief. A strong knowledge base will allow clinicians to identify patients and families who are at risk for complicated grief. Educating patients and families about the nature of grief and its manifestations in the context of palliative and end-of-life care should be approached early. Normalizing the distressing symptoms in the early phases of grief should not take the place of ongoing assessment to identify the presence of risk factors for developing prolonged grief or severe depressive symptoms that should be addressed pharmacologically.

The potential disruptive impact of complicated grief on bereaved individuals and society as a whole highlights the urgent need for evidence-based interventions that can hopefully be applied in community settings. In a study of 135 widowed individuals, more than 90% of participants with complicated grief stated that knowing their symptoms were part of a recognizable, diagnosable, and treatable psychiatric disorder would make them feel relieved. In the same sample, all participants with complicated grief reported interest in receiving treatment for their symptoms (Johnson et al., 2009). Shear, Frank, Houck, and Reynolds III (2005) conducted a randomized controlled trial of an intervention for the treatment of complicated grief comparing 16 sessions of interpersonal therapy, in lieu of a control, with 16 sessions of complicated grief treatment. Results showed that even though participants in both groups improved, participants who received the complicated grief treatment experienced faster improvement of greater magnitude. Complicated grief treatment involved a combination of modified in vivo and imaginal exposure focusing on processing traumatic symptoms related to the death, promoting a sense of connection with the deceased loved one, and on restoration from the grief.

Effectiveness of cognitive-behavioral therapy and nonspecific counseling approach were compared in a study of 54 bereaved individuals with significant levels of complicated grief (Boelen, de Keijser, & van den Hout, 2007). Treatment conditions were exposure therapy, cognitive restructuring, and a combination of exposure and cognitive restructuring. Pure exposure and the combination of exposure and cognitive restructuring were shown to be more effective than supportive counseling in reducing complicated grief symptoms, as well as general psychopathology.

Recently, treatment of complicated grief has been tested in randomized controlled studies combining Shear's therapy for complicated grief with pharmacotherapy (Simon, Shear, Fagiolini, et al., 2008). Results showed that adding an antidepressant improved compliance with treatment in the experimental group, but not in the control (interpersonal therapy) group. Interpretive, supportive group therapy and cognitive-behavioral group therapy have been studied with promising results (Piper, Ogrodniczuk, Joyce, Weideman, & Rosie, 2007; Sikkema et al., 2006). Escitalopram, bupriopion, and paroxetine have also been studied in the context of complicated grief and have been shown to reduce symptoms of depression, without worsening grief symptoms (Simon, Shear, Thomson, et al., 2007; Zisook, Shuchter, Pedrelli, Sable, & Deaciuc, 2001; Zygmont et al., 1998).

Family interventions should be the preferred choice when the family as a system is at risk, if there are children or adolescents at risk, or if one or more family members develop a substance use disorder as a way of managing emotional difficulties. Family Focused Grief Therapy, developed by Kissane and Block (Kissane & Block, 1994) is a six- to eight-session family therapy intervention aimed at reducing emotional distress and dysfunctional communication patterns among family members, while facilitating appropriate expression of emotions.

A three-week Internet-based, pretest, post-test manualized cognitive-behavioral intervention was delivered to 35 individuals bereaved in the previous 14 months (Wagner & Maercker, 2008). During the intervention, each participant communicated via e-mail with a facilitator and was encouraged to describe the circumstances of the death, explore the biography of the deceased, keep a daily diary of social activities and sleeping patterns, and engage in cognitive restructuring of maladaptive thoughts (especially related to feelings of guilt), family communication, coping skills, and bond with the deceased person. In addition to lowering depression and complicated grief symptoms, a different sample of this intervention showed an increase in posttraumatic growth in the treatment group of 26 participants (Wagner, Knaevelsrud, & Maercker, 2006). Results in the reduction in symptoms of complicated grief were maintained 1.5 years postinterventions.

In a case report from Italy, Nesci (2009) described integrating various media, such as pictures of the deceased, writing, and music, with psychodynamic psychotherapy in the treatment of a patient with complicated grief.

CONCLUSION

At times, the grieving process may symbolically become stuck and the griever may continue to experience severe symptoms of acute grief, with no relief or resolution. In these cases, grief is described as complicated and warrants focused and professional treatment that may include a combined use of psychotherapy interventions and psychotropic medication. According to the new nomenclature informed by recent research, grief that is complicated represents a separate disorder, Prolonged Grief Disorder, which will be included in the new edition of the DSM. Clinicians working with palliative care patients, hospice patients, and their caregivers, need to develop a thorough understanding of the risk factors associated with the development of complicated grief. The presence of risk factors does not necessarily mean the bereaved individual will develop prolonged grief disorder; however, risk factors do represent a psychological and social vulnerability that should be assessed and addressed in order to facilitate the normative grieving process. Grief and bereavement assessment should start at admission and include family members and other caregivers. The palliative care and hospice team should provide bereavement support to patients and caregivers during the various transitions of care, identifying and addressing potential risk factors through professional psychotherapeutic interventions. Clinicians working with patients and bereaved caregivers should also be familiar with their own personal grieving styles and individual risk factors. This personal awareness will ideally inform clinicians' professional perspectives, allowing them to understand and accompany bereaved individuals during their difficult journeys through the "dark woods" of loss and death.

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CHAPTER

11

Health-Care Teams

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Mental health providers working with individuals with life-limiting or terminal illness and their families will want to be familiar with the medical system in which the patients and families find themselves. Mental health providers may be part of health-care teams or consultants to these teams and expected to communicate and coordinate care with other providers. However, most mental health professionals do not receive systematic training in interdisciplinary team processes or functions, or interdisciplinary education and, thus, do not have a good understanding and appreciation for the roles, responsibilities, and models of training of other professionals. This lack of training can constrain providers' abilities to provide effective integrated care. This chapter reviews different types of health-care teams, which may be caring for individuals with life-limiting or terminal illnesses, challenges of teamwork, and specific practice issues when working with these patients in the context of their health-care teams. The chapter focuses on ways to promote effective communication. Much of what is covered here also applies to practitioners functioning in other medical settings, such as primary care, nursing homes, home health agencies, or hospice.

BACKGROUND

A majority of individuals with terminal illnesses are diagnosed and treated in hospitals (Llamas, Pickhaver, & Piller, 2001), whether through primary care or specialty clinics, acute care or subacute medicine wards. The hospital also is the most common setting in which people spend a significant proportion of their final days or die (Higginson et al., 2002). Hospitalized dying patients often have limited family or social support, more severe physical symptoms and a shorter terminal period in comparison to terminally ill patients being cared for at home (Higginson et al., 2003). The degree to which the needs of hospitalized palliative care and terminal patients are met varies significantly with location of hospital (urban versus rural), teaching affiliation (White, Cochran, & Patel, 2002), and available palliative care resources—for example, a single provider with little specialized training in palliative care versus a dedicated palliative care unit with multidisciplinary staff who have specialty training in hospice and palliative care (K. J. Llamas, Llamas, Pickhaver, & Piller, 2001). Typically, the needs of individuals with advanced and terminal illnesses are extensive and exhaust the expertise and training of any one discipline and require an interdisciplinary team of professionals (Hall, 2005). The degree to which palliative care is interdisciplinary or integrated care may depend on the setting in which the individual is receiving care (e.g., hospital, nursing home, outpatient clinic), the type of team and professionals providing care, and the dynamics of the team.

WHAT IS A TEAM?

A team is a group of people possessing a particular expertise, who meet together to collaborate and coordinate information and activities to achieve a common goal. The goals for health care teams often are twofold: to direct patient care and to do "team work"—in other words, attending to the process of working together in addition to the quality and effectiveness of patient outcomes. Members identify a shared mission, develop group norms (i.e., regarding the type of information shared), generate a structure for team decision making, and create guidelines/expectations regarding the roles of respective team members (e.g., identify types of decisions such as who will discuss advanced directives, conduct bereavement calls, run family meetings, or address psycho-spiritual distress). A team works best through promoting an atmosphere of trust and mutual respect among the members.

TYPES OF TEAMS

Five types of teams have been identified (Heinemann & Zeiss, 2002; Takamura, 1985; Takamura, Bermost, & Stringfellow, 1979). *Unidisciplinary teams* are comprised of members from a single discipline who share the same skills and training and function in the same role within the group. An example of a unidisciplinary team is visiting nurses providing infusion therapy in the home to individuals with advanced cancer. A unidisciplinary approach to care also is represented by psychologists in private/group practices with other psychologists. *Intradisciplinary teams* are composed of members from a single discipline who have different levels of training and skill. Roles and responsibilities are assigned by training level. An example would be an ICU team with attending physicians, medicine fellows, residents, and medical students.

Both uni- and intradisciplinary health-care teams may have limited experience working with mental health professionals and often patients served by these teams experience distress and other psychiatric problems that are underrecognized and undertreated (Holland & Chertkov, 2001). Mental health providers likely will need to educate medical providers about their roles and the ways in which they can assist medical staff (Zeiss & Gallagher-Thompson, 2003).

In *multidisciplinary teams*, members of different disciplines work together but function independently, with minimal coordination or consultation with each other regarding care. Multidisciplinary teams are hierarchically organized and led by the highest ranking member, usually a physician. Leadership and decision making are not shared (Lickiss, Turner, & Pollock, 2004; Zeiss & Steffen, 1996; 1998; Zeiss & Gallagher-Thompson, 2003). Individual disciplines own their treatment plan, though often integrate input from others. Decision making is vertical—so even if collaborative, one person has the final say. The major advantage of multidisciplinary teams is faster decision making, as only one person needs to be convinced when presenting an opinion (versus all members of the team), and, therefore, discussions may be less stressful. The primary disadvantages of these teams are that team members may feel ineffectual or undervalued. Mental health professionals may perceive that psychosocial-spiritual information is considered extraneous (DeFord, 2003). In an attempt to illustrate how this information can be relevant to other team members, mental health professionals may want to ask themselves, "What are the practical implications for the medical providers of the psychosocial-spiritual issues being identified and addressed?" "What information is most relevant to treatment planning and how do I communicate this information, clearly and concisely, in a language that is nonjargon and easy to understand?" A hospital consult-liaison team is an example of a multidisciplinary team.

Interdisciplinary or interprofessional teams are composed of providers from different disciplines that collaboratively and interdependently plan, implement, and evaluate outcomes of health care. Division of tasks among team members is based more on patient problems and needs than on traditional role definitions (Zeiss & Gallagher-Thompson, 2003). Decision making and leadership are shared and flexible (Zeiss & Steffen, 1996; 1998). Team members have consensus and clarity regarding goals and strategies, recognize their shared responsibility for patients, and the unique competencies, contributions, and roles of each discipline, as well as the areas of overlapping function (Lickiss et al., 2004; Zeiss & Steffen, 1998). The team spends time attending to the process of working together and developing effective working strategies, in addition to monitoring the quality and effectiveness of patient outcomes. These functions are easiest when team members are part of an integrated, comprehensive service (e.g., Palliative Care service) versus an ad hoc team in which members barely know one another. Hospice teams are examples of interprofessional teams. Degree of collaboration and style of decision making are the major differences between multidisciplinary and interdisciplinary teams (Zeiss & Gallagher-Thompson, 2003).

Interdisciplinary teams have been shown to be cost-effective for a range of chronic medical and mental health conditions (Zeiss & Okarma, 1985) and to result in shorter length of stays, lower staff turnover, and better patient outcomes in diverse settings, particularly with older adults (Yeager, 2005). In addition to these advantages, well-functioning interdisciplinary teams result in reduced duplication of services, decreased likelihood that problems will fall through the cracks, more creative interventions, increased staff morale, and lower turnover (Hendriksen, Lund, & Stromgard, 1984; Lichtenberg, Strzepek, & Zeiss, 1990). See Lichtenberg (1994) and West and Poulton (1997) for reviews of research on effectiveness of interdisciplinary teams.

Though interdisciplinary teams are preferred in working with medically ill individuals with complex, multiple problems (e.g., hospice and palliative patients), they are not necessary in settings in which patients have straightforward, routine problems (e.g., undergoing a specific procedure). In addition, interdisciplinary teams are not organized to provide a rapid response to crisis situations. Should a rapid response be required, the team must be able to allocate authority for making emergency decisions to a particular team member with the understanding that the issues will be raised at the next team meeting. Although shared decision making is the ideal on interdisciplinary teams, it may be difficult to maintain equal contributions and responsibilities across all disciplines. Alternatively, when no clear answer to complex problems exists, responsibility may be diffuse across all team members.

Finally, *transdisciplinary teams* are comprised of professionals from different disciplines who teach, learn, and work together across traditional disciplinary or professional boundaries. Each member is familiar with the concepts and approaches of colleagues from different disciplines, as well as their own. Roles and responsibilities are shared, disciplinary lines are blurred, and there are few seams between the members' functions, which often results in the phenomenon known as "role release" (Larson, 1993). These types of teams are less common, particularly when patients need the special skills of specific disciplines. Transdisciplinary teams may require more negotiation to decide which team member will complete which task because the usual fallback option of "This is the social worker role (or psychologist or nurse role)," is not invoked. In addition, teams may be transdisciplinary with respect to some tasks (e.g., case management, bereavement contacts, or quality improvement projects) but interdisciplinary or even multidisciplinary with respect to other tasks (e.g., administrative responsibilities).

In summary, we have identified types of teams that mental health professionals may encounter in medical settings when working with individuals with life-limiting or terminal illnesses. Although these teams may be found in the ICU, outpatient specialty clinics, or acute medicine wards, one of the most common teams following individuals with advanced and terminal illness is a Palliative Care Consult team. A Palliative Care Consult team ideally is interdisciplinary and composed of professionals with advanced competencies in hospice and palliative care, as promulgated in the *Clinical Practice Guidelines for Quality Palliative Care, Second Edition* (National Consensus Project for Quality Palliative Care, 2009). Comprehensive interdisciplinary assessment and treatment of the patient and family is emphasized throughout the guidelines (see www.nationalconsensusproject.org for the complete guidelines), and has been adopted as a preferred practice for palliative and hospice care by the National Quality Forum (2006).

PALLIATIVE CARE CONSULT TEAMS

Palliative care consult teams offer consultation throughout a facility, assisting the primary care team with planning and guidance on pain and symptom management and other care issues, such as goals of care discussions, advance care planning, or escalation of care. Palliative care consult teams also offer emotional and spiritual support, and facilitate communication among and between medically ill individuals, family members, and care providers. Typically, a palliative care team includes a physician and nurse/nurse practitioner and possibly a social worker and chaplain (Billings & Pantilat, 2001). The palliative care team also may include a coordinator whose responsibilities may entail managing referrals, coordinating team meetings, facilitating communication with community hospice agencies, serving as a resource for staff, and ensuring that all members of the team demonstrate their competency in palliative care by current certification, or attendance at continuing education programs. Some hospitals have a separate palliative care unit where care for individuals with advanced and terminal illness and their families is available, with dedicated full-time equivalent (FTE) staff and resources (Hallenbeck, 2003). Palliative care teams—in comparison to conventional care—have been associated with small but positive effects, particularly with pain control and symptom management (Hanson, Usher, Spragens, & Bernard, 2008; Higginson et al., 2003), patient satisfaction, and reduced cost savings (Back, Li, & Sales, 2005; Hearn & Higginson, 1998; Morrison et al., 2008).

Palliative care consultation often requires a blend of two different models of consultation: (1) giving advice to the primary physician or ward team or (2) taking over some aspect of care, which can be challenging to navigate (Hallenbeck, 2003). Consulting team member(s) can face additional challenges. Many referring clinicians are unfamiliar with what palliative care teams offer and do not know when it is appropriate to request a palliative care consult. Furthermore, clinicians, patients, and families themselves may resist consults because of the belief that the consult symbolizes evidence of the patient's deteriorating clinical course, the consult restricts or negates the current plan of care, or in the case of the referring clinicians, the consult infringes on an area of expertise (e.g., pain management service) or is unnecessary because the issues can be managed internally, even though the providers likely have received little training in palliative care (Feeg & Elebiary, 2005; Hallenbeck, 2003; Rodriguez, Barnato, & Arnold, 2007).

Consultants also can experience conflict in their roles. Particular situations likely to evoke conflict include when the referring provider requests help with symptom management but asks the consultant to avoid other topics and the medically ill person or family specifically bring up those topics or ask for help with questions not covered in the scope of the consultation request;

when emergent symptom management arises during the consultation; when communication problems between the patient/family and referring provider are a focus of the ill person's concerns; and when the consultant has concerns about the referring provider's management of the case (Meier & Beresford, 2007). In addition, palliative care consults often are emotionally charged but not explicitly stated. For example, the consult may state, "Assist with goals of care discussion" when what really is being asked is:

> Please fix. The patient seems to understand that he is no longer responding to curative measures but the daughter, who is his durable power, is unable to see the forest through the trees. She evades conversations regarding transitioning to comfort care and is adamant that she is not "giving up" on her dad and does not want him to lose "hope." We do not know what else to do with her.

Hallenbeck (2003) outlines some useful general principles to consider when performing palliative care consults. First, consultants will want to identify key stakeholders such as the ward team, oncologist, family or medically ill person. Second, consultants should identify overt (e.g., discuss goals of care) and covert issues in the consult (e.g., patient and family in conflict over whether to pursue additional chemotherapy. The patient is leaning toward discontinuing treatment but the family does not want him to "give up" and is angry that he does not want to fight harder for them). Covert issues can to be elucidated through chart review and conversations with key stakeholders, focusing on their respective understanding of the situation and points of convergence and divergence. Third, consultants may need to clarify their role as consultant (e.g., facilitate goals-of-care discussion, conduct pro/con analysis, assess factors affecting decision-making process), highlighting the intention to help and neutrality with respect to particular outcomes (e.g., whether to discontinue treatment), while being clear about one's opinion and recommendation (e.g., patient seems to have decision-making capacity with respect to this decision). Fourth, consultants should identify options (e.g., continue chemotherapy but only if it continues to demonstrate benefit and symptom burden does not escalate; discontinue chemotherapy but revisit after a few weeks if patient improves; elect hospice with palliative chemotherapy; or elect hospice with no further palliative chemotherapy). Fifth, consultants are encouraged to give opinions, being clear about what is being recommended and on what basis (considering stakeholders' stories).

Sixth, consultants will want to offer a few key recommendations, some of which they can help implement, rather than a list of suggestions, and reinforce what the referring providers are doing well. This approach avoids increasing workload or implying that the referring team does not know what they are doing. Finally, consultants need to document the consult and thank the referring team member for the consultation.

CHALLENGES OF TEAMS

There are several inherent benefits and challenges in working on interprofessional health-care teams. One significant challenge is conflict, which must be navigated in order for the team to function effectively. Conflict on a team can result from a variety of factors such as ineffectual leadership, personality clashes, scarcity of resources, poorly managed organizational changes, large caseloads, deficiencies in communication, gatekeeping, clash of ideas, principles and values, poorly defined roles or role expectations (Lickiss et al., 2004; Oliver & Peck, 2006), disputes over roles and responsibilities (Yeager, 2005), or unmet or inconsistent expectations (e.g., team members do not know what others expect of them or are not clear of their own expectations of others) (Larson, 1993). A useful framework for conceptualizing types of conflict and ways to respond organizes sources of conflict into three primary domains: interdependence of role, complexity of ongoing assessment versus comprehensive care and, disagreement resulting in destructive conflict versus integration of multiple perspectives (Heineman & Zeiss, 2002).

Interdependence of Roles

While team members from different disciplines contribute unique knowledge and skills, they also have overlapping skills that blur roles. In well-functioning teams, skill overlap can be a source of confidence and basis for collaboration. However, turf battles can erupt in which members fight over who "should" be doing various activities (e.g., social work or psychology engaged in family therapy; chaplaincy and psychology providing bereavement support). The team's task is to develop team-specific agreements and norms on how such activities will be distributed and shared, which requires knowledge of, and respect for, unique and shared abilities (interdependence). Team members can facilitate this process by the following steps: (a) delineate all clinical services that medically ill persons can receive from the team, (b) elucidate sources of conflict because of overlap, and (c) clarify for each discipline what the respective professionals offer uniquely to the team and what the team will expect them to provide (Heineman & Zeiss, 2002). Knowledge of individual disciplines skill sets as well as training models and professional culture is imperative for effective navigation of interdependent roles.

Complexity of Ongoing Assessment Versus Comprehensive Care

By definition, interdisciplinary teams are established to deal with the interrelationships among medically ill persons' biological, functional, social, psychological, and spiritual problems. On well-functioning teams, discussion of these complex interrelationships leads to a breadth and deepening of understanding that allows for effective, comprehensive care. However, on less well-functioning teams, this process can lead to information overload and frustration when cases are discussed seemingly without clear purpose, with no improvements in case conceptualization or clearly developed, coordinated treatment plan. The team's task is to develop strategies for integrating information and capturing the team's complex understanding of medically ill individuals in a way that facilitates treatment planning and implementation (Heineman & Zeiss, 2002). The team should have a structured format for guiding and documenting the treatment planning process, which specifies problems to be treated, goals of treatment, treatment strategies, team members to be involved, time frames, and ongoing reassessments (Heineman & Zeiss, 2002).

Disagreement Resulting in Destructive Conflict Versus Integration of Multiple Perspectives

Interdisciplinary teams rely on different perspectives and knowledge that can create conflict, when perspectives are contradictory rather than complementary. Teams that are not functioning well are likely to treat these differences as issues in which one member is right and the other is wrong, which compromises cohesion and patient care (Heineman & Zeiss, 2002). This reaction often occurs in situations in which there are deep philosophical differences about how to proceed (e.g., truth telling about prognosis, decisions to stop eating or drinking), or discrepancies in information shared by the team (Larson, 1993). In well-functioning teams, conflict is viewed as an opportunity to learn something more about the medically ill person (e.g., the patient seems more comfortable sharing emotional reactions with the massage therapist—why might that be?) and/or the team members themselves (e.g., the chaplain's and psychologist's different personality and interview styles elicit different information; the social worker and psychiatrist evidence different thresholds for perceiving and responding to danger to self/others, or different stimulus value to the ill person). Well-functioning teams are able to consider and integrate multiple perspectives. This process is facilitated when team members have good conflict resolution skills, which can be a particular challenge for hospice teams given that they often avoid conflict based on the belief that nice people agree and hospice providers tend to see themselves as nice (Larson, 1993).

One approach to conflict resolution that we adopt focuses on identifying shared interests and avoiding positional bargaining (Fisher, Ury, & Patton, 1991). Strategies that can minimize positional bargaining include distinguishing observations from interpretation, options from solutions, and balancing technical language with a shared language. We also suggest using the following strategies that not only facilitate conflict resolution but help build good working relationships with other disciplines. Give timely, frequent, concrete, non-judgmental feedback about how others' behaviors affect you while being open to the same feedback from others. Ask "What can I do differently that would make things better for other members of the team?" (Larson, 1993). Build in meetings focused both on patient care and on team process. Conduct visits with fellow team members and maintain regular, informal, brief communication. Nurture relationships with empathy, praise, and celebration of personal events, professional accomplishments, and one other. Be aware of issues affecting individual team members, including stressors in their personal lives and provide appropriate support.

In the first half of the chapter, we provided an overview of the different types of health-care teams that may be treating individuals with life-limiting or terminal illnesses as well as some challenges of teamwork. In this next section, we discuss specific practice issues when working with these individuals in the context of their health-care teams, focusing on effective communication.

GENERAL CONSIDERATIONS WHEN WORKING WITH TEAMS

Mental health providers who work with individuals with life-limiting and terminal illnesses need to be flexible in how, where, and under what conditions they see patients (e.g., accommodating delays in meeting time or multiple interruptions from medical staff due to unanticipated medical needs; conducting home visits). At times, even when there is no emergent medical issue, medical providers may act as though mental health providers are not visible, and will interrupt sessions. These interruptions can serve as an opportunity to educate staff about your role and the nature of your work with the patient, asking politely not to be interrupted except when medically necessary. Some interruptions are necessary, but others are not and can be postponed. Ideally, you would attempt to coordinate visits so that they do not occur around the time when patients typically receive personal care, medications, or are seen during physician rounds or for specialty clinic appointments.

As a mental health professional working with individuals with life-limiting or terminal illness, you also may find yourself engaged in activities outside your traditional purview, such as intensive case management, answering call lights, or wheeling the person to an appointment in another area of the hospital. Although outside the boundaries of traditional disciplinary roles, these activities can build respect with the treatment team and allow you to be seen as a team player. These activities also can facilitate rapport with medically ill persons and their families and promote their willingness to engage in psychotherapy. Finally, working with this population can be emotionally intense and stressful, which necessitates greater attention to self-care. Without proper self-care, the demands of the job may take a toll.

Self Care and "Team Care"

Various terms have been given to the symptoms of stress in providers caring for individuals in emotionally charged, intense, and ongoing caregiving situations (e.g., individuals who are terminally ill or have severe psychiatric illness), including burnout (Maslach, 1993), secondary traumatic stress (Figley, 1995) or compassion fatigue (Figley, 2002), and vicarious traumatization (McCann & Pearlman, 1990). Burnout is a form of chronic job stress characterized by emotional exhaustion, depersonalization of patients, and low professional efficacy. Vicarious traumatization refers to harmful changes that occur in professionals' views of themselves, others, and the world as a result of exposure to traumatic material. Secondary traumatic stress or compassion fatigue refers to a syndrome similar to Posttraumatic Stress Disorder (PTSD), which occurs as a result of helping individuals who have experienced traumatic experiences. Compassion fatigue often is discussed in the context of professional caregivers, who can become surrogate family to medically ill persons, but informal caregivers, such as family members, also are at risk.

Empirical research suggests that stress and burnout actually may be less of a risk in palliative care than other areas in health care (Graham et al., 1996; Sherman, 2004; van Staa, Visser, & van der Zouwe, 2000). Burnout often is associated with more general job-related variables such as staffing shortages, communication problems, lack of supportive leadership, lack of institutional visibility and support (e.g., opportunities for professional development), disruptive patient and/or family behaviors, and poorly defined roles among team members (Le Blanc, Hox, Schaufeli, Taris, & Peeters, 2007; van Staa et al., 2000). However, certain characteristics of individuals with life-limiting or terminal illnesses can increase stress among people caring for them. These characteristics include being younger, in intractable pain, having difficulty accepting their illness or being afraid to die, and experiencing psychiatric problems (Alexander, 1990). Characteristics of the caregiver or caregiving situation also contribute to stress and burnout. Such factors include lack of awareness of stressors or an unwillingness to process reactions to stressors and just push on to the next task; overinvolvement with, or taking too much responsibility for, medically ill persons and/or their families; unrealistic expectations and perfectionism (e.g., striving to achieve the perfect death); poor communication skills; history of psychological illness; fear of death or dying; inability to tolerate high levels of ambiguity and uncertainty; and disagreement over goals of care or other aspects of care (Alexander, 1990; Meier, Back, & Morrison, 2001).

Mental health professionals can assist their colleagues in managing these issues. For example, mental health professionals can offer in-services, present at grand rounds or organize continuing education workshops on topics such as stress management, limit setting and assertive communication, emotional responses to one's work, and psychoeducation regarding compassion fatigue and burnout and ways to mitigate them. Informal rituals and opportunities to process emotional reactions to the work also can be useful. For example, the beginning of every interdisciplinary care planning meeting at our inpatient Hospice and Palliative Care unit (author JKG) is opened with a "reflection" in which the chaplain invites other team members to share, or offers herself, a blessing, poem, story, relaxation exercise, and even the occasional Mad Libs time is set aside at the daily team meeting to review deaths that occurred during the previous 24 hours. The chaplain also organizes "times of remembering" for staff to share stories and experiences about persons who have died. In addition, the psychologist periodically facilitates a drop-in support meeting for each nursing shift, in which nursing staff are invited to discuss concerns and feelings particularly as they relate to job demands, conflict, and challenging patients and families. The psychologist provides a safe place to seek support and express concerns but also problem solves with staff on ways to raise issues with nursing management and feel empowered to facilitate change where they can. The psychologist then serves as a liaison with nursing management to brainstorm potential solutions. In addition, all of the mental health professionals on the team (chaplaincy, social work, psychology) informally check in with individual staff members in the hallway, in the break room, or in the context of providing feedback regarding a referral issue. The team also arranges periodic social events both within and outside of work (e.g., birthday parties, baby showers, potlucks, graduation dinners for palliative care fellows) as a way to relax and build community, under the premise that people can work better together as professionals when they know one another as people.

Several other practices can be critical to promoting mental health and reducing risk for compassion fatigue and burnout. Mental health professionals can encourage team members to examine their own beliefs, feelings, and attitudes toward death, the meaning of life and spirituality as well as their own experiences with grief, family conflict, and unresolved issues. They can help staff acknowledge both the challenges and the gifts of hospice and palliative care work (e.g., Vachon, 2000) as well as explore ways to leave the work behind, maintaining appropriate distance and engaging in self-care. Mechanisms for doing so include transitional activities (e.g., reflecting on the day during the commute home then once home, leaving the work day behind, symbolized by changing out of one's work clothes); building, nurturing, and mobilizing social support (Figley, 2002); cultivating healthy lifestyle practices (exercise, nutrition, sleep, pleasant activities, meditation, prayer, or relaxation practices); and maintaining a sense of humor. Finally, mental health professionals can encourage professional development. See Jones (2005), Keidel (2002), Meier et al. (2001), and Patrick (1987) for examples of how to conduct a self-assessment regarding risk factors for burnout and develop a self-care plan to mitigate against this risk. See Chapter 16, "Professional Self-Care," for more information about cultivating self-care practices.

COMMUNICATION

Good communication is the cornerstone of an effective team. Often when teams start to notice problems, it is from a breakdown in communication. Some examples include perceived failure to communicate necessary facts or ideas; problems conveying what one intended to convey; differences in preferred style of communication; lack of shared language or use of jargon; and storytelling without a clear means of processing emotions or reactions. Among health-care providers, ineffective communication can lead to increased stress, low job satisfaction, and emotional burnout (Fallowfield, 1995; Ramirez et al., 1995).

Effective communication among medically ill persons, families, and health-care providers also is a cornerstone of good palliative care (von Gunten, Ferris, & Emanuel, 2000). When effective, communication influences adherence to treatment regimens, rate of recovery, effective pain control, and psychological functioning (Fallowfield, Hall, McGuire, & Baum, 1990; Razavi et al., 2000; Stewart, 1996; Stewart, Brown, & Weston, 1989). Ineffective communication is associated with poorer patient adherence with recommended treatment regimes (Turnberg, 1997) and can result in medically ill individuals feeling more anxious, uncertain, and generally dissatisfied with their care as well as experiencing poorer psychological adjustment (Mager & Andrykowski, 2002; Schofield et al., 2003).

Communication in palliative care often centers on advance care planning. 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; Tierney et al., 2001). However, advance care conversations are among the most difficult in which to engage (e.g., Tulsky, Chesney, & Lo, 1995). Many physicians find it challenging to communicate directly and initiate goals of care conversations, especially when the situation involves a diagnosis of a potentially life-threatening or life-limiting illness. Some providers feel inadequately prepared or inexperienced in giving bad news. Others fear the news will be so distressing as to affect adversely the medically ill person, family, therapeutic relationship, or the course of the business day. They may fear the appearance of giving up on the ill individual, or of the person losing hope.

The vast majority of individuals want to know if they have a life-threatening illness, however. Communicating in a direct and compassionate manner typically fosters collaboration among the patient, family, physicians, and other professionals, strengthens the physician-patient relationship, improves the patient's and family's ability to plan and cope, and supports the patient and family emotionally. Comprehensive recommendations have been developed recently to assist physicians in delivering bad news appropriately (Barclay, Blackhall, & Tulsky, 2007; Clayton, Hancock, Butow, Tattersall, & Currow, 2007; Ngo-Metzger, August, Srinivasan, Liao, & Meyskens, 2008; Tulsky, 2005). Though beyond the scope of this chapter, these guidelines are an excellent resource for providers engaged in difficult conversations with medically ill individuals and their family members.

Although direct communication and advanced care planning may be preferred by many medically ill persons and their families, cultural variations exist. Some family members are reluctant to engage in advance care conversations about the patient's wishes given cultural norms of indirect communication and avoidance of topics that are perceived as negative. In some cases, family members may not want to initiate goals of care conversations but will discuss end-of-life issues once the physician initiates the conversation (Kwak & Salmon, 2007). Among other families, the discussion of future, untoward events is believed to lead to their occurrence and care conversations are considered appropriate only at the time of the event (Kitzes & Berger, 2004). Families may differ greatly on their preferences for how information is shared and with whom. For example, some families, particularly African Americans, may prefer family-based, oral communication rather than written documents (Welch, Teno, & Mor, 2005).

NAVIGATING MEDICAL SYSTEMS AND IMPROVING COMMUNICATION WITH PROVIDERS

Individuals living with advanced and terminal illness may feel overwhelmed at different times throughout the course of their illness. Many have had little experience with the medical system. For those individuals who have experience, the anxiety associated with diagnosis of a life-changing, and potentially life-threatening illness can affect the ways they usually process information. Patients are given a great deal of information, often in a language they do not understand, and are expected to make decisions quickly under stressful conditions. They may have difficulty digesting and making sense of their interactions and communication with health-care providers, which can be varied, and, at times, discrepant.

Mental health professionals can encourage medically ill individuals to become educated and actively participate in making decisions about their care and treatment. Some will feel intimidated, and may never have taken an active role with medical professionals. Learning to work in partnership with their medical team is a process that involves acquiring new skills. Since mental health professionals are well-versed in assisting individuals with skill acquisition, they can play an important role in helping those patients. Asking questions is a helpful way to start.

Ask patients what they understand about their illness at this point. It is not unusual for individuals to say they do not know or have not been informed about any of the details of their diagnosis. However, often medically ill persons have been told and may be using "healthy denial," they were unable to process all the information, or they may not want to know. It is helpful to be in contact with patients' physicians to know what patients were told about their disease. In addition, keep in mind that there are individual differences in need for information (Miller, 1987). Some individuals cope best by gathering as much information as possible about their illness ("monitors"). They tend to become anxious when their questions are unanswered or when they feel excluded from an active role on their treatment team. Others become overwhelmed when given more information than they wish to know ("blunters"). Most often it is the mental health professional on the team who is aware of these critical differences in ways of coping. Appreciating and attending to these differences is beneficial for patients, families, and members of the medical team. In fact, incorporating other team members into the discussion has been shown to facilitate physician-patient communication, particularly about end-of-life care (Carline et al., 2003). Of note is that differences in preferences for information can change across the disease continuum. Individuals who have wanted a lot of information and involvement in decision making at the time of diagnosis may want/need to know fewer details at the time of transition to a primarily palliative approach. It is helpful to inform physician colleagues about patients' changing needs or desires for information so that they can revisit these preferences with them.

Understanding one's illness also may include the ways in which patients and families make sense of the efficacy of treatment and disease recurrence. When medically ill individuals have a period of remission followed by relapse, or have outlived a prognosis, they and/or their family members may have a range of reactions. For example, they may view the period of remission as a "gift" in that they were living on "borrowed time"; or, they may find it difficult to believe that they will not "beat" the disease again this time. They may experience guilt that they did something wrong or failed to do something that could have prevented the disease (e.g., "if only I had been more positive or done my mindfulness meditation, the cancer would not have returned"). Flushing out these beliefs can assist the team in sensitive goals-of-care discussions and facilitate end-of-life tasks.

Overall, it is important to advise and review with medically ill individuals how to get what they need from visits with their physicians. Here are some suggestions to consider during these discussions:

Help prepare a list of questions and concerns patients want to discuss, and suggest they take these questions to their appointment. No matter how well-prepared, it is difficult to remember what to ask during the appointment. Since communication is a two-way process, mental health professionals can help individuals be prepared and organized for physician visits. Mental health providers can remind patients and families to write down the answers they get. Allowing opportunities to think through their concerns may help patients realize what is most important to them. Such discussions may help increase their confidence and sense of mastery in a situation that could otherwise be intimidating.

Be attentive to patients' underlying fears while helping to identify and formulate questions. Sometimes individuals are not well-informed about their disease because of fears or concerns of which they may not be aware. Mental health professionals can listen for and explore these unspoken concerns. For example, one person may believe that if she asks questions, the physician will tell her that things are even worse than she thought. Gently probing with questions such as "What would that mean for you," and/or "What might that be like for you" may help her to articulate what she is trying to avoid that may be causing her distress. Individuals also may have a difficult time communicating with health-care providers because of a poor sense of mastery or a poor self-concept from problems that occurred prior to the diagnosis of life-limiting disease. They are especially vulnerable to feelings of discouragement, helplessness, and distress. It is important to support the possibility for change and growth, even in the context of palliative/end-of-life care. Hearing that their needs are as important as others, that they have a right to their physician's time and attention, can have a transformative effect. Mental health professionals can help medically ill individuals find the language to express their needs. Providing attentive, positive regard and encouragement, modeling, and opportunities for rehearsal are some interventions that can foster feelings of being valued and taken seriously.

Help patients set priorities for time with the physician. Appointment time is limited to 15, 20, or 30 minutes at the most. The physician needs time to examine patients and review their goals for the appointment. There will not be time to review a long list, so mental health providers can help medically ill individuals prioritize their concerns so they can discuss two or three questions that are most important to them. They have a powerful ally in the physician's nurse partner, so mental health providers might suggest that patients seek the nurse out to review questions. There may be additional members of a team such as a psychologist, social worker, or spiritual care counselor, with whom questions and concerns also may be discussed.

Suggest patients bring a family member or friend along to the appointment. An extra set of eyes and ears may hear different details during the discussion. The additional support and opportunity to review the content of the appointment at a later time are invaluable. Some individuals may prefer to bring a tape recorder along to their appointment. They can replay the tape for themselves or family member at a time of their choosing, sometimes hearing things they may have missed during the appointment.

Suggest patients repeat what the physician says. A summary statement in which medically ill persons repeats back what they have heard will clarify what information "got in," what needs repeating, and what may have been misunderstood. This process is helpful for both the ill person and the physician and may help their communication skills over time.

Assist patients in preparing for upcoming procedures or tests. Individuals nearing the end of life are less likely to go through invasive procedures. However, they may be apprehensive about a scan not previously experienced, or chemotherapy or radiation therapy for palliation of symptoms. If they previously have experienced difficulties during a procedure, each time it is repeated, they are likely to experience increased apprehension or anxiety in anticipation of the procedure. Mental health providers can help prepare individuals by asking what they know, and reviewing the steps or stages of procedures. Mental health providers can suggest that patients go see an MRI machine prior to a scan, or talk with other patients who have experienced the same treatments.

Help patients identify where they may have choices. Medically ill individuals often feel powerless in the medical system. It is important to help them learn when and how they can make choices. For example, they can request that an injection be given in a different arm. Or they may choose to wait until after an important family event for a procedure or test. They can ask to bring music or a relaxation tape, perhaps one made together with their mental health provider, into a procedure to help decrease anxiety.

Consider accompanying them on the visit, with the explicit purpose to clarify understanding and allow time to validate, normalize, and process emotion. Expressions of strong emotion make many providers uncomfortable. Mental health providers often are better trained to sit with strong emotions than their physician colleagues. Nonetheless, as with other providers, mental health professionals may have strong reactions and tendencies such as to want to flee, fix, or fill the space. Supporting medically ill persons and their family members requires tolerating and managing one's own emotions in order to be fully present for them. The most frequent error is to talk—this reaction is counterproductive. A key skill is listening more and talking less (Lynn & Harrold, 1999). A shared understanding of the news and its meaning enhances the patient-provider relationship and facilitates future decision making and planning. Unhelpful actions noted among providers include changing the subject, focusing just on physical symptoms, ignoring concerns, being defensive, rationalizing, placating, using multiple "why" questions, and providing premature reassurance or advice (Moore, Wilkinson, & Mercado, 2003).

Physicians often fear that if they acknowledge emotions, the encounter will take too much time. However, there is some evidence that when emotional cues are missed, clinical interactions last longer (Levinson, Gorawara-Bhat, & Lamb, 2000). These cues may be subtle as individuals may not always report their emotions or concerns, yet those individuals may be the ones who need most to discuss these issues. The better able physicians are in detecting concerns and providing a space to be heard, the less distress and suffering patients report (Schroepfer, 2007). Being able to process, express, and manage emotions or concerns is associated with decreased anxiety, less depression later in illness, and improved satisfaction (Butow et al., 1996; Fallowfield et al., 1990; Mager & Andrykowski, 2002; Morita et al., 2004; Schofield et al., 2003).

Once their emotions are identified, acknowledged, and expressed, most individuals will be able to continue difficult conversations. However, mental health providers will want to revisit patients' and family members' understanding as they may not have fully processed or integrated the information.

It also is important to be aware of cohort or cultural norms that lead individuals to not ask questions because it would be considered inappropriate or seen as challenging the physician's authority or status. Be mindful of the influence, power, and authority inherent in one's role.

CLOSING SUGGESTIONS FOR COMMUNITY MENTAL HEALTH PROVIDERS

The inpatient medical environment is likely unfamiliar to many mental health providers in the community. The norms of inpatient medical units are different from those of private practice, and psychiatric inpatient services. In this section, we offer some suggestions for community mental health providers on how to navigate the medical system in order to continue to provide mental health services to patients when necessary.

Community mental health providers need to be able to clearly articulate what they can offer to an inpatient treatment team that is currently caring for an individual who the mental health provider previously served on an outpatient basis. Mental health providers can assist medical providers and other members of the treatment team in identifying and understanding factors that influence reactions to life-threatening, life-limiting, or terminal diagnoses.

For example, you are the outpatient psychologist for Ms. O., a 45-year-old whom you have seen in therapy for several years. Ms. O. calls you to come see her in the hospital where she was admitted for intractable bone pain from progression of her breast cancer. She has an active coping style and seeks as much information as possible as a way of managing fear and anxiety. In the past, she has utilized nonpharmacological techniques to help decrease stress and facilitate a sense of control. After a brief visit with Ms. O., you talk with her primary nurse who reviews some of the challenging pain management issues, and then she pages the attending physician. The physician is open to any assistance that you can provide. After briefly reviewing a focused breathing and relaxation technique, you help Ms. O. generalize her skills with these techniques to use in facilitating the effects of medication for pain management. With the patient's agreement, you teach her nurse to act as her coach in using these techniques during this hospitalization.

Using another example, the palliative care team calls you to help with the care of Mr. G., admitted for symptom management related to advanced stage lung cancer. The team is unable to account for his current level of significant distress. Your knowledge of this patient's history of witnessing his father's protracted, painful death from lung cancer is invaluable. He reports increased frequency in images of his father's death since he was admitted to the hospital. Utilizing systematic desensitization and supportive psychotherapy, you are able to help Mr. G. decrease his anxiety and breathe more comfortably when these images occur. The palliative care team provides education and information about significant advances in pain and symptom management to assure Mr. G. that the end of his life does not have to involve the suffering he witnessed during his father's last days.

Although you may have a long-standing relationship with patients, you will want to be mindful not to enter as the "expert." You should find out which members of the medical team have established relationships with the patient and family and be respectful of those connections. Be aware of ways in which professionals from different disciplines may be of help to you, get their input, and communicate with them. A potential challenge for mental health professionals outside of the medical system is that clinicians may doubt your credibility and dismiss your input, particularly if there is a discrepancy between the medical provider's experience of the individual and your own. In this case, you may have to wait until problems arise and establish credibility through addressing the problem. In addition, be clear about those things you will *not* be able to do. For example, you cannot "fix" long-standing problems/issues such as addiction to alcohol or drugs.

It is often a good idea to start with the social worker when new to a hospital setting. Social workers are available in most hospitals, especially university-based teaching hospitals. Social workers are trained to look at the medically ill individual and family through a "systems lens." They are strong patient advocates, and they are interested in helping individuals maintain their supports throughout their illness experience. That advocacy includes supporting the community mental health professional's role. Social workers also are interested in knowing good, accessible referrals in the community. If your patient/client is in a small, community hospital or a social worker is not involved, then the primary nurse caring for the patient, or the head nurse on the unit, are valuable professionals to contact.

If you want to remain involved in your patient/client's care on an ongoing basis, ask the hospital team members about their preferred form of contact. Get some parameters about the frequency and timing of desired contact. Some medical professionals want to be informed only when there is "a change for better or worse." Hospitals and medical environments are busy, hectic places. In conversations or in written notes be brief and concise about the information that is most essential to communicate to medical professionals. Avoid the use of psychological or psychiatric jargon. Make every effort to have some knowledge about the person's disease so you can ask informed questions. Know and use the language of physicians and other disciplines involved in the individual's care.

Perhaps the best way to become part of the "extended" medical team is to begin to establish relationships with the treatment team as soon as you are aware that your patient/client has been diagnosed with a potentially life-threatening disease. It is critical for the treatment team to know that your involvement is important to your patient/client and it is important for the treatment team to know the ways you can support the person through the illness experience. Ask your patient to sign a blanket authorization for permission to talk with professionals who are involved in their care.

Finally, working with individuals, family members, and professionals in medical settings in the context of life-limiting illness is rewarding and challenging. Two of the most critical personality characteristics required are flexibility and tolerance for interruption. It is important to know when to alert other team members of changes in the medically ill person's status, and to learn what information they need to make decisions about treatment. Comfort and skill in giving and receiving education from other disciplines, and the capacity to listen comes with confidence both personally and professionally. Unlike the solitude of the private practice setting, the inpatient hospital team setting demands that you work closely with others, be observed, and perhaps even be questioned.

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CHAPTER

12

End-of-Life Care in Long-Term Care Settings

MARY M. LEWIS

As the baby boomers age and require more services, the need for supportive long-term care (LTC) residences, including nursing homes (NH) is likely to increase. Long-term care residences include continuing care communities, retirement communities, assisted living facilities, and nursing homes. Although older adults are more often turning to assisted living and retirement communities, more than 90% of those adults needing LTC reside in nursing homes (He, Sengupta, Velkoff, & DeBarros, 2005). Currently there are almost 2 million nursing homes beds available in the United States, and these are filled to 86% capacity (more than 1.6 million people; U.S. Census, 2001). Although only 4.5% of older adults reside in nursing homes, approximately 43% of older adults are projected to spend time in nursing homes at some point in their lives, primarily for rehabilitation for expected (e.g., hip replacement, knee replacement) and unexpected (e.g., heart attack) events (He et al., 2005; Kemper & Murtaugh, 1991).

End-of-life (EOL) care is a salient issue for LTC providers, including mental health professionals, given that the top two reasons for discharge from LTC are hospitalization (29%) and death (24%; Jones, 2002). Approximately 20% to 25% of all deaths occur in LTC and fully one-third of LTC residents die within 12 months of admission (Flory et al., 2004). These numbers are expected to increase to 40% by year 2020 (Christopher, 2000). This means that most LTC residents will have their EOL care provided within the nursing home, these residents will observe many deaths during their LTC stay, and that a significant portion of older adults will die in LTC settings.

Ideally, most individuals want to die at home and not in an institution. One review of the international literature found that the preference in the general population for a home death was between 59% and 81% (Higginson & Sen-Gupta, 2000). Similar preference for death at home has been found in U.S. samples (Hays, Galanos, Palmer, McQuoid, & Flint, 2001; Tang, 2003). The preference was unconditional for some patients, while for others it was determined by certain situations such as pain control (Fried, van Doorn, O'Leary, Tinetti, & Drickamer, 1999; Gruneir et al., 2007; Hays, Gold, Flint, & Winer, 1999). In contrast to these stated desires, most deaths occur in an institutional setting such as LTC or a hospital (22% and 41% in 1998, respectively; Flory et al., 2004).

Given that almost one-quarter of all deaths occur in an LTC setting, these sites are expected to be well-equipped to handle EOL concerns, but research reveals how poorly prepared LTC facilities are to support dying well. The quality of care at the EOL is not well-measured for older adults in LTC. Existing research documents significant issues with pain control, emotional distress, numerous hospitalizations, little use of hospice, poor communication, and dissatisfaction by families (Hanson, Danis, & Garrett, 1997; Oliver, Porock, & Zweig, 2004; Vohra, Brazil, Hanna, & Abelson, 2004). For example, although mandated by the Patient Self-Determination Act (PSDA, 1990), advanced care planning is not adequately implemented in LTC settings (Oliver et al., 2004). When discussions occurred, 90% of those discussions only occurred once (Bradley, Peiris, & Wetle, 1998) and even with a living will or DNR statement in place, surrogate decision makers may not make the decision that the patient would have wanted (Ditto, 2006). As an individual's health condition changes from acute to terminal care, EOL discussions should continue and be revisited by the resident, the family, and the staff. This is only one of the barriers to providing a positive or quality EOL experience to residents, families, or staff in the LTC setting.

This chapter discusses the relevant concerns for older adults, families, and LTC staff at the EOL, as well as identifies issues complicating a quality EOL experience in the LTC setting. The chapter also provides a description of points of intervention that mental health professionals can engage in to assist older adults, their families, and staff have a quality EOL experience. Although the end-of-life process may include the dying process as well as the time prior to the end of a person's life, which may be months or years, most EOL services and research focus on the last six months of life and, therefore, this chapter focuses primarily on the last six months of life in LTC. Further, although LTC settings can include nursing homes, assisted living, independent living centers, and retirement communities, this chapter focuses primarily on LTC in nursing home settings.

END OF LIFE IN LONG-TERM CARE: CONCERNS FOR OLDER ADULTS, FAMILIES, AND STAFF

Residents, family, and staff face numerous concerns when dealing with death in LTC, including how EOL services will be delivered, as well as the psychological and psychosocial impact of LTC and EOL. This list is not meant to be comprehensive, but rather serve as a beginning guide for health-care providers working with older adults who are facing death, whether imminently or in the future, in LTC settings.

Delivery of End-of-Life Services in LTC: Three Options

There are three primary options for EOL care and service delivery within the LTC setting, which includes hospice services, palliative care units, and consultation services (Froggatt et al., 2006).

Hospice. Hospice is a term that refers to any program that focuses on quality of life for individuals identified as terminally ill. At this time, hospice care is reimbursed for terminal illnesses that have a prognosis of six months or less to live. Hospice services can be provided in multiple settings, including within the LTC setting, home, or a specific in-patient hospice location. Hospice programs offer multiple layers of services, starting with specialized nurses and aides, with additional support from a hospice social worker, chaplain, and trained volunteers.

Research on use of hospice in LTC settings indicates that those older adults enrolled in hospice at the EOL have better pain management and detection of pain (Miller, Mor, Wu, Gozalo, & Lapane, 2002), fewer trips to the hospital (Miller, Gozalo, & Mor, 2001), and higher levels of family satisfaction (Hanson et al., 1997). Hospice care in LTC also results in fewer rates of physical restraints or feeding tubes (Miller, Gozalo & Mor, 2000). Further, LTC residents receiving hospice care are more likely to have a Do Not Resuscitate (DNR) order and living will in effect (Parker-Oliver, Porock, Zweig, Ranz, & Petroski, 2003). Overall, it appears that hospice care in LTC provides increased quality of life at the EOL (Miller et al., 2000).

Palliative Care. Palliative care emphasizes comfort, including pain and symptom relief, as well as improving the quality of life. This care is provided independent of the individual's prognosis and can be provided even if the individual is receiving curative treatments, unlike hospice. Palliative care can be provided at any time during illness for any symptom that needs alleviation, such as pain, nausea, or agitation. LTC facilities may have dedicated palliative care units, or rooms, although many facilities provide palliative care services in the room where the individual has resided during their stay. Long-term care facilities may provide palliative care without specifically identifying it as such.

Consultation Services. Specialists may be asked to support facilities with services that are not included in the LTC facility. These are generally provided in a reactive, rather than proactive way. Consulting agents primarily focus on symptom control and pain management, but the potential for assistance in additional areas is unlimited, such as assisting with decision making and care pathways (Froggatt et al., 2006).

ISSUES FOR RESIDENTS

Numerous psychosocial and psychological issues are associated with both LTC and EOL (see Werth & Blevins, 2005; Werth, Gordon, & Johnson, 2002). The psychological and psychosocial issues are further influenced by culture and past experience with death, and can be identified by the individual within the context of a psychosocial or psychological assessment.

Psychosocial Concerns

Loss. One of the most common psychosocial issues for older adults in LTC is loss. The older adult in LTC has often given up a home, condos, or independent living to come to the LTC facility. Most residents have also experienced physical loss, whether it is the loss of ability to walk, toilet, or eat without assistance. Social losses may include the loss of a spouse, a sibling, a child, or friends. The loss of control is a universal experience in LTC. In many LTC facilities there are schedules for eating, sleeping, bathing, even toileting. Privacy is also lost, particularly for those in double-bed rooms where thin curtains cannot disguise voices, procedures, or smells. Almost any sight or sound may remind the individual of the control and freedom that they have lost prior to coming into the LTC facility.

Grief. LTC residents are also at risk for complicated grief or may re-experience past, unresolved grief as they are facing their own dying process. The grief may arise from the losses the individual has experienced from coming into the LTC facility, or from the impending loss of a death. Older adults may also begin to grieve future losses, such as loss of relationships or loss of health (Werth et al., 2002).

Meaning and Suffering. The meaning of LTC can also be foremost on the older adult's mind, whether it is "A place to die." or "A place to live out my life." Individuals may feel as if they are "in prison," being "punished" by their children, or "put in a corner, left to die." The stigma of LTC may amplify these feelings, and individuals may feel the last days are filled with suffering and no meaningful interactions (Hanson, Henderson, & Menon, 2002). Chan and Pang (2007) explored EOL concerns with elderly LTC residents and found that existential concerns and spiritual distress was frequent, including questions about value and meaning in life, and evaluation of life as a whole.

Dignity. The LTC residents often face the loss of dignity, specifically the dignity to not be treated as an object, but as a person. Staff language denies dignity by referring to "the COPDer in bed A, room 241" rather than "Mr. Smith, the retired teacher who has COPD." Definitions of dignity may be linked to culture and individual values, but can change over time. For example, what an individual finds undignified at the beginning of their terminal illness may not necessarily be found undignified at the end of their illness (e.g., getting assistance while showering). Therefore, definitions of dignity and links to values and culture should be reviewed with the older adult throughout the LTC stay and EOL experience (Werth et al., 2002).

Adjustment. Individuals coming into a LTC facility or dealing with EOL often are experiencing changes in diagnoses, prognosis, or functional status. They may have unspoken concerns about how death will occur, or worry about family or financial concerns. Further, older adults may experience emotional distress related to being around others who are ill or dying, particularly if they have limited prior experience with illness or death. Some of the LTC residents I work with say, "I'm not afraid of dying, I'm afraid of *how* I might die." This may be an expression of fear of potential future pain and suffering. These individuals also ask questions such as "Who will tell my family?" "Will I be in pain?" or "Will my wishes be respected?" These questions arise from the individual seeing other residents dying alone, smelling others losing control of their bowels and bladder, and hearing some individuals crying out in pain or distress. This can increase the fear of what might happen during the LTC stay or during the dying process, as well as impede adjustment to the LTC environment. One resident reported to me, "Who will advocate for me and my wishes in this place when I am unable to speak like these poor people across the hall?"

Pain and Suffering. One of the most frequent questions I am asked by dying residents is about pain and suffering at the EOL. Pain is one of the most studied areas of EOL care, but also the one that could be most improved at EOL. Miller et al., (2002) found that a large number of older adults in LTC experience pain daily, but do not receive adequate pain medication. The use of hospice increases use of pain medication, but hospice services may not be engaged early enough to control pain through the dying process (Happ et al., 2002; Miller et al., 2002). Further, there are a number of residents who deny themselves pain medication because they fear addiction and over-use of pain medication. Pain management is a significant issue both in LTC and in EOL situations.

Mental Health. The psychological issues associated with LTC are well-documented. Studies report that a significant portion of older adults in LTC have a mental health diagnosis, including dementia, depression or anxiety (Lair & Lefkowitz, 1990; Molinari, Hedgecock, Branch, Brown, & Hyer, 2009; Rovner et al., 1990). Additionally, there is significant comorbidity of mental health and physical disorders, particularly with older adults. For example, heart attacks and coronary artery disease are medical problems associated with depression in older adults (Roose, Glassman, & Seidman, 2001). Chronic pain, breathing problems, infections, and stroke are other examples of physical problems linked to affective disorders in older adults (Roose et al., 2001).

Although there is little research about how older adults with serious mental illness (e.g., schizophrenia or bipolar disorder) deal with death or go through the grief process, it is likely that individuals with altered perceptions of reality will continue to struggle with the mental illness throughout the dying process. Delusions, hallucinations, or active paranoia may impact the ability to understand prognosis or make EOL choices. Additionally, little is known about how personality disorders can impact a person's EOL decisions, particularly in older adults (Werth et al., 2002). Literature does indicate that personality factors can clearly impact how health-care professionals work with these individuals, particularly in regards to countertransference (Gutheil, 1985; Segal, Coolidge, & Rosowsky, 2006).

In general, mental health issues are frequently underutilized in LTC (Smyer, Shea, & Streit, 1994; Spayd & Smyer, 1996), although recent research indicates that more facilities are offering mental health services to their residents (Molinari et al., 2009). As Molinari et al. (2009) indicate, barriers to mental health services continue to exist, even in facilities where mental health services are readily available. In LTC facilities where psychological services are provided, research indicates that less than 20% of individuals with a mental disorder receive services (Smyer et al., 1994).

CASE STUDY—ALAN

Alan is a 74-year-old Caucasian male who came to the nursing home initially for rehabilitation due to complications of Parkinson's disease and chronic pain. Although Alan did not start as an EOL case, it did end that way. Alan is presented as a sample case to reflect the multiple layers of emotional, physical, and psychosocial factors that impact LTC and EOL.

Several months prior to his stay, Alan's wife of 51 years had died. Alan was expressing significant depression, grief, and passive death wishes. He reported that he wanted to "be with my wife," and noted that he had "lived all the life he wanted to," but had no specific plan for suicide. He stated "I don't want to wake up in the morning." He also demonstrated difficulty sleeping, weight loss, and lethargy. He was frequently tearful and spoke of feeling like he was "a burden" to his daughters. Staff also reported to the psychologist that Alan's physical condition was declining due to his poor appetite and occasional refusal of medication, and believed he wanted to die. Alan also began to refuse to participate in physical or occupational therapy, refused to come out of his room, and often asked family to leave after short visits.

Alan was referred to the psychologist for treatment of depression and recommendations for the staff. Initially, it appeared as if he might be at the EOL, given his declining physical status and reluctance to engage in healthy behaviors. He was treated for his depression and grief with cognitive-behavioral psychotherapy over a period of 16 weeks. During that time, the psychologist worked with the physical therapy and occupational therapy staff on how to interact with Alan in a positive way, as well as provide specific and focused feedback for positive interactions. Dietary staff was also consulted with the goal of increasing his food intake and weight. With these interventions, his mood improved and he reported increased interest in life. He also gained 10 pounds and started to participate in physical and occupational therapy, and no longer made statements of hopelessness or wanting to die. However, Alan's Parkinson's worsened and he was unable to return home. He became a long-term resident of the nursing home. With guidance from the psychologist and Alan's daughters, the staff became close to Alan, and socialized with him as often as possible. Although he did not become active in group social activities in the facility, he did spend time playing cards in his room and talking with his three daughters, who frequently visited.

Issues for Families

Research indicates that satisfaction for EOL care within LTC is varied. Some studies indicate lower satisfaction than hospital EOL care (Hanson et al., 1997) and other research reveals higher levels of satisfaction of death in LTC versus hospital (Vohra et al., 2004). Use of hospice services within LTC significantly increases satisfaction rates for families (Hanson et al., 1997), as does allowing families and the resident to participate in the decision-making process, providing physical comfort, educating families on patient EOL care, as well as giving emotional support to the family both before and after death (Teno, Casey, Welch, Edgman-Levitan, & Fowler, 2001). However, most research continues to indicate that EOL care within LTC continues to have multiple barriers to patient and family satisfaction.

Family members do need help to identify options and to know what is available to them at EOL, including information about the trajectory of dying, medical and pain management options, as well as what care the LTC facility can provide in-house. Miscommunications between medical staff and family members may complicate choices about how and where death occurs. For example, when no EOL plan exists, hospitalization is a common, and often default occurrence with between 33% and 50% of residents hospitalized at least once in the year before death (DeSilva, Dillon, & Teno, 2001; Travis, Loving, McClanahan, & Bernard, 2001). Frequent trips back and forth from the LTC facility to the hospital can create an additional source of suffering and complications for the older adult (Mezey, Dubler, Mitty, & Brody, 2002). This is another reason to encourage hospice admissions and open discussions about EOL wishes as individuals on hospice care have fewer hospitalizations than individuals not receiving hospice (Miller et al., 2001).

Further, family members often worry about pain control, and can be sensitive to the pain and suffering of their loved ones. Unfortunately, research continues to indicate that family members feel their loved ones did not have adequate pain medication at the EOL, and almost half of bereaved family members had reported their loved one's pain to a health-care professional in the LTC but were not informed about medication to alleviate the pain (DeSilva et al., 2001; Hanson et al., 1997).

Families want staff to provide their loved ones with dignity and sensitivity but characteristics of the physical environment may undermine staff with the best intentions. Semi-private rooms even with the curtain drawn cannot hide the sound of moaning or pain, the odor of an unwashed body, or the smell of a bowel movement. Individuals can be left in bed for hours with no human contact due to understaffing or inability to ask for assistance when needed. Even an individual who is in a semi-conscious state needs some type of warm, caring human interaction unless otherwise specifically requested by the family. Even a dying individual has the right to be treated as a person, rather than an object.

As families move through their own grief and bereavement process, they may need support from the facility or other sources. Research indicates that there is little communication between facilities and families either before or after death (Murphy, Hanrahan, & Luchins, 1997), despite research indicating that emotional support increases satisfaction with EOL care (Teno et al., 2001). At most, the facility may send a sympathy card after the death; however, there is little contact after that point (Murphy et al., 1997). This may occur even though these family members may have been coming to the facility for years to visit their loved one. Families are often left to find resources for bereavement on their own, possibly community support groups or individual counseling (Murphy et al., 1997). Caregiver support groups that are run by facility social workers provide an opportunity for attendees to use those groups as an outlet for grief and working through the loss, particularly with people who have known their loved one and understand the stress of caregiving.

Issues for LTC Staff

Although LTC staff are the primary caregivers for individuals in LTC, few studies have examined how they experience the deaths of residents

(Anderson & Gaugler, 2006–2007; D. P. Oliver, Porock, & Oliver, 2006). Many LTC staff, especially nurse aides, become attached to residents and are likely to experience distress when the older adult dies (Hanson et al., 2002). Some staff may avoid attachment in order to protect themselves from sadness with the resident dies (S. Z. Moss & Moss, 2002; Wilson & Daley, 1998). Unfortunately, some residents experience these avoidant staff members as "distant" or "uncaring." When a resident dies, more than half of NH staff report feeling sadness, and one-quarter report crying or difficulty accepting the death (Rickerson et al., 2005). The death can even impact relationships with other residents (Rickerson et al., 2005). After a resident dies, staff seek support from other staff, family, friends, or religious individuals, although they are willing to use additional sources of support if they were only offered (e.g., support groups or counseling; Rickerson et al., 2005).

When the focus in LTC is on curative care (as in rehabilitation) or maintenance care (as in long-term nursing), death can be a hidden or ignored area or may be seen as a "failure" rather than a natural part of the lifespan (Oliver et al., 2006). Beds need to be filled to keep the facility financially solvent, so when someone in the LTC facility dies, it is quite likely their room will be cleared, the bed cleaned, and another individual will be in that bed by the next day. Staff may not be given time to grieve, nor process the death of residents. This also gives an unspoken message to other LTC residents about the meaning of death and its significance within the facility. Consultants may not even be informed that one of their patients has died. When I go to facilities, the first indication I may have that one of my clients has died is an empty bed or a missing chart. I frequently read the local obituaries in the newspaper so that I am aware of at least some of the deaths prior to arriving at the facility.

Nursing assistants may be uncomfortable in talking about dying with residents and addressing resident fears of death. When I observe staff working with older adults with concerns about death, I hear things like "don't talk that way," and "you'll live a long time," rather than letting the resident express their concerns. Even the language used in the LTC setting can be indicative of how the facility staff copes with death. I often overhear staff refer to the deceased person as "expired," like a carton of milk, rather than a person. This may be a useful term for staff to use as a way to "distance" themselves from the death, but it can be emotionally difficult for others to hear. Mental health professionals can play a role in assisting the facility to provide higher quality EOL care by facilitating staff attention to the language used around death and dying, as well as exploring ways to give meaning to the death of a resident while meeting the pressure of administration to fill rooms. These interventions can increase the sense of compassion and improve the quality of care for individuals living in the facility at the EOL.

WHAT MAKES A "BAD" DEATH IN LTC?

Research literature clearly documents a number of common factors that contribute to the perception that a death is "bad" in LTC. These include medical factors, poor communication, poor planning, and inadequate staffing (Kayser-Jones, 2002; Kayser-Jones et al., 2003).

Medical Factors

One medical factor contributing to a "bad" death in LTC is the lack of recognition of treatment futility by the physician or staff (Kayser-Jones, 2002; Kayser-Jones et al., 2003; Travis et al., 2002). Medical staff may be concerned that a family member will accuse them of "letting my loved one die" and may push for curative care well beyond the point when it is helpful. Family members may ask for an escalation of care, even if it is not curative, fueled by feelings of guilt or concern that they are letting their loved one suffer if they do not ask for the additional interventions.

Some staff concerns arise from their difficulty with prognosis—for example, dementia is not a common reason for referral to hospice, even though it is a terminal condition (Albert, 2004; Lewis, 2007). This is due partly to the difficulty with prognostication in dementia, where the time of death from initial diagnosis can range from three to nine years (Robinson et al., 2005; Wolfson et al., 2001), as well as the underestimation of dementia as a cause of death (Wachterman, Kiely, & Mitchell, 2008). No matter the medical diagnosis, family, staff, and medical personnel may not agree on course of care or the prognosis of the older adult (Kayser-Jones, 2002).

Even loving families and caring facilities may have difficulty agreeing on the course of care. One family member may feel that "comfort care" includes hydration and antibiotics, whereas another disagrees. Many medical conditions do not have a predictable prognosis (e.g., dementia), as described in Chapter 2. Interventions during one phase may be defined as aggressive, but as palliative at a different time. In these cases of variable decline, do families identify tube feedings as “aggressive” care or comfort care? Are antibiotics seen as “routine” or “extraordinary” measures? These questions are often not asked until the older adult is physically declining or near death. Mental health professionals could help answer these questions by providing psychoeducation to families that would inform certain care decisions, such as the use of artificial nutrition (e.g., “feeding tube”) and how it does not result in longer survival nor prevent against aspiration in an individual with dementia (Finucane, Christmas, & Travis, 1999; Robinson et al., 2005). Ultimately, the determination of “terminal decline” and what influences the decision for continuing treatment may be difficult to identify by staff or family, but factors that may influence that decision include quality of life, cultural and family values, individual and family wishes, and financial concerns by the individual or family.

Poor Communication

Poor communication or the lack of communication between resident, family, staff, and physician can also significantly interfere with a positive dying process (Kayser-Jones, 2002; Kayser-Jones et al., 2003). A lack of access, lack of time, or lack of understanding will all impact the dying process. Medicare currently does not reimburse for phone calls, so physicians may be reluctant to spend time calling back families with complex cases, knowing that they will spend 30 minutes or more on the phone with a “demanding” family. Shield and colleagues (2005) reported physicians were “missing in action” (p. 1) when family members had questions about their loved one, or wanted to discuss a plan of care. Further, staff may be overworked and unable to provide personalized care to the individual (Shield, Wetle, Teno, Miller, & Welch, 2005). For examples, residents have said to me that the staff “wants to do things their way, not my way, because it’s faster.” This may add to the emotional and physical family burdens in that some family members feel they need to do more personal tasks, such as personal grooming (e.g., combing hair, putting on lipstick, cutting fingernails) that staff are unable or unwilling to do (Shield et al., 2005).

The communication barrier also includes inadequate provision of information as well as insensitive communication. Some of my residents have either overheard inappropriate conversation between staff and doctors, or have been told to their face “there’s no hope” when they wanted to be told in a more sensitive way. Residents report being told test results are “bad” and that they may want to prepare for "the end," with no specific explanation of prognosis, diagnosis, or possible treatment. Frequently in these cases, the physician spends less than 5 minutes with the patient before needing to attend to another patient in the LTC facility.

Culturally sensitive communication is a crucial piece of quality EOL care. For examples, in some cultures, it is inappropriate to tell the older adult they are dying, and decision making should be discussed with family first (Richmond, 2006; Werth et al., 2002). Conversations need to be direct and private with sensitivity to their cultural preferences. Staff, consultants, and families should avoid conversations in public spaces that could allow hearing a discussion of their terminal condition from out in the hallway or the family learning that their loved one has been told of prognosis prior to the family being informed. Breaches of communication trust can create a significant barrier to future positive communication between staff and the family. The consideration of an individual's cultural background and endorsement of cultural values should be considered both during the EOL decision-making process as well as throughout the death and dying experience (see Chapter 4).

Poor Planning

The failure to implement EOL care in a timely fashion is also a significant barrier to life quality at the end of life (Kayser-Jones, 2002). Generally, hospice services are associated with better pain management and higher rates of family satisfaction at the end of life (Oliver et al., 2004). However, hospice services tend to be underutilized. Even when hospice is instituted, it is commonly initiated only two to seven days prior to death (Happ et al., 2002), limiting the impact of quality care. Some hospice nurses express frustration about the expectation that they are to provide a year of bereavement support services to the family "pro-bono" if they were only paid to provide services for two to three days. Bereavement services are difficult following short-term care because they have not had a chance to get to know the resident or the family. The use of hospice services does vary dramatically between facilities, however (Jones, Nackerud, & Boyle, 1997).

Inadequate Staffing

Inadequate staffing is a commonly discussed concern in LTC facilities that is exacerbated by EOL care demands (Kayser-Jones, 2002; Kayser-Jones et al., 2003). Facilities already are understaffed, and individuals who are at the end of life often have more needs than other residents (e.g., needing to be turned, fed, bathed). They may be too weak to reach their water pitcher (which is often large and heavy) or the water glass is placed out of their reach. If they are disallowed oral ingestion of fluids or food, moisturizing swabs may be left out of their reach or they are physically unable to use them. The television is frequently left on, but on programs that residents would not choose if they even wished to have the television on. Staff spends less and less time with each resident as work demands increase. Semi-private rooms may trap a dying person with roommates whose comings and goings are disruptive for the dying resident. In addition, the lack of supervision, especially on weekends and evenings, can sometimes lead to even more negative behaviors and frustration at residents by staff (Kayser-Jones, 2002; Kayser-Jones et al., 2003).

CASE STUDY, CONTINUED

About a year after Alan was treated for depression, he started having difficulty eating and complained of loss of appetite, low energy, and difficulty concentrating. He lost 15 pounds in approximately one month and became lethargic to the point of giving up his card-playing. The psychologist was called in to conduct an evaluation for depression and recommendations for treatment. Alan reported to the psychologist that he was not depressed, but rather he had made peace with his life and was ready to die. He expressed continued interest in his life and family, but noted that his Parkinson's had made it difficult to eat and he was tired often due to the constant shaking. It appeared that Alan's increasing Parkinson's symptoms explained his increasing lethargy and difficulty swallowing food (resulting in weight loss), as well as difficulty getting food to his mouth. The psychologist reported back to the staff and physician that he was not depressed, but rather having difficulty due to the progression of his Parkinson's. Consultation with Alan's daughters revealed that they agreed that he was not depressed, but was ready to "move on." A hospice consult was recommended as part of the evaluation and in concurrence with Alan and his daughters' wishes.

Unfortunately, the facility physician disagreed with the psychological evaluation on the basis of one evening shift nurse's report. Without seeing Alan or speaking to the psychologist or family, the doctor called in a phone order for Remeron 15mg QD to treat depression in response to the nurse's request.

Within five days of starting the medication, Alan was slurring his words, having nightmares, and noting worsening daytime lethargy. After consultation with the family and discussing with Alan his end-of-life wishes, the psychologist re-approached the physician and staff, and requested discontinuation of the antidepressant medication, as well implementation of a hospice referral. The social work staff and charge nurse were also consulted and given the recommendations. Three days later, the medication was discontinued, but hospice was once again not consulted. Alan's condition worsened, so much so that he was unable to eat without assistance. Family requested a hospice referral for the third time, but it was not completed until five days after this final request. Alan died with one day of initiation of hospice service. His family was angry and upset with the facility physician, who had not physically seen Alan in the last month of his life.

What Makes a "Good" Death in LTC?

Common factors contribute to quality EOL care in LTC settings, including agreement between individual, family, and health-care team members, both on prognosis, course of care, and EOL care plans (Kayser-Jones, 2002; Kayser-Jones et al., 2003). Further, adequate symptom control, including pain management, management of thirst, hunger, discomfort, need for dressing changes, and so on, are critical at the end of life. Even personal cleanliness and attendance to spiritual and emotional needs are considered crucial to positive end-of-life care (Reynolds, Henderson, Schulman, & Hanson, 2002).

A quiet, supportive, and respectful environment at the EOL can promote a quality and satisfactory EOL experience for the older adult, his or her family, and the staff (Brazil et al., 2004; Kayser-Jones, 2002). This includes respect of last wishes and honoring choices that staff may not agree with, such as preferences about family members being present, or the absence or presence of music or specific types of food. It may be important to discuss with family members the role of hydration and nutrition at the end of life, particularly as individuals who are dying have diminished appetite, thirst, and may not be interested in food (O'Connor, 2007). Family may want the individual to eat, or try to "force" food on them, which may result in a conflict between staff and family, or emotional and physical distress on the part of the older adult (O'Connor, 2007). Mental health professionals may be able to assist navigating the cultural and emotional factors involved in offering food between family and staff, as well as again, providing psychoeducation and support about the idea of eating for pleasure, or having food available (but not necessarily "forcing" the individual to eat).

Additionally, there should be respect and support for emotional, cultural, social, and spiritual needs. Support for preferred EOL rituals may need to be negotiated by the mental health professional. Some cultures use incense for EOL rituals, but most LTC facilities do not allow candles to be burnt or incense to be lit because it is a fire hazard; however, nonflame candles would be appropriate for the EOL ritual and still be within facility guidelines. Other rituals may include bathing of the loved one by family, calling of a religious leader, prayers, specific music, or culturally sensitive food.

Finally, having sufficient institutional resources promotes a quality EOL experience. For example, the availability of a private hospice room may facilitate a quiet environment where family members can come spend time with the older adult, away from noise or distractions. Facilities may wish to provide volunteers to sit with dying residents, or offer on-site mental and spiritual health care for the dying person and their family members. Further, increasing one-on-one staff time for care of dying residents may provide comfort for both the older adult and their family (Hanson et al., 2002), although there is little funding for this increased amount of care. Each of the aforementioned recommendations individualizes the EOL experience and potentially facilitates increased family satisfaction.

FACILITATING A "GOOD" DEATH IN LTC: BARRIERS

Above and beyond the individual factors discussed that impact the quality of EOL care in LTC settings, two fundamental principles underlying LTC also create barriers to quality end-of-life care. First, policies regulate the focus of care in LTC facilities through reimbursement models that reward facilities for treatment rather than palliation. Second, the medical model concentrates care on physical status with less status given to emotional or spiritual status. Without a holistic EOL experience, the LTC facility cannot provide a high-quality EOL experience.

Policy Barriers

State and federal regulations provide the underlying structure for the care that LTC facilities provide. The primary tool that allows regulators to evaluate nursing home care is the Minimum Data Set (MDS). The MDS is mandated for Medicare or Medicaid-certified LTC facilities, and focuses on care for categories such as cognition, mood, functional status (e.g., ability to transfer), health conditions (e.g., pain, falls), medications, treatments and restraints, to name just a few (Centers for Medicare and Medicaid Services [CMS], 2008). At this time, the CMS MDS data have no specific EOL marker. However, other indicators on the MDS could be used to identify quality EOL care, such as pain or presence of bedsores. For example, if pain were to be used as a marker for quality EOL care, then enrolling the individual in hospice would provide a quality EOL experience because individuals receiving hospice care in LTC are twice as likely to receive pain management on a daily basis than residents not receiving hospice care (Miller et al., 2002).

Although hospice access by itself may be an indicator for "good" death, at this time, the MDS 2.0 only has one spot for hospice, found under "Special Treatments" (e.g., "check if received during the last 14 days," CMS, 2008). For MDS 3.0 (still under revision), hospice continues to be under the "Special Treatments and Programs" section as a "check if received in the last 14 days" (Saliba & Buchanan, 2008, p. 32) The MDS 3.0 has also added a question under "Resident's Overall Goals" that states "End-of-life care (includes palliative care AND hospice)" (Saliba & Buchanan, 2008, p. 34). If the MDS and quality indicators paid more attention to EOL care, it is likely that the actual EOL care in LTC settings would improve (Oliver et al., 2004).

Focus on Physical Status

The focus of care in LTC settings throughout the older adult's stay is primarily on physical factors, such as pain, bowel/bladder, hydration, nutrition, oral care, bathing. Long-term care staff may not trained to handle the emotional or spiritual needs of the older adult, families often mention emotional and spiritual needs as being unmet at the end of life in LTC (Reynolds et al., 2002). Even when hospice services are involved, the focus remains on physical comfort. Most hospice workers are nurses and aides, although hospice services do have a hospice social worker (typically an LSW) and a hospice chaplain that provide emotional and spiritual support. Trained hospice volunteers provide friendly visits for social support.

As mentioned previously, mental health issues are frequently undertreated in LTC. Unfortunately, the underutilization may be more significant for older adults who are near the end of their lives. In one study of individuals in LTC who eventually received hospice care, only 3.6% of residents were evaluated by a licensed mental health specialist in the last 90 days (Buchanan, Choi, Wang & Huang, 2002). This low number is surprising given the fact that 47% of the sample demonstrated disturbances of mood, 20% were taking antidepressants, 17% were taking anti-anxiety medications, and 8.8% were on antipsychotic medications (Buchanan et al., 2002). There is little data on the use of mental health services at the end of life, and due to the fact that Medicare does not reimburse for mental health treatment when an individual is receiving hospice services except under certain conditions (Haley, Larson, Kasl-Godley, Neimeyer, & Kwilosz, 2003; Lewis, 2006), it may be difficult to identify whether the use of these services is efficacious at providing a quality EOL experience.

INTERVENTIONS IN LONG-TERM CARE FOR THE END OF LIFE

Clearly, there are numerous areas of intervention for mental health professionals. Werth et al. (2002) identify six roles for mental health professionals at the end of life, including advocate, counselor, educator, evaluator, multidisciplinary team member, and researcher. Psychologists can be involved throughout the EOL process, from the time of diagnosis to after the death itself (Haley et al., 2003). For example, professionals can work with residents on specific concerns in EOL, such as reduction of pain, processing of existential suffering, resolution of complicated grief, or treating anxiety or depression arising from fears about death. Mental health professionals are uniquely equipped to provide a confidential setting for LTC residents to discuss the quality of care they see being provided to other residents, and explore feelings and thoughts about that care, as well as provide an opportunity for a conversation about what the individual wants for their own EOL.

Additionally, mental health professionals can facilitate family and staff understanding of how psychosocial and psychological factors can impact the EOL experience within the LTC setting, promote open discussion about EOL concerns, and act as a mediator between families and staff who have differing concerns for the individual. Professionals can also provide in-service training and education to staff to improve the care for their patients at the EOL (see Henderson, Hanson, & Reynolds, 2003).

CONCLUSION

In sum, although the EOL care in LTC facilities can vary greatly, general EOL care in LTC is poor and there are significant areas for improvement. At this time, numerous barriers block quality EOL care, including the underutilization of hospice services and mental health services to treat the emotional distress that may be present at the end of life. However, a quality EOL experience can be provided if the older adult, family members, and staff work together and are aware of the potential pitfalls that exist. Mental health professionals can play a crucial role in providing a positive EOL experiences for families, residents, and staff if given the opportunity, and can be a consistent support throughout the EOL experience.

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CHAPTER

13

Advocating for Policy Change

The Role of Mental Health Providers

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Policies regulating end-of-life care can be found at every level from the local institution through the federal government. Policies generally are intended to allow for the orderly, timely, and lawful provision of services to people at the end of life, but some lead to unintended consequences that may instead erect barriers to this service provision. When this happens, opportunities exist for affected professionals to advocate for policy change. Indeed, professionals actively providing services may be the only group that dwells in the problem long enough to identify the policy changes that would have a positive impact. Psychologists are not specifically required to advocate for policy reform by the American Psychological Association Code of Ethics, but an argument can be made that upholding several of the general ethical principles requires psychologists to engage in just this sort of advocacy. In contrast, the National Association of Social Workers' Code of Ethics mandates that social workers act to change policy in ways that benefit individuals and society as a whole.

In this chapter, we review some of the current salient policies at federal, state, and local levels of regulation, and indicate ways in which these policies can serve as barriers to providing optimal end-of-life care. We also discuss ways in which psychologists, acting in a policy advocacy role, can promote ethical care of patients at the end of life.

FEDERAL POLICY ISSUES RELATED TO MENTAL HEALTH AND END OF LIFE

For many older adults over the age of 65 and for individuals who are permanently disabled, the primary health insurance policy is Medicare. As such, it is perhaps the primary source of care for individuals with life-limiting illnesses, especially those receiving hospice care. Medicare is a federally run program that is a frequent trendsetter for other health insurance policies and procedures. Two specific federal policy issues related to Medicare impact mental health care at the end of life: parity and the hospice benefit.

Medicare mental health parity. From the inception of Medicare, mental health services have been differentially covered from physical health services. Specifically, physical health services are covered at 80% of the contracted amount, and mental health services (with the exception of the initial interview) are covered at 50%. Therefore, older adults who are in need of mental health services are required to either provide the other 50% copay, or have secondary insurance that may or may not cover mental health services. Unfortunately, as many older adults are on a fixed income and may not have significant savings, the copay may be a significant barrier to services. Older adults at the end of life may be struggling with depression, anxiety, or grief issues and need mental health services. These individuals also are paying for various treatments, medications, and transportation to the physician's office, necessitating difficult choices about which professionals to see and what is affordable.

Advocacy by providers has been successful in reducing this particular federal policy barrier to mental health services. In 2008, Congress voted to eliminate the discriminatory mental health copay in Medicare over a series of years (H.R. 6331, Sec. 102). Beginning in 2010, the copay for mental health services will gradually reduce, with the goal of having parity with physical health coverage reached in 2014. If implemented as legislated, this new law will make mental health services more affordable for older adults and facilitate increased access to mental health care.

The hospice benefit. A second federal policy barrier to provision of mental health services at the end of life is restrictions on mental health services when an older adult is receiving hospice services. Counseling for mental health services are "bundled" into the Medicare hospice benefit and found labeled under "counseling services." Counseling services are defined to include spiritual counseling, dietary counseling, and bereavement counseling. Bereavement counseling is to be provided by a "qualified professional," usually a hospice social worker or clergyperson in the current environment (CMS Manual System, 2008). Theoretically, any mental health professional could provide these services. However, by practice, rarely are psychologists or licensed counselors hired due to fiscal constraints. The hospice provider receives one reimbursement amount for all the services provided to an older adult under their care, and must pay the providers from that check. A psychologist's services cost more than a salaried social worker or chaplain, therefore hospice services are reluctant to utilize those services (Haley, Larson, Kasl-Godley, Neimeyer, & Kwilosz, 2003).

Psychotherapy by a psychologist or licensed social worker is a covered benefit under certain conditions. Medicare will reimburse for psychotherapy with an older adult on hospice if: (1) the individual has a mental health condition that is unrelated to the hospice diagnosis and in some cases, (2) if hospice service agrees (Haley et al., 2003; Lewis, 2006). More commonly, mental health providers who want to provide psychological support during the dying process for a patient seen previously will be required to provide these services *pro bono*.

It is important to work with the hospice-contracting agency to collaborate on services for the individual. For example, a resident may be seen for treatment of an anxiety disorder related to a traumatic experience in her past. This client may reexperience the trauma during baths, toileting, medication administration, and other intimate situations, and would work in psychotherapy to learn relaxation techniques to manage the immediate anxiety as well as working through the trauma using existential and interpersonal interventions. The psychologist may also want to discuss specific behavioral interventions and self-soothing options for the hospice care staff providing personal care for the individual.

Theoretically, psychologists also could use the new Health and Behavior codes, which enable reimbursement for the delivery of psychological services for an individual whose problem is a physical illness and does not have a mental health diagnosis (Haley et al., 2003). However, this has not been tested or discussed by APA at this time, nor has it been specifically examined by any of the current Medicare carriers. In regard to billing, in Ohio for Palmetto GBA (Medicare Part B Carrier for Ohio, South Carolina, and West Virginia), psychologists should use the modifier code

GW for services "not related to the hospice patient's terminal condition" (www.palmettogba.com). Ideally the psychological disorder would be documented prior to initiation of hospice to be considered as "not related" to the terminal condition. Each individual Medicare Carrier should have information on its Web site regarding the hospice modifier and particular code that is to be used.

The impact of these policies is varied. Some older adults may delay hospice care if they are working with a psychologist and know they will have to discontinue if they receive hospice. Other individuals may choose to receive hospice services, but not get the specific mental health treatment that they need. It is important for psychologists to be aware of the potential federal policy barriers to mental health treatment at the end of life for older adults and work with the individual, families, and caregivers to overcome those barriers.

Examples of policy change targets. Within the federal health-care regulations, there may be a number of targets ripe for policy change. One of those, specifically greater recognition of the need for patient access to previously engaged mental health services throughout the hospice benefit period, is mentioned above. At this writing, although health-care reform championed by the Obama administration has passed, it remains to be seen how the changes brought about by this effort will impact mental health professionals and their ability to work with patients near the end of life. Continued opportunities exist for mental health professionals to voice their opinions, both directly to their members of Congress and indirectly through their professional organizations, about issues such as payment specifically for counseling patients about end-of-life planning issues well before those plans are needed, and billing health insurance (rather than mental health coverage) for interventions designed specifically to address physical symptoms. Undoubtedly there will be other issues arising from this effort, as well as in the "normal" course of events, about which vigilant and vocal mental health professionals may wish to advocate for change.

State Policy Issues Related to End-of-Life Care

Although the provision of mental health services to persons near the end of life is primarily regulated by federal policy, there are some important state policy issues that significantly impact end-of-life care and that may be relevant for psychologists' advocacy efforts. Chief among these policies are those having to do with the provision of adequate pain management services to these persons.

The federal government, through the federal Controlled Substances Act and resulting regulations, provides the highest level of regulatory control over the use of these substances to manage pain and other symptoms, such as anxiety, nausea, and dyspnea. State legislators and regulators, however, provide much more significant regulatory oversight in these areas, as they are responsible for a second layer of legislation (in state controlled substances acts) as well as for defining the appropriate practice of medicine, nursing, psychology, and other disciplines.

The agencies regulating the use of controlled substances to manage pain, in particular, are forced to reconcile two somewhat contradictory public health needs: the need to provide these medications to individuals who need them for the relief of pain, and the need to prevent these medications from falling into the hands of individuals who would divert and/or use them for purposes of abuse. The Pain & Policy Studies Group (PPSG) at the University of Wisconsin (www.painpolicy.wisc.edu) has labeled the policy requirements posed by this dilemma as reflecting the need for "balance." Simply stated, the principle of balance requires that public policy be structured in such a way as to simultaneously meet both of these significant needs.

Over the past 20 years, through efforts of groups such as state pain initiatives and their national organization, the Alliance of State Pain Initiatives (aspi.wisc.edu), health-care professionals have worked together to institute and modify state pain management policies to achieve greater balance. These efforts have resulted in significant improvement in these policies, as seen in the PPSG Progress Report Card (Pain & Policy Studies Group, 2008). This comprehensive document sets out criteria by which state policies can be evaluated with respect to the principle of balance, evaluates the extent to which each state's policies meet these criteria, and from that evaluation derives a "grade" for each state's pain policies. A state that achieves the grade of "A" has demonstrated policies that present no significant barriers to the provision of appropriate pain management through the use of controlled substances while also displaying a significant number of policy provisions that encourage the appropriate management of pain through this modality.

As a further aid to policy advocates, the PPSG Report Card also provides specific citations for how state statutes, regulations, and guidelines meet these criteria, and later discusses potential changes that could overcome "negative" criteria that may lower a state's grade. These specific citations enable policy advocates to easily identify targets for intervention within their states, and also can be found at the PPSG web site referenced earlier.

Although the use of controlled substances to manage pain is directly under the purview of physicians and other prescribers, mental health providers working in end-of-life settings can easily describe the cognitive, emotional, and even spiritual toll taken by uncontrolled pain and other symptoms. This toll applies not only to the person who is near the end of life, but also to those in close contact, such as close family members. Allowing a person to die in uncontrolled pain contributes to a variety of symptoms in survivors, including complicated bereavement, increased anxiety about their own end-of-life processes, and even symptoms commonly associated with posttraumatic stress disorder (Cameron & Parkes, 1983; Holing, 1986; Hull, 1990; Koop & Strang, 1997; Kristjanson, 1997).

Because of their extensive experience with these issues, mental health professionals are ideally situated to effectively advocate for improved policies encouraging or mandating regular assessment and documentation of pain and the results of attempts to manage it, as well as improved policies allowing patients access to the most effective means available to control their pain and other symptoms, despite the fact that some of these treatments may be expensive and thus severely restricted or not covered by health insurance. Policies requiring "step therapy" or "therapeutic switching," for example, may be instituted by a pharmacy benefit manager (PBM) to the detriment of both patients and their health insurance companies. These attempts to control drug costs may result in increased symptomatology, serious iatrogenic disorders that could be extremely expensive, and even patient deaths. For some patients, pharmacy benefits are provided by one company, while coverage for medical treatment is provided by another company, as a result of a contracting process focused on obtaining coverage for the lowest cost. When this happens, attempts by the PBM to limit drug costs may cause increased medical expenditures, but the PBM has no financial incentive to prevent or control this cost shift; to the contrary, it actually has an incentive *to* shift the costs to another company. Unfortunately, these practices are rarely regulated, and the PBM cannot be held liable for its results.

Another factor suggesting a policy advocacy role for mental health providers in this arena is the difficulty many regulators (not to mention many members of the general public) have in understanding the nature of addictive disease in the context of the use of controlled substances for pain and symptom management. Confusion about distinctions among physical dependence, tolerance, addiction, and pseudoaddiction leads to the implementation of policies that, while well intentioned, may impose an unintended consequence of erecting more barriers to the provision of adequate pain management for persons near the end of life. Several professional organizations have issued policy statements attempting to define relevant terms further, including the American Society of Addiction Medicine (American Society of Addiction Medicine, 1998), the Federation of StateMedical Boards (Federation of State Medical Boards, 2004) and a joint statement issued by the American Pain Society, the American Academy of Pain Medicine, and the American Society for Addiction Medicine (American Academy of Pain Medicine et al., 2001). These documents provide some helpful talking points for mental health providers, who, perhaps to a greater degree than other professionals, should understand the nature of addictive disease and be able to educate responsible regulators about the distinction between behaviors seen in individuals with these diagnoses versus individuals using controlled substances for symptom management. Helping legislators and regulators understand these distinctions and see the likely negative impact of their policies can be instrumental in avoiding these untoward outcomes. Mental health professionals may wish to review the PPSG Report Card for their states to determine if the existing policies are problematic, and undertake efforts to remedy this situation if it exists.

Becoming involved in policy advocacy at the state level will almost invariably involve significant outreach on the part of mental health providers to allies within other professions and practice organizations within the state. Seeking involvement in an interdisciplinary organization such as the state pain initiative (see aspi.wisc.edu/stcont.htm for contact information in each state) may be a valuable first step. Participants in these initiatives have a major focus on policy advocacy at the state level, seeking improved policies for all individuals with pain, including those at the end of life. Beyond these organizations, contact with the state hospice and palliative care organization, state long-term care organizations, and even state medical and nursing societies can position psychologists to play valuable and effective roles in efforts to eliminate policy barriers that impede adequate pain and symptom management. Often, individuals within these groups have already made efforts to understand the issues presented by current policies, and thus can serve a tutorial role for novice policy advocates.

Psychologists working in this policy arena also need to be cognizant of the fact that achieving significant policy change at the state level can be a tedious and protracted process. Changes to statutes commonly require more than one legislative session, and in states where the legislature may meet only every other year, the impact of this is multiplied. The legislative process also is rife with potential pitfalls, as representatives of many interests can appear unexpectedly and at the last moment to advocate for contrary legislation or for amendments that weaken or effectively nullify the intent of the proposed legislation. Within the regulatory arena, the outcomes are somewhat less unpredictable, but the process may be just as time-consuming. Changes to guidelines (typically practice guidelines promulgated by professional licensing bodies) may be the easiest to achieve, but may end up being least effective because they do not carry the force of law. Thus, the message to advocates entering this arena is that abundant patience and vigilance are also required if effective change is to be achieved.

Individuals who do not have the time, temperament, or ability to involve themselves at this level can still have powerful effects by playing secondary roles. These roles would have the mental health professional get to know his or her legislators, keep their contact information on file, and be ready to respond to action requests from other professionals or organizations involved in advocating for change. Given the number of constituents represented by state legislators, even a few messages of support for a given policy position may significantly impact a legislator's vote. An added benefit of such contact is that the professional involved may be noted by the legislator as someone to consult for education and advice if other related issues arise in the future.

Local/Institutional Issues

Symptom assessment, triage, and treatment. Most of the policy issues encountered on a more local level are based within specific health-care institutions, such as a hospital, hospice, or long-term care facility. As such, these policies typically will focus on practices such as symptom assessment, triage, and intervention. Mental health providers certainly can provide valuable input on these topics to the policy makers in their institutions, given that at least some, if not many, of the symptoms in question have significant psychological components.

An example of this involves the requirement by the Joint Commission that all patients in accredited health-care organizations have their pain assessed routinely, and that appropriate care be provided for any pain that is found. Psychologists, with their expertise in assessment, can provide valuable assistance to hospital committees designing appropriate assessment instruments and evaluating their effectiveness through an ongoing performance improvement effort.

Additionally, given that there are a number of nonpharmacological interventions that may be effective in relieving both acute and chronic pain (see Chapter 8), mental health providers can work with the appropriate institutional authorities to develop algorithms to identify patients who may benefit from these interventions and then to provide those services. Collecting outcome data as part of this clinical enterprise may demonstrate to the institution the cost savings, quality of life benefits, and patient satisfaction improvement resulting from these interventions.

Starting pain and palliative care clinical services. The second major area in which mental health providers may play a significant role within institutions is in starting clinical services designed to provide quality pain management and palliative care. These services can be organized in a number of different ways, such as consultation-based versus based on the pain and palliative care team becoming the primary service for the patient's care. There are many examples of services that were started at least in part as a result of the efforts of psychologists. For instance, one of this chapter's authors (RKT) played a role in starting both inpatient pain management and inpatient palliative care consultation services at an academic medical center.

Starting a new clinical service of this nature in a health-care institution certainly requires the development of an interdisciplinary team that can advocate for the service from the point of view of each of the disciplines represented. At a minimum, involved professionals need to include physicians, nurses, social workers, psychologists, and chaplains; other disciplines or services such as physical and occupational therapy, respiratory therapy, the ethics committee, and even the institution's financial management department may be required as well.

One key obstacle to the startup of new services typically is financial, with concerns raised by the institution that making an investment in pain management and palliative care may be costly and the financial benefits may be hard to realize. It is often true that these services are hard-pressed to demonstrate benefits to the institution in terms of increased revenue, and may actually decrease revenues. This is because, depending on exactly how services are structured, it may not be possible to bill for services provided; while this is happening, effective mental health intervention may reduce the need for other procedures that might bring more revenue to the institution.

Although increased revenues may be difficult, as alluded to earlier, there are opportunities to demonstrate significant cost savings (greater than the reduction in revenue) to the patient, the institution, and the health-care system in general. These savings are realized through such means as reducing days in intensive care units, days in the hospital, procedures performed, tests conducted, medications used, and so forth. Tracking these savings requires some financial sophistication, and is made much easier if the institution's financial management personnel are part of the team and invested in proving the financial value of the team.

CONCLUSION

As this chapter outlines, significant policy advocacy opportunities for mental health providers exist at federal, state, and local levels. In their ongoing effort to provide the greatest benefits to their patients, mental health providers can be seen as being ethically obligated to participate in these advocacy efforts in ways that are consistent with their practice and knowledge. This participation often requires the development of new skills for mental health providers. The alliances among health-care professionals and their representative groups that must be developed will serve all of those involved far beyond the immediate issue at hand. If current efforts to reform health care in the United States are to succeed, such alliances will be absolutely essential. The unique skills inherent in the practice of psychology, social work, and other counseling professions make mental health providers ideal professionals to initiate and nurture these alliances. After all, one of the central functions of mental health providers is the initiation and maintenance of a therapeutic relationship with clients. Application of these skills to relationships with individuals representing organizations with allied causes is really a small stretch, yet can have a huge impact on policy change.

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CHAPTER

14

Physician-Assisted Suicide in the United States

Issues, Challenges, Roles, and Implications for Clinicians

Silvia Sara Canetto

This chapter focuses on physician-assisted suicide in the United States. Specifically, it examines physician-assisted suicide policy in Oregon, the state where physician-assisted suicide has been legal for more than a decade. Its main goal is to educate clinicians about current issues, debates, complexities, and challenges in physician-assisted suicide policy and practice. Some may think this is well-trod territory for mental health professionals, but the information reviewed here draws attention to facts and perspectives sometimes overlooked in the literature. Whether or not clinicians work in a state where physician-assisted suicide is legal, it is important that they are informed about current issues and debates in physician-assisted suicide so as to be able to critically examine relevant evidence as well as contribute their expertise to its policy and practice. Another goal of this chapter is to articulate the implications of Oregon's physician-assisted suicide policy for a diversity of older adults in the United States. Older adults are the most affected by physician-assisted suicide policies because older adulthood is the time of life when physician-assisted suicide is most likely to be considered.

DEFINITIONS AND TERMINOLOGY

Physician-assisted suicide typically is defined as the deliberate and knowing provision, on the part of a physician, of means and/or information to enable a patient's suicide (American Medical Association, 2008–2009). Physician-assisted suicide is distinguished from *euthanasia*, which involves the physician directly implementing the means (e.g., administering the lethal dose of medication) to end the patient's life. There is debate on the best terms for these forms of death (Gordon et al., 2000). Some prefer words such as *physician's-aid-in-dying*, *physician-assisted death*, or *patient-directed aid in dying*. The intent of these terms is to accent the *aid* part of the behavior, and to frame the life-ending act of a terminally ill person as something other than a suicide (Farrenkopf & Bryan, 1999; Tucker & Steele, 2007). Consistent with this perspective, the Oregon Death with Dignity Act (Oregon Department of Human Services [ODHS], 2009) states that, "ending one's life in accordance with the law does not constitute suicide." Yet others object to using terms like *physician-assisted death* for physician-assisted suicide because such use appropriates for *hastened death*, terms that can refer to physicians providing medical care at the end of life (Callahan, 2008). Most professional publications in the field, including Oregon's Death with Dignity Act (ODHS; http://egov.oregon.gov/DHS/pj/pas), use the term *physician-assisted suicide*. In fact, some advocates of assisted suicide, including a founder of *The Hemlock Society*,[1] object to renouncing the term *assisted suicide*, calling the substitute "death with dignity" "wildly ambiguous" (Humphry, 2006, p. A8). Hence, *physician-assisted suicide* is the term of choice in this chapter, with the term *hastened death* used here to refer to either assisted suicide or euthanasia or both.

HASTENED DEATH POLICIES

In the United States, physician-assisted suicide has been legal in Oregon since the passing of the Death with Dignity Act in 1997. The Oregon Death with Dignity Act is similar to legislation enacted in 2008 in Washington State. In December 2009, Montana became the third state to legalize

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[1] *The Hemlock Society* merged with *Compassion in Dying*, with the new organization adopting the name *Compassion and Choices*. The new organization's name completely avoids an association with death.

physician-assisted suicide. The Montana Medical Association has no policy on physician-assisted suicide. By contrast, the Washington State Medical Association opposes physician-assisted suicide, consistent with the American Medical Association's (2008–2009) policy, which views physician-assisted suicide as "incompatible with the physician's role as healer," difficult or impossible to control, and risky. The Oregon Medical Association has maintained a neutral stance on physician-assisted suicide. Internationally, physician-hastened death is legal since 2002 in the Netherlands (though it has been permitted since the 1980s), and since 2001 in Belgium. In the Netherlands, where both assisted suicide and euthanasia are legal, unremitting pain and suffering, rather than terminality, are criteria for assisted suicide and euthanasia. Similarly, in Belgium, euthanasia is available for individuals who report constant and unbearable physical or psychic suffering due to a medical condition without exit. Finally, hastened death has been legal since 1918 in Switzerland, where it does not require a physician's involvement, and where, since 2006, it is permissible for individuals with mental disorders (Appel, 2007).

Oregon's Death With Dignity Act

Under the Death with Dignity Act, adult Oregon residents can obtain and use prescriptions from a licensed Oregon physician "for self-administered, lethal medication" as long as certain conditions are fulfilled. These conditions include that the individual is "diagnosed with a terminal illness that will lead to death within 6 months," with the prescribing and a consulting physician confirming the diagnosis and prognosis. The statute does not specify how the prescribing and consulting physicians are to be chosen with regard to specialty or relationship to the patient. No provision is made for an independent selection of the consulting physician. The prescribing and consulting physician must determine whether the individual is capable ("defined as able to make and communicate health care decisions"). They also have the responsibility to determine whether the patient is acting voluntarily and is making an informed decision. If either physician believes the patient's judgment is impaired by a mental disorder, the patient must be referred for a psychological examination. "No medication to end a patient's life in a humane and dignified manner shall be prescribed until the person performing the counseling determines that the patient is not suffering from a psychiatric or psychological disorder or depression causing impaired judgment," it is stated. In addition, "the prescribing physician must inform the patient of feasible alternatives to assisted suicide, including comfort care, hospice care, and pain control." Finally, "to receive a prescription for lethal medication the following steps must be fulfilled: The patient must make two oral requests to his or her physician, separated by at least 15 days. The patient must provide a written request to his or her physician, signed in the presence of two witnesses." The statute does not indicate whether the prescribing physician must, may, or may not be present at the patient's death (ODHS; http://egov.oregon.gov/DHS/pj/pas).

A Critical Analysis of Oregon's Death With Dignity Act

In this section, I review individual clauses of Oregon's Death with Dignity Act. Specifically, I describe what they are intended for, evaluate a diversity of views as to their applicability and impact, and report on empirical evidence that may enlighten the analysis. I also consider the possible different meanings and impact of Oregon's assisted-suicide policy on a diversity of older adults, by sex, social class, ethnicity, and health/ability status, in light of the large variability of U.S. older adults' values, social status, power, experiences, and resources, and also in the context of this country's dominant ideologies of aging, gender, ethnicity, and illness. This analysis aims at a contextualized examination of the meaning and impact of end-of-life policies, experiences, and decisions. In the United States, the dominant discourse is that physician-assisted suicide is about individual choice and agency. Self-determination values and assumptions are built into Oregon's Act conditions for eligibility and approval. This analysis is meant to reveal the complexity of the meanings and implications of physician-assisted suicide policies for a diversity of U.S. older adults.

The individual is diagnosed with a terminal illness that will lead to death within six months. This clause is meant to ensure that physician-assisted suicide is available only to individuals whose death is imminent because of a terminal illness.

A complexity in this clause is that different criteria—ranging from statistical criteria to disease severity—are used in medical practice to define terminality (Cohn & Lynn, 2002). "Persons with atherosclerotic disease are not considered to be terminally ill even though their deaths may occur at any moment," observe Drickamer, Lee, and Ganzini (1997, p. 149).

In addition, terminality prognoses are subject to error (Fox et al., 1999). Physicians generally view as difficult to predict with reasonable reliability a six-month life expectancy. This is true also of Oregon physicians, who, when surveyed, were not confident they could make such a prediction (Lee et al., 1996). In fact, accurate life-expectancy prediction is generally considered unfeasible until days before death (Cohn & Lynn, 2002). Prognostic accuracy also depends on the conditions involved—better in cancer, worse in cardiovascular disease (Foley & Hendin, 2002). Furthermore, prognostics for survival are affected by treatment, "which can depend on patient and physician choice, availability of services, or the nature of the illness, or some combination of these" (Cohn & Lynn, 2002, p. 254). A complexity in the application of the Oregon policy is that the law does not specify whether the six-month period is to be estimated with or without treatment (Foley & Hendin, 2002).

Because of ambiguities in Oregon's Act terminality clause, the Washington Medical Association recommended (unsuccessfully) that its state policy restrict eligibility to incurable and irreversible illnesses. The Washington Medical Association also proposed that its law require more documentation of the illness than is the case in Oregon (O'Reilly, 2009). Other medical experts noted that the Oregon's Public Health Division data on the Death with Dignity Act indicate that a significant number of individuals who receive a lethal prescription live beyond the six-month prognosis. To allow an evaluation of the reliability of the terminality criterion, they recommended that a record be kept of the months elapsed between the time when the individual receives the six-month prognosis for the purpose of obtaining a lethal medication prescription and the time of death. In the meantime, absent this information, the terminality clause in the Oregon statute is of unknown reliability (Hendin & Foley, 2008).

The debate on terminality assessment has implications for clinicians providing psychological care for individuals at the end of life. Clinicians should take the initiative to educate themselves and their mental health colleagues about medical debates on terminality, and to promote a more nuanced understanding of terminality. Clinicians should also ensure that individuals at the end of life are informed about the imprecision of most terminality prognoses.

The prescribing and consulting physician must determine that the individual is capable ("defined as able to make and communicate health care decisions"). This clause is to ensure that individuals requesting assistance in suicide are cognitively and emotionally well enough to make and communicate "reasonable" health-care decisions.

A major problem with this clause is that a definition of capacity is not given. Also, standards for decisional capacity specific to requests for physician-assisted suicide are not available. In other words, "there are no criteria and no agreed-on standards for identifying the impairment that may make a patient incapable" of such a grave decision as assisted suicide (Foley & Hendin, 2002, p. 152). Furthermore, the Act does not specify whether capability is to be determined on the basis of the "logic" of the decision-making process or the "rationality" of the outcome.

Yet another complexity in applying the capability criterion to assisted-suicide situations is that persons requesting assisted suicide are seriously ill, and therefore cognitively and emotionally taxed by the effects of the illness as well as the powerful medications they may be taking. This means that assisted suicide petitioners are unlikely to be consistently capable of making and communicating complex decisions. They may be capable one day or one hour, but not the next; or they may be capable to deliberate and communicate about some issues but not others (Martyn & Bourguignon, 2000). Some advocates of assisted suicide have argued that to meet the assisted-suicide capability requirement, the individual does not need to demonstrate global psychological capability, only capability in the decision about physician-assisted suicide (Farrenkopf & Bryan, 1999). The Death with Dignity Act does not specify how consistently (over time and over issues) capable the petitioner is to supposed to be to pass the capability test.

Some advocates of assisted-suicide believe that assisted-suicide-specific capability standards and evaluations can and should be developed. For example, Werth, Benjamin, and Farrenkopf (2000) argue that assisted-suicide-specific capability evaluations are feasible as long as one conducts extensive interviews, uses both structured and open-ended methods, and extends the assessment over a period of time. Werth and colleagues also state that, given the complexity and implications of the assisted-suicide evaluation, it is not appropriate to use general mental capacity questions (such as identifying the name of the current President) or quickly administrable instruments. They recommend probing into the many possible motivations for the assisted-suicide request, including "cultural . . . issues, ambiguity, ambivalence, anxiety, depression, hopelessness, helplessness, or rigid thinking . . . fears of pain, death and dying, or being a burden . . . feelings of guilt, self-punishment, or the perceived need for atonement … loss of control . . . feelings of rage and/or revenge . . . personal and social system resources . . . financial pressures . . . the person's value structure," and so on (p. 268). Other advocates of physician-assisted suicide (Sullivan, Ganzini, & Younger, 1998) agree that capability assessment is a complex task, but precisely because of the task complexity, they recommend the opposite; that is, that no capability evaluation be performed. Capability to make logical, rational decision is a social, not a scientific construct, they argue. In the case of assisted suicide, a capability evaluation ends up being a subjective evaluation of the patient's quality of life, they note. Specifically, according to them, "in the absence of robust independent standards," physicians will evaluate assisted-suicide requests against personal values, based on their personal answers to questions like: "Do I agree that this patient has an intolerable quality of life? Would I consider such a quality of life intolerable for myself? Would I consider suicide morally acceptable in this situation?" According to Sullivan and colleagues, physicians "should not have the social authority to use themselves as the measure of when it is right to die" (1998, p. 26). In other words, according to these assisted-suicide advocates, the capability evaluation is a pseudoscientific requirement to be omitted from the evaluation process because it arbitrarily delays the exercise of self-determination in dying.

Opponents of assisted suicide concur with the perspective that the capability evaluation clause is unworkable because of conceptual and empirical limitations, but they view these limitations as an argument against assisted suicide rather than a reason to proceed without such an evaluation (Hendin & Foley, 2008). Disability experts (Coleman, 1992, 2002; Gill, 1992, 1998; Longmore, 2005; Olkin, 2005) have raised other concerns about the capability clause. They point to evidence that people without disabilities assess the quality of the lives of people with disabilities to be dramatically lower than do people with disabilities, and they wonder whether a request for physician-assisted suicide from a person with disabilities might then "be subject to less scrutiny because the decision makes sense to others" (Olkin, 2005, p. 70). "A 'competent' person knows that society considers the need for assistance in activities of daily living to be degrading and undignified," writes Coleman (2002, p. 224). "In other words, when asked to describe the 'indignities' that assisted suicide would help people avoid, proponents describe disability" (Coleman, 2002 p. 220). "If professionals think that of course the disabled person would want to die" because of the indignities of disability, "might not these expectations play a disheartening role in someone's decision to seek physician-assisted suicide?" asks Olkin (2005, p. 70).

In conclusion, capacity assessment may be "the Trojan horse" of assisted-suicide policies (Martyn & Bourguignon, 2000, p. 388). Like the Trojan horse, it is meant to provide protection, but it hides dangers. Its chief danger is that it is subjective. As advocates of assisted suicide recognize, "clinicians are left to decide on their own [what to use and] how strict a standard to use" (Werth et al., 2000, p. 356).

Clinicians asked to bring their expertise on assessments of the capability to make requests to die should exercise great caution in what they promise they can deliver. They should be educated and educate others about the limits of scientific knowledge on capability assessment. They should also be aware about the danger, in the absence of scientifically robust standards, that ableist biases influence evaluations of the rationality of physician-assisted suicide requests.

The patient must be determined not to suffer from a mental condition impairing judgment. If either physician believes the patient's judgment is impaired by a psychiatric or psychological disorder, the patient must be referred for a psychological evaluation. No medication to end a patient's life in a humane and dignified manner shall be prescribed until the person performing the counseling determines that the patient is not suffering from a psychiatric or psychological disorder or depression causing impaired judgment. This clause, like the one about capacity, is meant to provide safeguards against the influence of psychological disorders on judgment, but it is so vague and weak to be practically meaningless. First of all, it is an "exceedingly minimalist" clause (Burt, 2000, p. 383) because it rules out only mental conditions that impair judgment. In other words, the clause allows for petitioners to have mental disorders as long as these disorders do not impair judgment—an oxymoron based on current U.S. mental evaluation standards (Burt, 2000; N. G. Hamilton & Hamilton, 2005; Sullivan et al., 1998). Another paradox in the mental disorder clause is that within current standards, suicidal ideation is a symptom par excellence of impaired judgment and mental disorder. In fact, suicidal ideation is one of the few legal justifications for involuntary psychological treatment (Sullivan et al., 1998). Based on current clinical standards, the presence of suicidal intention calls for an automatic finding of incompetence and obligates the clinician to suicide prevention, including removal of lethal means. By contrast, within the physician assisted-suicide competence model, providing the lethal means is the main decision to make in response to suicidal intention (N. G. Hamilton & Hamilton, 2005). Whether petitioners receive suicide prevention or suicide enabling depends solely on their health or disability status, which disability experts view as evidence of, and a vehicle for ableist ideologies (Coleman, 2002).

The issue here, as in the case of capacity assessment, is that there is no clinically or scientifically meaningful system for separating rational from irrational suicidal thoughts. The paradox of the mental-disorder clause in the Oregon statute may be lost on some prescribing and consulting physicians because neither is required to be a psychiatrist; that is, to have training in mental disorders. Studies show that physicians are not reliably capable to diagnose depression, let alone to evaluate whether the depression is interfering with judgment (Foley & Hendin, 2002). In fact, nearly all Oregon psychiatrists participating in a survey reported they could not adequately determine whether a psychiatric disorder impairs the judgment of a person requesting assisted suicide (Ganzini, Fenn, Lee, Heinz, & Bloom, 1996). Oregon physicians have problems in identifying depression in individuals requesting assisted suicide and this is confirmed by a study of the prevalence of depression in individuals who received a prescription for a lethal drug under the Act (Ganzini, Goy, & Dobscha, 2008). This study found that one in six individuals who received a lethal prescription met the criteria for depression. This finding is remarkable considering that this study's protocol allowed suicidal ideation to count toward a diagnosis of depression "only if the patient endorsed suicidal thoughts or plans aside from aid in dying" (p. 2).

Another paradox in the statute is that the mental disorder clause is paired with a requirement for treatment when petitioners are found to have a mental disorder that impairs judgment. Theoretically at least, individuals requesting physician-assisted suicide are to be treated for their judgment-impairing mental disorder, say depression, so that their disorder can be lifted and they can proceed with the suicide. Consider what this clause means in practice. When the relief sought by the individual is assisted suicide, "how many trials of how many different kinds of interventions would be appropriate before the clinician and patient are prepared to agree that the end had been reached?" given that, in this case, "there is one pharmacological intervention looming over this interaction that will obviously and completely eliminate the patient's problems by, of course, eliminating the patient," asks Burt (2000, p. 384). In practice, this dilemma rarely materialized in Oregon because during the 12 years the Act has been in force, a minority (8%) of petitioners were referred for mental health consultation, with the percentage of referrals declining over the years (the referral percentages were 0% in 2009, 3% in 2008, and 0% in 2007) (ODHS; http://egov.oregon.gov/DHS/pj/pas). This decline in referrals is despite the call for "increased vigilance and systematic examination for depression among patients who may access legalized aid in dying" by the authors of a study revealing that 17% of Oregon individuals who received a lethal prescription and died of assisted suicide were depressed (Ganzini et al., 2008, p. 5).

In conclusion, the Oregon's statute guidelines regarding mental disorders in persons requesting physician-assisted suicide are vague, minimalist, and inconsistent with current diagnostic standards and practice. Therefore, it is not surprising that even according to under-inclusive criteria, 17% of cases of depression in Oregon individuals who received a lethal prescription under the Act were missed or overlooked (Ganzini et al., 2008). Studies conducted outside of Oregon have found much higher percentages of depression in individuals interested in hastened death (Blank et al., 2001, Breibart et al., 2000; Chochinov et al., 1995; Emanuel, 2005; Emanuel, Fairclough, & Emanuel, 2000; Rosenfeld et al., 2006; Wilson et al., 2000; Wilson et al., 2007). For example, in a Canadian study of terminally ill individuals with cancer, the prevalence of depressive symptoms was 59% among individuals with a pervasive desire to die, but only 8% among those without such desire (Chochinov et al., 1995). What accounts for the differences in depression between Oregon's and other locations' patients interested in hastened death is undetermined and debatable.

Most vulnerable to being undiagnosed under Oregon's mental condition criteria are persons whose depression is assumed to be normal because of their challenging personal circumstances. Depression and the wish to die are more typically overlooked and normalized in individuals who are older, seriously ill, and/or have disabilities (Canetto, 1997; Coleman, 2002). For example, studies show that suicide by an older person is considered less tragic than suicide by a younger person. Similarly, physical illness is perceived as the most understandable precipitant of suicide (Canetto, 1997).

The implications for clinicians of the Oregon Act's mental condition clause are manifold. Because this clause defines clinicians' role in ambiguous and contradictory ways, clinicians should strive to participate in policy review and development. For example, clinicians should use their expertise about mental disorders to educate about the tensions and contradictions, in evaluations of requests to die, between the general mental disorder model and the assisted-suicide mental disorder model. They could also contribute to articulating the scientific and ethical dilemmas in the expectation that mental health professionals treat depressed assisted-suicide petitioners so that the depression is lifted and the assisted-suicide prescription is granted. Furthermore, clinicians could contribute to policy development insights from studies on ageist and ableist biases—specifically how these biases may influence not only perceptions of the rationality of assisted suicide requests, but also the will to live of stigmatized individuals (Levy, 2009).

The prescribing and consulting physician must determine that the patient is acting voluntarily, that is, free from undue outside influences. The clause of voluntariness is meant to safeguard against external pressure and coercion. Assessing voluntariness is another well-meaning but unattainable condition under the Oregon statute guidelines. In the Act, voluntariness is defined as freedom from undue outside influences. To start, it is to be recognized that being sick creates a situation antithetical to independent decision making. In fact, being seriously sick requires reliance on caregivers for almost everything, including judgments and decisions about health care. In this context, it is easy for professional and/or family caregivers to inadvertently exert inappropriate and even coercive influence (Cohn & Lynn, 2002). For example, physicians have control and authority over key information regarding prognosis, treatment, and treatment appropriateness. "Like many technical experts, they are masters at framing the options to guarantee a particular outcome," note Kass and Lund (1996, p. 408). When a physician tells a patient about an illness with a terrible prognosis and includes among the options "a 'gentle quick release,' " what will the patient likely choose, especially in the face of a spiraling hospital bill? (p. 408). Furthermore, professional and family caregivers bring their own needs, emotions, and agendas to the situation. That these needs, emotions, and agendas are not directly communicated to the ill individual, and that they may, in fact, be unconscious, does not make them less powerful. For example, physicians may feel frustrated and inadequate about irreversible medical problems in their patients, and may have difficulties responding therapeutically to seriously ill or dying patients (Miles, 1994). Similarly, family members may feel burdened by the care demands of seriously ill relatives. They may be demoralized about the intractability and severity of their relative's illness. They may wish to withdraw from the sick person to avoid the anguish of caring for someone without hope for recovery. In such emotionally intense conditions, professional and family caregivers may acquire an inflated sense of their insight into the sick person's feelings and wishes. For example, they may interpret as constant and inevitable the sick persons' demoralization or as unambiguous their death wish; and they may end up steering the sick person toward assisted suicide because of their own, rather than the sick person's discomfort with the dying process (Meier, Myers, & Muskin, 1999; Muskin, 1998; Wolf, 1996).

A voluntariness evaluation would be difficult to obtain even with information from individuals who have influence on the petitioner, that is, at a minimum, family and professional caregivers. Oregon Act's, however, does not require that the petitioner's family be informed about the assisted-suicide request. There is also no requirement that the prescribing or the consulting physician consult with the petitioner's usual professional caregivers, or with other physicians the petitioner may have contacted to obtain a lethal prescription. Without information from individuals who may have influenced, or may know who influenced the assisted-suicide decision, the Oregon's Act assessment of voluntariness is reduced to a legal formality (Burt, 2000).

Another challenge in voluntariness evaluations has to do with the role of social ideologies on perceptions of voluntariness as well on the actual voluntariness of the suicide request. A place to start is gender ideologies. Women and men face distinct and sometimes contradictory gender-related pressures with regard to the independence of their assisted suicide decision. On the one hand, women experience more of the life conditions that are assumed to involve poor quality of life and that may make their request for physician-assisted suicide appear rational and freely chosen. For example, older women are more likely than older men to be widowed and to live alone or in extended care facilities (Canetto & Hollenshead, 1999–2000). In addition, women live longer than men, and in poorer health. Therefore, at a certain age, women may be perceived, and/or may see themselves as having lived enough—especially if they have been homemakers and thus may be seen, and/or see themselves as having fulfilled, according to a biographical criterion of a "completed life," their life purpose (Canetto & Hollenshead, 1999–2000). According to Callahan (1995), death is tolerable when it involves persons who have reached a certain age, accomplished their life goals and fulfilled their moral obligations. On the one hand, precisely because women experience more social and economic adversities, especially when older, they are also more likely to be viewed as vulnerable to coercion in physician-assisted suicide (Canetto & Hollenshead, 1999–2000).

The role of gender ideologies on decision making is also complicated. On the one hand, men are assumed and expected to be more independent and rational thinkers than women (Jecker, 1994). As a result, the voluntariness of men's decisions, including assisted-suicide decisions, may be less questioned. For women there is an expectation and a presumption of subordination, with the consequence that their decisions, including assisted-suicide decisions, may be less likely to be, or to be interpreted as, independent (Canetto & Hollenshead, 1999–2000; Wolf, 1996).

Women's and men's decisions are also influenced by experiences and social ideologies associated with their other characteristics and identities, including their ethnicity, education, and ability status (Gordon et al., 2000). In general, individuals with lower status, power, and with fewer resources (e.g., ethnic minorities) are, and/or are assumed to be more vulnerable to coercion than higher status, more powerful, and resource-rich individuals.

Assessing assisted-suicide voluntariness is yet more complex than taking into account of intersections of identities and power. It requires considering dominant ideologies of assisted suicide, and in the context of other social ideologies (e.g., ideologies of gender, ethnicity). In this respect it is notable that the U.S. dominant discourse of assisted suicide, while in some ways geared toward men in its emphasis on self-determination, is also in many ways framed to appeal to women. Assisted suicide is labeled "gentle deliverance," "a soft landing" (Lessenberry, 1997, p. 82), and "a graceful exit" (Basta, 1996). Its practice is medicalized—it is a "procedure" requiring a prescription, and delivered by a powerful authority (Canetto, 1995; Canetto & Hollenshead, 1999–2000). Assisted suicide is also presented as a form of empowerment, as a new freedom for women—the "last choice" of modern, independent, intelligent, fashionable (White) women, as argued in *Vogue* magazine (Friedman, 1997). Furthermore, physician-assisted suicide is promoted with white female faces. Nearly all cases of hastened death publicized in the media have involved White women (Canetto & Hollenshead, 1999–2000, 2000–2001; Wolf, 1996). That White women have embraced assisted suicide for themselves, though they may be wary of it when it involves others, is suggested by the fact that (White) women represent about half of Oregon's assisted suicide cases (ODHS; http://egov.oregon.gov/DHS/pj/pas)—despite the fact that in surveys women are less likely than men to support hastened death (Gordon et al., 2000). The strong representation of women (47%) among Oregon's assisted suicides is striking in light of the fact that in the United States, women are a minority of the suicides, particularly in the age group when assisted suicide is most common. Among persons 65 and older, the rate of female suicides is 7.7 times smaller than males' (American Association of Suicidology, 2010).

In conclusion, assessing assisted suicide voluntariness requires evaluating a complexity of social and individual factors. This analysis suggests that a diversity of factors may bring one vulnerable group, older White women, to view themselves, and to be viewed by others, as particularly appropriate candidates for physician-assisted suicide.

Being aware of the limitations of the voluntariness criterion in Oregon's assisted-suicide policy, clinicians may be inspired to take initiatives to stimulate, at the local and national level, professional discussions and research on the topic. An outcome of these activities would be new clinical and research evidence to contribute to policy.

The prescribing physician must inform the patient of feasible alternatives to assisted suicide, including comfort care, hospice care, and pain control. This clause represents an attempt to guarantee that individuals requesting assistance in ending their lives are informed about other options, including palliative care.

A limitation of this clause is that prescribing physicians are not required to be knowledgeable about alternatives to assisted suicide, nor required to refer the petitioner to a colleague who is. If they do not have expertise about alternative care, they are also unlikely to be able to offer good information about other options (Hendin & Foley, 2008).

Another limitation of the clause on providing information about alternatives is practical. It is one thing to be informed about other options, and another to be able to access them. In the United States, a major barrier to health-care choices for many is cost. By way of the privilege associated with being male, White, educated, employed, having a good income, and/or good medical benefits, some individuals can access many care alternatives, and even worry about excessive and futile treatment. By contrast, less privileged others have few or no options. For the latter group, being informed about alternatives to assisted suicide—all of which cost more than assisted suicide—does not mean much in terms of access. Studies show that individuals are more likely to refuse care if they are concerned about cost (Covinsky et al., 1996). The idea of tempting health-care providers to encourage the sick to minimize end of life costs via assisted suicide has been suggested (Kreimer, 1995). Consider, for example, the article entitled "Dying for money: Overcoming moral hazard in terminal illnesses through compensated physician-assisted death." Its author, an economist, proposed that financial incentives be offered for electing hastened death over life-extending interventions. He dedicated the article to his mother, whose death he wished had been hastened (Fung, 1993).

Another condition influencing access to care is a sense of entitlement. Individuals differ in their sense of entitlement. These differences are influenced by social ideologies about the value of different kinds of individuals, depending on characteristics such as sex, age, and functional status. In the United States, women, the very old, and persons with disabilities are socially devalued, relative to men, the young, and those who are conventionally able. Other personal characteristics, such as being an ethnic minority, are also typically associated with lesser social value. Entitlement is also influenced by the degree to which individuals internalize prevalent social norms about their worth and rights. Compared to, for example, ageist stereotypes (which become relevant during a fraction of one's life), gender stereotypes involve lifelong exposure and influence (Jecker, 1991). For this reason, women are likely more vulnerable to internalizing a socially-driven low sense of personal value and entitlement than say, older adults. Because of variability in the disability experience, including the age when the disability started, there are likely differences in the extent to which individuals with disabilities internalize dominant ableist views and expectations about themselves (Coleman, 2002; National Council on Disability, 1998). Being an ethnic minority also brings threats to self-worth and entitlement. At the same time, there is some protection against negative ethnic stereotypes for ethnic minorities who, by virtue of being part of an ethnic minority community, are exposed to ideologies, experiences, and models challenging dominant racist discourse and practices (Dawson, 1998).

Studies of preferences about, and receipt of, care across a diversity of older adults are consistent with the entitlement analysis above. Women ask for less, and receive less quality care than men. For example, women are less likely to express a preference for, and to receive life-extending care than men (Bookwala et al., 2001; Frankel, Oye, & Bellamy, 1989; Garrett, Harris, Norburn, Patrick, & Danis, 1993). They are also less likely to receive major diagnostic and therapeutic interventions when seriously sick (Council on Ethical and Judicial Affairs, American Medical Association, 1991). In addition, women are more concerned than men about being a burden when sick (Canetto & Hollenshead, 1999–2000, 2002). When terminally ill and dying, women receive less assistance than men from family members, even when they are married (Emanuel et al., 1999). By contrast, ethnic minorities receive less but they want more medical care. For example, they express a preference for more care, independent of the medical condition (Blackhall et al., 1999; Caralis, Davis, Wright, & Marcial, 1993; Hornung et al., 1998). Ethnic minorities are also well aware of the discrimination they face, and therefore enter medical relationships with a healthy distrust (Dula, 1994). For example, in a study of concerns about end-of-life care, older blacks expressed concerns about past inequities and what these inequities mean for current care. By contrast, older white women, like older white men, thought it would be important to have care choices (Duffy, Jackson, Schim, Ronis, & Fowler, 2006).

In conclusion, requiring physicians to inform petitioners about alternatives to assisted suicide is insufficient to support petitioners' consideration and access to a diversity of options. Because of their mixed experience of privilege and discrimination, older White women may be particularly vulnerable to elect assisted suicide with limited awareness of the social influences on their choice. Being aware of the complexity of explicit, practical, as well as implicit, psychological barriers to end-of-life care options, clinicians should take the lead in educating other professionals about the role of internalized stigma on end-of-life choice, and in facilitating consideration, by their end-of-life clients, of a range of care alternatives.

CONCLUSION

This chapter aimed to inform clinicians about issues, debates, and complexities in assisted-suicide policy and practice, in consideration of the diversity of U.S. older adults. Another goal was to highlight end-of-life issues to which clinicians can contribute their expertise. As a way to focus, attention was directed to the Oregon Death with Dignity Act, a policy in effect for more than 10 years.

"Oregon's assisted suicide law has been hailed as a model statute, legalizing a purportedly narrow right to assisted suicide, with safeguards carefully crafted to prevent abuses and coercion," wrote Coleman (2002, p. 223). As Coleman, a disability lawyer, as well as other medical and law experts (Burt, 2000; Coleman, 2002; Hendin & Foley, 2008; Martyn & Bourguignon, 2000) have noted, the Oregon law is, however, far from being carefully crafted and narrowly framed. This review shows that in its current form, the Oregon statute does not offer the protections it intends and promises. What is presented as an opportunity for individuals to safely exercise a new choice—that is, self-determination in dying (ODHS, 2009)—is fraught with vagueness, loopholes, and inconsistencies. This review suggests that some socially disadvantaged groups may be more vulnerable than others under Oregon's Act. Perhaps paradoxically, the most vulnerable are not individuals from the most socially disadvantaged groups. This may be because individuals from these groups (e.g., Black women) have learned to distrust dominant medical institutions and prescriptions. Case in point: Blacks in the United States show neither interest nor participation in so-called right-to-die options (Dawson, 1998). In the case of assisted suicide, it is older White women who appear particularly vulnerable, likely as a result of their unique experience of both privilege and discrimination.

Because the Act has been in effect for more than 10 years, the risks are that not only its problematic practice continues unexamined and unchallenged in Oregon, but also that other states uncritically adopt its stipulations. The latter is exactly what Tucker, a pro assisted-suicide lawyer, was quoted as wishing, after the Supreme Court approved assisted suicide in Montana: "Montana doctors should now feel comfortable adopting procedures that doctors in the other two states use" (Associated Press, 2009). Once familiar with Oregon's Act, many clinicians are likely not going to be comfortable with it. The information generated by this analysis calls for vigorous participation, on the part of clinical researchers and practitioners, in assisted-suicide education and policy development, to help articulate and change, using the best of clinical science, the limitations in the current statute.

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CHAPTER
15

Creating Ethics Conversations in Community

Malham M. Wakin

Much attention has been directed to ethical decision making on end-of-life issues over the past 30 years by national media exposition of the cases of Karen Ann Quinlan, Nancy Cruzan, and Terri Schiavo. All of these young women were described as being in a persistent vegetative state for several years and their bodily functions were being maintained by life-support interventions in long-term care facilities. After numerous court judgments associated with these three highly publicized cases and several others, a pattern of conclusions about legally and morally accepted practice has developed. It seems clear that the principle of respect for patient autonomy has received overwhelming support. What does this patient want done medically? What has she told us about treatment preferences when she was competent to make decisions about her own health care? Did she sign a living will? Is there a signed medical power of attorney? Who speaks for her when she is no longer able to speak for herself? Is there agreement among family members, friends, and primary caregivers about treatment and palliative care?

The lengthy dispositions of the three cases mentioned above were caused because there were no advance directives indicating the wishes of the three women. There were disagreements among family members, hospital administrators, primary medical caregivers, attorneys, even politicians, concerning the discontinuance of life-sustaining treatments including ventilators and stomach tubes (oxygen assistance and artificial nutrition and hydration). Eventually, each of the three cases was decided by the courts (the Cruzan case reached the Supreme Court) and in each case the aggressive medical interventions were discontinued in favor of palliative care and each of the young women died. In all of the cases, it was determined that there was no cognitive brain activity in the patients.

These highly publicized cases have caused us to pay much more attention to the question of advance directives and to ways we can spare our loved ones the terrible emotional trauma that sometimes accompanies the dying process. We have learned that there is great reluctance on the part of individuals to discuss or take action in preparing advance directives, especially when death is not perceived as imminent. We have also experienced extreme reluctance on the part of family members to discuss end-of-life wishes with a loved one, even one for whom death is a likely outcome in the near future. There is often even reluctance on the part of caregivers to initiate a conversation about patients' wishes for fear of offending or of causing discomfort because of a lack of experience or confidence concerning a workable process.

ONE COMMUNITY'S APPROACH

In 1996, a small group, including physicians, elder attorneys, probate judges, ethicists, clergy, and older citizens, sponsored a discussion of end-of-life ethical issues at a courthouse in Colorado Springs. This was followed soon after by a larger conference held at the University of Colorado in Colorado Springs with expert speakers and spirited public interaction. One result of these community meetings was the formation of an action group called the Pikes Peak Forum for Health Care Ethics. This group's membership included many health-care professionals, elder attorneys, probate judges, nurses, health-care insurance people, representatives of several religions, nursing home staff members, ethicists, lay senior citizens, hospital staff members—a good cross-section of involved health-care constituents, numbering as many as 65 concerned members of the local Colorado Springs community.

The Pikes Peak Forum for Health Care Ethics became an incorporated nonprofit 501c organization and set out an ambitious agenda for discussion and research. Initially, its agenda included using subcommittees to study such issues as neo-natal technology advances, long-term care facilities and practices, physician-assisted suicide initiatives around the country, and other issues. The primary focus, however, was clearly on end-of-life issues and gradually all of the other issues and subcommittees were abandoned in favor of developing a set of community guidelines for assisting decision making at the end of life. Monthly meetings and discussions eventually led to the development of a set of 11 basic ethical principles and eight guidelines. So much interest developed around the issue of artificial nutrition and hydration that a subcommittee developed a lengthy description of the various tube-feeding options and the questions relevant to their use and issues surrounding their discontinuance. During this process, four members of the Forum met bimonthly with four members of a Denver-based group called the Colorado Collective for Medical Decisions, and jointly discussed the proposed guidelines for end-of-life decisions. Unlikely as it may seem, after four years of monthly discussions by the Pikes Peak Forum and two years (overlapping) of the bimonthly discussions with the Denver group, agreement was reached on the wording of eight guidelines. Each of the two committees subsequently published and distributed their own versions of these agreed-upon guidelines. The Pikes Peak Forum for Health Care Ethics obtained grants to fund publication of a total of 13,000 pamphlets entitled *Decisions About the End of Life . . . Help for Those Who Must Decide*. The Forum also paid the Colorado Springs *Gazette* newspaper to publish the pamphlet as a supplement to a Sunday edition so that it had the potential for being read by 170,000 subscribers. Numerous meetings were held with hospital staffs, adult discussion groups, church-related forums, senior center audiences, related college level courses, and medical ethics committees throughout El Paso and Teller counties in Colorado.

A newly formed group of medical professionals called the Thanatology Committee of the El Paso County Medical Society assumed the task of educating medical professionals on dealing with end-of-life issues. Two-day seminars were offered, principally to physicians, 4 times during a four-year period. A third committee, the Robert Wood Johnson Foundation–sponsored Rally Points Committee, was formed as a community-oriented group ultimately aiming toward the development of a "toolkit" to assist medical staff members in initiating discussions with patients about their treatment preferences long before they were facing serious terminal illnesses and while they were fully competent to make serious decisions concerning their treatment preferences. As it turned out, several of our community volunteers were members of all three committees.

In 2004, in the interest of consolidating efforts and reducing the number of meetings, the three committees were joined into one, known as the Pikes Peak Forum for Health Care. This new committee published a second edition of the "Decisions" booklet in 2008, including in it a ninth guideline dealing with the "Physicians Order for Life Sustaining Treatment" or POLST. The POLST form, in closely similar versions, had been officially adopted in at least 14 states but not in Colorado. The form is usually a brilliant color (shocking pink or chartreuse) so it will be easily spotted. It makes provisions for a patient to specify levels of treatment in a life-threatening illness (full treatment, do not resuscitate, artificial nutrition and hydration, dialysis, ventilator, etc.), must be signed by the patient or designated proxy, and in most states also by the primary physician. A statewide committee is currently pursuing the official adoption of a similar form for Colorado. The advantage of this form is that it is retained at the top of a patient's records, goes with a patient from nursing home to hospital (for example), has on it the information normally included in a living will, and most importantly, in the states where it is presently used, it is reported to be used in more than 90% of the patient cases where the form is in the patient's records. This far exceeds the reported usage of existing living wills. With the consolidation of the three local committees into the Pikes Peak Forum for Health Care, focus was placed on producing a "toolkit" to assist those responsible for initiating "conversations before the crisis" with patients who have a relationship with medical caregivers. Central to this toolkit is an 11 minute DVD produced by members of the Pikes Forum for Health Care. In this DVD, several local professionals give advice and suggestions about starting the conversation with patients and/or family members about advance care planning. These conversations may be initiated by various health-care practitioners, including medical receptionists, aides, social workers, chaplains, nurses, physicians, medical ethicists, and so on. The subjects of these conversations should be patients with complex illnesses, patients whose death would not be a surprise if it occurred within the next 12 months, patients who are establishing a stable connection with a primary caregiver, and so forth. Family members or other loved ones may also be present. Importantly, these conversations ought to take place while the patient is competent to make decisions and prior to emergency end-of-life crises.

In addition to the previously mentioned DVD entitled "Conversations Before the Crisis," the toolkit includes the booklet, *Decisions About the End of Life . . . Help for Those Who Must Decide*; a copy of the *Colorado CPR Directive*; a pamphlet entitled, *Your Right to Make Health Care Decisions* published by the Colorado Health and Hospital Association; the *Five Wishes* booklet; the Caring Connections resource project for advance care planning titled, "It's About How You Live"; a two-sided placard titled, *Conversations Before the Crisis;* a sample copy of a typical POLST—"Physicians Orders for Life Sustaining Treatment" or MOST (the proposed Colorado version); and *The Southern Colorado Guide to Home Care and Hospice*. A Resource List, including information on where to acquire each of the items in the toolkit, is included at the end of this chapter.

In 2008 and 2009, members of the Pikes Peak Forum for Health Care have engaged in meetings with hospital committees and representatives from large health-care practices throughout Colorado Springs, El Paso County, and Chaffee County to acquaint them with the "Conversations Before the Crisis" toolkit. Copies of the complete toolkit are made available to each of the medical offices. Thus far the toolkit has been received enthusiastically by the practices with requests being made by them and from other agencies throughout the state of Colorado for more toolkits. It seems clear that this approach and the toolkit itself fill a need by medical practitioners in initiating help for those who must decide about end-of-life medical treatment.

A FEW SPECIFIC MEDICAL ETHICS PRINCIPLES

In the decision-making process associated with end-of-life concerns, there are a number of moral principles that may help caregivers along the way. Following the many medical ethics works now readily available, and leaning heavily on Tom Beauchamp's and James Childress's *Principles of Biomedical Ethics* (Oxford University Press, five editions), here is a review of four well-known and helpful moral guides frequently employed by decision makers in care giving. The first of these is the *Principle of Nonmaleficence* or *primum non nocere*. It advises that first of all, health-care professionals ought not to harm the patient. It can be seen that often caregiver standards of due care rely on nonmaleficence as a fundamental starting point. Second, the *Principle of Beneficence* states that there is a duty to *prevent harm*, to *remove harm*, and to *provide a benefit* to the patient, and spells out clearly what medical caregiving is all about. Third, the *Principle of Patient Autonomy*, receiving strong emphasis and impetus over the past 35 years, says that the patient has a right to make decisions about his or her treatment. Health-care providers support "informed consent," the rights to confidentiality and privacy, and the right to refuse treatment. Emphasis on autonomy has largely restructured a former dependence on medical paternalism in the United States. Finally, the *Principle of Justice*, which in health care is concerned with "Distributive Justice" and the issue of how health-care providers can justly provide treatment to their citizens when resources are often limited, expensive, and always in demand. Often asked is the question of whether care can be provided *equally* to all who seek it. Should it be made available based on the *ability to pay*? Should the *worth* of a patient to society be taken into account? Should those who are the cause of their own debilities be refused treatment (alcoholics, AIDS patients, tobacco users, etc.)? Who should pay? Who gets priority in the intensive care unit when there are not enough beds? I will not pursue the issue of distributive justice for health care in this chapter, other than to call attention to its enormous importance to society and its current concerns for health-care reforms.

No single principle employed in medical ethics is a *trump* principle. Sometimes these principles may provide a conflict in decision making and in those conflicts, no single principle always predominates. Only a careful evaluation by best thinking, taking into account all known circumstances and the moral rules available, can help with the task of choosing when a health-care provider is faced with a conflict of principles. The right choice is not always assured.

A classic case, borrowed from Beauchamp and Childress (*Principles of Biomedical Ethics*, 3rd ed., Oxford University Press, 1989, p. 414) may demonstrate how to make use of these basic ethical principles and how they may interact. The case involves significantly both the Principle of Autonomy and the Principle of Beneficence.

> Janet P., a practicing Jehovah's Witness, had refused to sign a consent for blood infusions before the delivery of her daughter. Physicians determined that the newborn infant needed transfusions to prevent retardation and possible death. When the parents refused permission for these transfusions, a hearing was conducted at the Columbia Hospital for Women to decide whether the newborn infant should be given transfusions over the parents' objections. Superior Court Judge Tim Murphy ordered a guardian appointed to sign the necessary releases, and the baby was given the transfusions. During the hearing, Janet P. began hemorrhaging, and attending physicians said she needed an emergency hysterectomy to stem the bleeding. Her husband, also a Jehovah's Witness, approved the hysterectomy but not infusions of blood. This time, Judge Murphy declined to order transfusions for the mother,

basing his decision on an earlier D.C. Court of Appeals ruling. Janet P. bled to death a few hours later. Her baby survived.

This case is based on a news report by Martha M. Hamilton in the Washington Post, November 14, 1974. It was prepared by James J. McCartney. (Used by permission of Oxford University Press.)

If we reflect on the principles of autonomy and beneficence in this case, we might note that in the issue involving the child, it appears that the principle of beneficence was judged to override the principle of autonomy. The obligation to remove harm and provide a benefit for the newborn child was deemed to override the parents' right to decide. However, in the mother's case it appears that the judge decided that her right to decide overrode the presumed duty to provide a benefit. I included this case to bolster the notion that no one of the normally helpful medical ethics principles can be viewed as always *the* overriding principle. I also acknowledge that there can be disagreement by thoughtful persons on whether the Superior Court Judge rendered the best ruling for both patients.

As our community group (the Pikes Peak Forum for Health Care Ethics) worked on the set of Guidelines for End-of-Life Decisions, the group developed a "Statement of Principles" thought to reflect important commonsense ethical values helpful to those who must decide. The Forum published 11 Principles. I include here the first seven of these principles to demonstrate the thinking of our community group and to note the reflection in these principles of our previous discussion of nonmaleficence, beneficence, autonomy, and justice.

Statement of Principles

1. Health-care providers must do no harm to the patient.
2. Among the primary tasks of health-care providers is to continue to care even if they cannot cure.
3. Health-care providers should tell the truth.
4. The free and informed judgment made by a competent adult patient (or duly appointed proxy/surrogate decision maker) concerning the use or withdrawal of life-sustaining procedures should always be respected.
5. Ordinarily, the patient (or proxy/surrogate decision maker) must give informed consent to the medical care given.

6. The religious faith and cultural heritage of the patient should be respected by all health-care providers.
7. Health-care providers must maintain confidentiality.

These principles again are the first seven of the 11 in the booklet, *Decisions About the End of Life . . . Help for Those Who Must Decide*. The nine guidelines in that booklet, agreed on after several years of meetings and discussions, specify a position on each of the nine following issues: appropriate end-of-life care; palliative/comfort care; decision making and shared responsibility; cardiopulmonary resuscitation; severe, progressive, irreversible brain disease and the permanent vegetative state; dialysis; artificial nutrition and hydration; patient autonomy, physician and institutional integrity, and medical futility; and advance directives, durable medical power of attorney, and physician orders for life sustaining treatment (POLST).

Because each of the topics mentioned in this chapter are of such significance to each of us who may become involved in making end-of-life decisions, our Pikes Peak Forum for Health Care is happy to share any of the materials we have developed or discovered. The resources list is included at the end of this chapter. Information for acquiring the booklets, pamphlets, DVD, and so on, is included in this list.

RESOURCE LIST

DVD—Conversations Before the Crisis
Booklet—*Decisions About the End of Life . . . Help for Those Who Must Decide*
Double-sided Placard—*Conversations Before the Crisis*
Pikes Peak Forum for Health Care
c/o Pikes Peak Hospice
825 E. Pikes Peak Avenue #600
    Colorado Springs, CO 80903
    Sally Sharpe RN—Forum Secretary
    719-633-3400 x608
    ssharpe@pikespeakhospice.org
Colorado CPR Directive—Patient/Authorized Agent's Directive to Withhold CPR
Progressive Services, Inc.
    1925 S. Rosemary St. #H
    Denver, CO 80231
    Ph. 303-923-0000 Fax: 303-923-0001
    www.printwithpsi.com

Pamphlet—*Your Right to Make Health Care Decisions*
Colorado Health and Hospital Association (single copy)
720-489-1630
or
Progressive Services Inc. (multiple copies)
Stockless Forms Management
1925 S. Rosemary Street #4
Denver, CO 80231
Ph: 303-923-0000 Fax: 303-923-0001
Booklet – *Five Wishes*
Aging With Dignity
P.O. Box 1661
Tallahassee, FL 32303–1661
888-594-7437
www.agingwithdignity.org
Caring Connections
National Hospice & Palliative Care's resource project for Advance Care Planning—It's About How You Live
800-658-8898
www.caringinfo.org
POLST—Physician's Order for Life Sustaining Treatments
MOST—Colorado initiative
Colorado Center for Hospice & Palliative Care
P.O. Box 50888
Colorado Springs, CO 80949
303-756-1360
jballentine@cochpc
Booklet—*Southern Colorado Guide to Home Care and Hospice*
Area Agency on Aging
15 S. 7th St.
Colorado Springs, CO 80905
719-471-2096
www.ppacg.org

CHAPTER

16

Professional Self-Care

E. Alessandra Strada

INTRODUCTION

If we have chosen to work in palliative and hospice care, we will commonly experience emotionally intense and difficult situations. "Take care of yourself" is an expression we often use when another team member has had a particularly difficult time working with a patient or a family. Almost invariably it elicits a simple response "Okay, I will." I have heard "take care of yourself" said casually to me and I have casually used it with other team members. Yet, these interactions represent an important, meaningful moment of connection among team members, because of the shared acknowledgment of the need to care for our "selves."

One day, after a difficult week, both professionally and personally, the full meaning of self-care emerged for me. I had been working intensely with a terminally ill patient and his family. The patient had suffered from severe anxiety and panic attacks, which were being exacerbated by his fear of dying. His family was not willing to accept that he was approaching death and wanted him to be transferred to another hospital to try an experimental treatment. The patient had stated clearly that he did not want to leave the hospital and did not want to pursue any more treatment. After several intense family therapy sessions and individual meetings with the patient, the family reluctantly decided to respect the patient's wishes and stopped planning for a transfer. However, when the patient entered the actively dying phase, all the family members could not tolerate the stress of the situation and stopped visiting. The patient had often verbalized his desire to die surrounded by his family. He kept asking where everyone was and I tried my best to advocate for him and to protect him from the difficult truth. Every time he asked where his family was, he would listen to my answer, and then look away, sad and disappointed. The family never came back to see him and he died shortly. That same week, I was told tests showed a probable recurrence of my mother's cancer. I shared this with some of my team members and as I was leaving, one of my colleagues gave me a hug and said "This has been a very difficult week for you. Take care of yourself." For the first time, I actually paid attention to the words. I felt scared, drained, tired, and afraid for my mother and for myself. I felt sad about the patient who had just died. And I asked myself "How can I take care of myself in this situation? How can I restore my well-being? What does it mean for me, right now, to take care of myself?" And I realized that I was not sure, because I was not even sure about what I was feeling. There were so many layers, professionally and personally. And probably for the first time I became fully aware of the complexity of the issue of self-care.

For those working with patients at the end of life, constant exposure to suffering, grief, and death is the norm. As helping professionals we are certainly not immune to the experience of death, loss, and suffering in our personal lives. Often, our personal lives may mirror our work, especially when we experience losses. Maintaining a stable sense of well-being in our personal and professional lives, in the midst of constant exposure to death and suffering is a challenge. As threats to well-being are a frequent risk for helping professionals, it is important that we explore the nature of the work we do on a daily basis in order to understand and correctly identify the risks.

Meaningful self-care requires attention to individual needs. The expression "Take care of yourself" can allow us to focus on the particular ways in which we can identify sources of support for ourselves and maintain a meaningful and vital connection to our work and our patients. This purpose of this chapter is to explore and deconstruct the meaning of self-care for palliative care and hospice providers. It begins by addressing the importance of self-assessment to identify risk factors and protective factors that will guide our choice of appropriate prevention strategies. Countertransference and working with patients after losses in our personal lives are also discussed.

SELF-ASSESSMENT

When asked why we have chosen to work in end-of-life care, some of us may answer that it is part of our nature. Working with patients and families who face the suffering of advanced illness and impending death may feel like the expression of our natural disposition to helping others. However, if we believe our work is the expression of our natural disposition we may also develop the belief that problems and challenges should not and will not occur. We may begin to underestimate our vulnerability. As a result, we may be unable to detect the initial signs of distress that threaten our well-being. In our training, we learn the clinical skills to care for patients and families. These skills are not easily translated to self-care. Being able to assess and treat psychological distress in our patients requires a precise skill set; developing the ability to assess our own level of emotional functioning and address our own distress implies a different skill set. We may be experts in helping our patients when they are in distress, but there may be a profound discrepancy between our professional abilities when they are other-focused and when they are self-focused. As a result, denial, suppression, and repression may become the main modalities we adopt in order to deal with stress in our personal and professional lives.

The fact that traditional psychology training programs and professional organizations devote little attention to self-care certainly does not help. In most cases, students and professionals are provided with a shopping list of self-care practices that they are supposed to choose from and add to their already busy schedules. The first misconception is that self-care is something we can get from the outside by simply implementing practices of well-being, such as exercise, meditation, journaling, healthy eating, and so on. Although the positive impact of these and other activities on well-being is generally recognized, they may not specifically address core risk factors related to ourselves and our work setting that may significantly compromise our ability to cope.

The choice of prevention strategies and well-being enhancing practices should be the result of accurate self-assessment to identify unique ways in which we can be vulnerable to stress and burnout, as well as unique ways in which we can protect ourselves and improve our resilience, coping, and professional satisfaction. Learning self-assessment skills is central to self-care and the maintenance of well-being. It is a skill that needs to be fostered, developed, and constantly nurtured. Self-care involves a daily process of self-assessment that will allow us to overcome challenges and maintain a meaningful engagement in our work.

ARE PALLIATIVE CARE PROFESSIONALS AT HIGHER RISK?

The relationship between working in palliative and end-of-life care and the personal risk to well-being is complex. For example, an Australian study of physicians of different specialties found that palliative care physicians did not present higher levels of psychiatric morbidity than other specialties (Dunwoodie & Auret, 2007). However, a study that explored presence of grief symptoms among long-term care staff (Rickerson et al., 2005) found that the majority of the staff experienced at least one grief symptom. Staff who had been exposed to a greater number of deaths, despite having more professional experience, had more grief symptoms. This seems somewhat counterintuitive as it would seem that more professional experience, with more time on the job, would automatically translate into the development of better strategies for dealing with the constant exposure to death and dying. One can be an excellent professional, with good assessment and intervention skills, but not have the skill to personally deal with loss. As mentioned previously, the issue of self-care is not commonly addressed in psychology training programs, social work, or medical training programs. Only a few doctorate level programs require a period of personal psychotherapy during which these issues may be addressed. In the study mentioned earlier, all staff reported that they would have accepted additional grief support, if offered by the institution for which they worked.

ASSESSING OUR RISK LEVEL

The threats to our well-being that come from work challenges are intensified by personal risk factors and risk factors in the work setting. Self-care requires a personal discipline of self-awareness that allows us to identify risk factors and develop protective strategies.

Individual Risk Factors

Lack of awareness of the stress level we may be experiencing is the first and perhaps most important risk factor. Lack of awareness prevents us from being able to identify what needs to be addressed or changed and does not allow us to develop protective strategies or seek help. At the end of each day, it can be helpful to spend a few minutes assessing our body and our minds. Eastern and Western practices of mindfulness can support this assessment by creating a focus on the well-being of the self as separate from challenges to mind and body. Answers to the following questions can then be focused on the goal of self-care.

- What was difficult to manage today at work?
- How am I feeling in my body and my mind, right now? Has my energy level been affected by the circumstance of the day? In what way? Does my body feel weak or tense? What about my mind? Does it feel anxious? Am I having difficulty letting go of the workday? What am I holding on to?
- Where am I most vulnerable? What are my needs, as far as work goes? Do I feel rewarded and energized when I feel validated and recognized for my good work? And what happens if I do not feel validated? Do I start feeling physically weak, tired, a little depressed? What about my interactions with other team members and other colleagues? How do I handle confrontation? Do I try to avoid conflict at all cost? And if I cannot avoid it, what happens to my energy level, my personal motivation, and my overall well-being?
- What would be the best way to relieve my internal stress right now? What does my mind need? What does my body need?

During the day, between patients or after difficult interactions with family members, or a tense team meeting, it can be helpful to take five minutes and perform a brief visualization centered on cleansing and letting go. If after the visualization we still feel that our energy level is off-balance, it is important to stop for a moment and acknowledge openly and honestly, at least with ourselves, what we think the problem is. This is the essence of self-assessment as it relates to self-care: the ability to get in touch with our personal truth, in the moment, no matter how inconvenient and embarrassing it may be.

Poor professional boundaries represent another important risk factor. Working with patients and caregivers who may have preexisting psychopathology and especially character pathology can also be challenging and can create physical and mental stress. Such patients and caregivers usually present their requests with intense urgency and may have the tendency to express anger or profound disappointment anytime we are unable to meet one of their needs. Patients with character pathology, especially borderline features, have a constant fear of real or imagined abandonment. Especially for these patients, our desire "to be there for them" can be draining. If feeling validated and appreciated by our patients is one of our main sources of meaning and motivation, we will probably be vulnerable when we work with patients who have the tendency to establish reactive attachments and idealize providers. We may feel really valuable for a while, but the picture may change if for some reason we are transformed into "bad objects" in the patient's mind.

A strong need for acknowledgment and validation is another risk factor. We may overextend ourselves at work in an effort to please everyone or obtain recognition from colleagues, supervisors, and even patients. This issue is strongly related to the previous risk factor, but it can become pervasive and affect the entire work setting.

Unrealistic expectations about goals can be particularly dangerous for our sense of balance. End-of-life care can tempt providers to develop a preconceived concept of a dying experience that is acceptable to them. This may result in the development of an agenda that may include goals that are not shared by the patients and the family, but have been idealized in the mind of the provider. For example, we all like the idea of being able to help patients and family members resolve old conflicts and reconcile prior to the death. The importance of reconciliation, forgiveness, and peaceful and graceful dying has been emphasized in some literature on death and dying and is often presented as a main goal of the death and dying process. I believe that the most important goal in end-of-life care is that which is identified as such by the dying patients. And it may be something far from forgiveness and reconciliation. Although we will use all of our clinical skills to facilitate communication and healing among family members, we need to recognize that our professional relationship with the patients and the family only provides us with a "shapshot in time" of what is a much deeper and often complex history. Therefore, it is essential to hold our personal agendas lightly, become aware of them, and then let them go. Only then, when our hands are empty, we will be able to receive the patients and the family and accompany them in the final portion of their unique journey.

A level of perfectionism can be challenging, especially when we work in an institutional setting. Perfectionism can make it difficult for us to accept our limitations and the limitations of the institutional setting. A peaceful acceptance of the imperfections in ourselves, others, and work is a central discipline in Eastern and Western practices of self-care for well-being. Can we release ourselves from the responsibility to continually evaluate and try to fix, change, and improve ourselves and others? The emphasis is on *continually*. Being able to identify problems and to find creative solutions is a desirable trait. But the amount of energy we spend trying to change and improve situations in the work setting, especially institutional, should be balanced by our ability to accept, honor, and celebrate.

Unprocessed grief has been repeatedly mentioned as a risk factor for stress and burnout. It is simple: If we do not process our own grief we may delude ourselves thinking that we can forever compartmentalize and suppress our emotions. However, this strategy alone will not support us for long and it will affect our well-being and our personal and professional satisfaction. Sadly, compartmentalizing and suppressing grief seems to be the main strategy utilized by many mental health and medical professionals.

RISK FACTORS RELATED TO THE WORK SETTING

Institutional Setting

Therese Rando (1984) eloquently described institutional challenges that can significantly impact our well-being:

> Another source of stress is the lack of organizational support that frequently occurs in human service systems: no opportunities for emotional debriefing; unrealistic expectations for support from other staff members, especially those in key roles; no explicit recognition of the need to incorporate staff needs into the schedule.

The limited amount of control that often characterizes the lives of professionals working in an institutional setting may result in work overload, and lack of recognition of ongoing stressful situations. The inpatient hospice setting can present particular challenges. Nurses, physicians, physicians in training, and social workers all experience deaths regularly. Often, the work demands do not allow enough time to debrief and acknowledge our feelings that result from the death of a patient we may have worked with for an extended period of time. As we attempt to say good-bye to a patient who is dying, we may have already left the room to answer a pager or address other patients' needs. As a result, we may simply suppress our feelings of sadness, frustration, or grief, in order to continue to function for the rest of the day. We may postpone thinking about these feelings in the belief we will deal with them once we get home at night. However, in many instances our daily life does not allow us to spend any time debriefing what happened at work. This is how we may start developing grief overload, which is the accumulation of grief that is never processed or worked through. In an institutional setting, the importance of the support provided by the team cannot be underestimated. Regular meetings that provide staff with the opportunity to debrief difficult deaths should be included in the schedule of the institution. A difficult death creates risk factors for complicated grief with prolonged and severe morbidity. It can occur when the relationship with the patient and the family has been particularly difficult, or particularly close. Although palliative and end-of-life care workers can and will likely experience grief, the protracted and severe experience of complicated grief is preventable (Becvar, 2003; Brehony, 2001).

Private Practice

The private practice setting can present challenges that are usually related to issues of continuity of care. Psychologists who work with patients with advanced illness in private practice usually follow the traditional model of seeing patients one time a week, or more frequently, often on the same day of the week and at the same time. This traditional model, which recognizes the crucial role of the setting, is often disrupted if the progression of the illness requires hospitalization. All of a sudden the therapist may find that a patient is missing appointments without notice. Confidentiality may prevent the therapist from investigating what happened to the patient. Even in situations in which patient and therapist have discussed and addressed confidentiality in case of emergency, the setting will necessarily change in case of hospitalization. The therapist may need to visit the patient at the hospital, literally conducting a session at the bedside. In some unfortunate cases, however, patients can be hospitalized for a rapid progression of the illness and subsequent deterioration and die before the therapist has had the chance to visit. This abrupt symbolic and literal termination of the therapeutic relationship can be challenging for the therapist. The isolation of private practice setting may prevent the therapist from being able to process the grief with team members.

UNDERSTANDING BURNOUT

Burnout was first described by Christina Maslach (1993). We usually recognize its disruptive impact at the end of the process, or when it has already progressed so far that it can no longer be ignored. Burnout reflects a condition of intense physical, emotional, and mental exhaustion, which may develop from poorly managed or long-term involvement in emotionally demanding situations. In its early stages, it often resembles a state of high activity, planning, and enthusiasm about professional and personal goals. This early stage is typically described as a honeymoon phase, characterized by high energy, a strong desire to "fix" things and really make a difference. Working effectively with someone who is dying and helping family members deal with devastating grief and bereavement can become overwhelming (Figley, 2002; Keidel, 2002; Larson, 1993).

Three main manifestations of burnout have been identified: emotional exhaustion, depersonalization, and reduced sense of personal accomplishment. Emotional exhaustion can manifest as a sense of being depleted, without energy. We may experience irritability and anger, as well as depression and guilt. The manifestations of depersonalization can include cynicism, feelings of resentment, and emotional withdrawal from our patients and colleagues, as well as social withdrawal. We may start feeling too tired to interact with family and friends after work. At the same time, we may develop avoidance at work. For example, if we work in an institutional setting we may begin to spend progressively less time visiting patients. We may attribute it to our busy schedule, but in reality we may spend less time with patients because clinical work has become exhausting and we may feel less emotionally involved. If we work in a private practice setting, we may start canceling appointments or hoping that patients will not show for the appointment, even if it hurts our practice. Or we may become more mechanical and withdrawn in our session, colluding with the intense transference that patients with advanced illness can bring in the session. We may begin to question other people's motives and their level of involvement with patients, or we may tend to label every family member who requests our attentions and asks questions as a difficult family. During team meetings, cynicism may result in numerous complaints about the system and about patients and caregivers, without offering a solution or a sense of hope. The third manifestation of burnout, reduced sense of personal accomplishment, may result in the development of a negative self-concept. We may start feeling worthless, inadequate, not as smart or skilled as other clinicians.

UNDERSTANDING AND MANAGING COUNTERTRANSFERENCE

Discussions of countertransference traditionally involve a relationship between a therapist and a patient, but it is important to realize that every empathic relationship will necessarily activate countertransference. Patients will elicit emotions and trigger memories, some of which may be painful, or simply unpleasant. Developing awareness of our personal grieving style and our loss history is a first important step. Self-awareness will allow us to know how our work with a particular patient or family may create difficulty for us. Traditionally speaking, countertransference refers to a set of reactions experienced by the provider working with a particular patient. In palliative and end-of-life care, three of the common countertransference reactions are:

1. The professional regresses to a helpless position, begins thinking that nothing can be done to help the patient and may start experiencing depression, death anxiety, and anticipatory grief.
2. The professional develops savior fantasies and starts making promises that cannot be kept.
3. The professional develops neurotic avoidance of the patient and the family due to the difficulty of managing the intense emotional demands required by the situation.

In order to successfully deal with countertransference reactions, we need to first identify that a countertransference reaction is taking place; label the type of reaction experienced; and manage it, through awareness, clinical experience, and supervision or peer consultation.

Countertransference reactions that are not identified as such will not be managed and will probably negatively affect our working relationship with the patient and the family, as well as undermine our personal and professional satisfaction.

DEVELOPING PROTECTIVE STRATEGIES

Protective factors are attitudes and behaviors that need to be cultivated at work and in our personal life. Protective does not mean that they will shield us from experiencing disappointment, stress, frustration, and guilt. They will give us a metaphorical extra layer of emotional and spiritual confidence that will allow us to be better prepared to use our natural defense mechanisms to cope with the demands of our personal and professional lives (O'Brien, 2006).

Social support has been identified as a protective factor to help deal with multiple stressors in a variety of settings. The literature shows that the crucial element is not the actual number of people we can identify as supportive in our lives, but it is the awareness that we have support, even if our network is limited in terms of number. One of the characteristics of support is that the individual feels understood and feels that the listener can actually relate to the experience we are describing and empathize without judging our feelings or reactions. Being able to be authentic and vulnerable without worrying about safety or retaliation can create well-being, which comes from a sense of acceptance, even if the stressor cannot be removed. In order to raise the likelihood that we will be understood when we discuss work-related stressors, it would be important to have part of our support network at work. This is not necessarily another member of the team, but at least someone who can relate to the nature of the work we do and can relate to the types of stressful situations and frustrations we can experience. Often, simply the ability to express feelings and reactions that are not considered politically correct, such as feelings of frustration and anger toward a supervisor, a colleague, a patient, or patients' caregivers, can help reframe the stressful experience and enhance coping (Jones, 2005; Pfifferling & Gilley, 2000; Sherman, 2004).

The value of continuing education as protective factor cannot be underestimated. Even if we consider ourselves well-trained professionals, we will benefit from continuing to enhance our knowledge and exploring professional issues that can have the potential to create stressful reactions. Rather than considering continuing education as a burden, we will benefit from considering it a practical application of self-care. We can choose to attend workshops or conference presentations focused on topics that we find particularly challenging. The time spent pursuing continuing education professional programs can be focused on ourselves and on our professional and personal needs.

A present-focused orientation rather than a past or future orientation will also help maintain perspective on our professional lives. Especially when we face many competing demands at work, we may lose a sense of our actual accomplishments and focus on what we still have not accomplished. Being constantly in catch-up mode can be disruptive, particularly because the emphasis of our professional life can easily become task-oriented, rather than reward-oriented. Professional satisfaction is less when workers feel that they are just accomplishing tasks, rather than developing creativity and professional growth.

Acknowledging and expressing grief is an important protective factor and it will decrease the likelihood that we will develop grief overload or become disconnected from our own grief and from our patient's grief (Worden, 2002).

Being able to acknowledge positive emotions expressed in the context of our work will balance the negative emotions and suffering we are exposed to during the day and will protect us from becoming cynical. Striving for balance should be an important goal of self-care. Recognizing our strengths and limitations will help us resist the tendency to polarize and develop extreme beliefs, such as "I never get anything right; I cannot make a difference," or "I am the only one who really understands this patient, this family."

Maintaining adequate professional boundaries is probably one of the most important protective factors. Many resources in the literature encourage maintaining our professional and personal life as separate. This means that unless we are on call or we are dealing with an emergency, we need to protect our personal time and support our other interests. However, many professionals resonate with the statement "My work is my life," and essentially feel that there is no difference between the personal and the professional. If work becomes the primary dominant source of personal validation and needed recognition, we may be more vulnerable to stress and frustration. In essence, our interactions at work or with our patients may become the primary relationships in our lives. If this is the lifestyle we have chosen, it would be helpful to develop a comfortable relationship with that choice and use strategies to maintain balance.

Reflecting on our sources of meaning and purpose in life can allow us to remain grounded in our awareness of our values and sources of motivation and hope. Other important questions that we could regularly contemplate are the same we ask our patients: Where do I find forgiveness? Who knows me and is always ready to give me a second chance?

Relaxation training can be helpful to decompress during the course of the day, or between patients. A brief visualization focused on cleansing and letting go can help us develop a sense of forgiveness for what we have not been able to accomplish in that particular encounter with the patient and renew our energy in order to be ready for the next patient.

The connection with our body is another area that deserves attention. To connect with patients who are dying we may notice that we unconsciously slow down, move more slowly, and may even start developing less of a bodily presence, in order not to disturb the energy of the dying person. As a result, at the end of the day we may feel that our bodily energy is stuck and heavy, which will increase the chance of developing physical symptoms. Any practice that can restore energy flow by focusing on the body would be helpful. A simple walk, sitting in silence breathing out heaviness and breathing in light and refreshing energy, a body massage, and a hot bath can help our energy flow and maintain mind-body balance.

WORKING WITH PATIENTS AFTER A PERSONAL LOSS

Working in palliative and end-of-life care can become especially challenging when we experience losses in our personal lives. Grief is a personal and unique journey and its path is not a linear one. An understanding of our personal grieving and bereavement style will allow us to determine how soon after the loss we are able to return to work. If our patients do not know about the loss and we think we are ready to continue our work, it is usually preferable not to disclose, in order to prevent the patient from spending a significant portion of time and energy thinking about us and our loss. But, if the patient becomes aware of the loss, and expresses concern about us, we should reassure the patient. Reassuring the patient in this context means reassuring them that we are back at work because we are ready and we are fully present for the patient. It would be appropriate to tell our patients that we appreciate their concerns and we thank them for their concern. Whatever course we choose, we should make sure that it does not add ambiguity and burden for the patient. Although we certainly do not want to burden the patient, we should not trivialize their concern for us by making statements such as "Do not worry, I am fine." Asking a worried or concerned patient not to experience what he or she is experiencing is probably not therapeutic or helpful. It may be best to acknowledge the concern, thank the patient, and, once again, calmly reassure the patient.

Even though we may be professionals trained to deal with the grief of others, this does not mean that we are necessarily better prepared to deal with our own grief. We are certainly not immune from the symptoms of acute grief, which can include distressing manifestations in the cognitive, physical, emotional, and spiritual domain. We will need time to process and adjust to our loss, just like everyone else. The amount of information we have as professionals can help us normalize the symptoms and difficulties we may be experiencing. However, when we tell our patients that grief is a process and it cannot be rushed, we need to remember that this principle applies to ourselves as well. Falling into the trap of minimizing the effect and the implications of our personal grief will not make us better therapists. It may, in fact, prevent us from being able to fully and meaningfully connect with our patients.

And how should we behave with colleagues? Should we not disclose our loss and continue as if nothing has happened? As a result of this course of action we may start feeling isolated in our grief, especially as the work demands continue and life goes on as if nothing has happened.

If we work in a private practice setting, we should be aware of the potential for professional isolation and grief overload, especially if we work with patients with advanced illness. At the beginning of treatment, as we discuss the basic aspects related to treatment, it would be advisable to review with patients their expectations and yours in special circumstances. For example, if the patient has cancer and there is likelihood that they could be hospitalized, how would they like us to behave? Would they like us to visit and continue the sessions in the hospital setting? If they have not disclosed to their family members that they are in therapy and they would like us to be informed in case they are hospitalized, what do they expect of us? To prevent confusion and disappointment later on, it may be helpful to develop a general sense of our patients' hopes and expectations. Joining a supervision group may be particularly important for psychologists in private practice, especially if we are not part of a practice group and we do not have the opportunity to debrief with colleagues after a difficult session, or share a difficult case with a treatment team.

CONCLUSION

The practice of professional self-care involves a lifelong commitment to a process of self-inquiry, self-assessment, and, ultimately, psychospiritual exploration and growth. The development of individual self-care strategies is a necessary skill to maintain a high level of professional satisfaction and avoid burnout. Constant exposure to death and suffering can have profound effects on physical, emotional, spiritual, and interpersonal well-being. Mental health professionals working in palliative and end-of-life care may be at risk for work-related stress in various domains of personal and professional functioning. Isolation, unprocessed grief, unmanaged countertransference, inadequate boundaries, and unsupportive belief systems may challenge our ability to maintain a sense of meaning and purpose in our professional life. Self-assessment is a necessary first step that can help identify personal risk factors, as well as work-related risk factors for burnout and professional dissatisfaction. In order to effectively neutralize or minimizing the impact of work-related stress, self-care strategies should address individual needs and risk factors. In the end, making a commitment to self-care will translate into more rewarding relationships with our patients and an improved sense of overall professional and personal well-being.

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CHAPTER

17

Embracing the Existential Invitation to Examine Care at the End of Life

Shirley Otis-Green

INTRODUCTION

Working with older adults offers rich vicarious learning opportunities. A geriatric specialization offers reflective practitioners multiple opportunities to witness how others cope with positive aspects of aging as well as grief and loss. This book focuses on how we can learn a myriad of lessons from working with those who are struggling to face their own dying (Remen, 1996). Regardless of age, coping with a life-threatening illness reminds us of the importance of having clarity regarding priorities in our daily lives.

Older adults have been tested by a lifetime of adjusting to change and loss (Schacter-Shalomi & Miller, 1995). Working with older adults invites us to consider the impact of these transitions in our own lives. We do not need to be seriously ill to benefit from reflecting on the lessons learned from those who have dared to face the possibility of one's own mortality. There are things we can do each day to mindfully make moments matter and to minimize regret (Krasner, 2004). This chapter invites us to consider the existential impact of the work we do and challenges us to have the courage to embrace the personal and professional opportunities for growth and leadership that are inherent in working with those at end of life.

IMPORTANCE OF REFLECTIVE PRACTICE

Working with those who are dying or bereaved puts us at risk for our own existential crisis, where our sense of meaning and purpose in life is called into question. Being a witness to unrelieved suffering can challenge our worldview and compromise our coping. As Tolstoy (2004) so poignantly described in his master work, *The Death of Ivan Ilych*, the multitude of losses that come at the end of life can threaten to overwhelm us. As we partner with those who struggle with a shattered sense of predictability and the loss of the comforting illusion of control, we, too, may feel powerlessness. We need to thoughtfully recognize the toll this can take upon us personally and consider the impact it can have on our career satisfaction and performance (Kearney, 2000). If we are not diligent with self-care, compassion fatigue can set in and depression, anxiety, and anger can become our constant companions. Our motivation for this work will be eroded and we may find ourselves facing deep disillusionment with our career path.

Randy Pausch's *Last Lecture* (enticingly titled *Really Achieving Your Childhood Dreams*) became a national phenomenon as he publicly embraced the existential invitation to explore what matters most with candor, humor, and compassion (Pausch, 2008). Following his diagnosis with what would prove to be terminal pancreatic cancer, he consciously considered the legacy that he was leaving for his friends, family, students, and colleagues, and invited us to do the same. Pausch asserted that a positive legacy is correlated with living well. Building a legacy to be proud of requires reflection and daily mindfulness. Most of us are unsure where to begin on such a journey. We may lack mentors. Yet working with older adults offers many cues regarding where to begin.

Working with those who face advanced progressive illness reminds us that the world is not as predictable as we may have once believed. Even a reluctant acknowledgment that we will someday die offers opportunities for concrete changes in the here and now (C. A. Corr, Nabe, & Corr, 2003). The collective wisdom of our faith traditions (Walsh, 1999) suggest that increasing our tolerance of life's ambiguities prepares us for the possibility of our own demise. But this takes moral courage (Kleinman, 2006). Recognizing that we are vulnerable invites us to face our fears of disfigurement, distance, disability, dependence, and ultimately . . . of death.

But this awareness of our own vulnerability is exactly what invites us to consciously reconsider our career path and the leadership legacy we are building. It is important that we periodically pause to reflect on the lasting impact that our choices have on others. If you were to leave your work tomorrow, how would you be remembered? What influences have you had on your institution, your profession, and your colleagues? Consider what motivated you to select this career—circumstances, duty, desire, obligation, guilt, love (Boldt, 1999; Duhamel & Dupuis, 2003). What continues to motivate you in this work—satisfaction, faith, habit? Was this path authentically chosen? Are you using your unique skills, wisdom, experiences, tools, insights, talents, gifts, and passions wisely (Levoy, 1997; Palmer, 2000)? Are you proud of what you have accomplished or filled with regret regarding lost opportunities? Are you living a life that is personally meaningful and that professionally matters? Periodic adjustments will be needed in ongoing efforts to align our dearest hopes and dreams with our daily behaviors (Palmer, 2004). We all do well to regularly reassess the "fit" of our current position with what we believe in and are energized by (J. Levey & Levey, 1998).

Embracing our mortality invites us to live passionately. Conscious legacy building invites us to consider the inevitable—a world without us. Facing these existential questions requires great courage but offers great rewards (Lee, 2008; Levine, 1997). Imagining our own dying is not just an intellectual exercise, but an existential challenge that we must each face at some time—for as we who work with older adults know all too well that death is inevitable and life offers no guarantees. Living is a dangerous enterprise filled with risks. Whether from war, aging, earthquake, flood, landslides, accidents, or illness, we are all only a heartbeat away from the need to face our own mortality.

CHALLENGES INHERENT IN WORKING WITH THOSE AT END OF LIFE

This book offers a collection of valuable resources to guide us as we care for older adults who are facing end of life or who are coping with loss. This is demanding work that few of us are well-prepared for. Although this field offers rich rewards and numerous opportunities for growth, the risks in this work are many and daunting. Some of these risks include the cumulative effects of compassion fatigue, vicarious traumatization, secondary stress disorder, the impact of chronic caregiving and the demoralizing impact of organizational downsizing (which challenges us to "do more with less").

Specialization in this work can lead to a lack of perspective. Working with the dying and bereaved will present occasions when we are asked to bear witness to intense and unrelieved suffering (Halifax, 2008). We can become frustrated when our interventions are less than ideally effective; that despite our best efforts we really can't always "make it better" (Pearlman & Mac Ian, 1995). We may experience conflicted motivations and may not always "practice what we preach." Many of us experience a lack of confidence in our role due to inadequate training and preparation (Taylor, 2007). We may perceive a lack of access to needed resources and a serious lack of time to process and digest the emotional toll that this work can take. We may face blurred boundaries and need to repeatedly consider whose needs we are trying to meet in any given situation. We may not have ready access to seasoned role models and may experience a serious lack of team, peer, and institutional support for this difficult work. Staff shortages may limit our ability to take needed time away.

Chronic lack of support, respect, and understanding among others may lead to unrealistic expectations and place us at risk for misdirected or projected anger and blame. It is exhausting to constantly invent solutions, yet, in end-of-life care we are often asked to do what has not been done before (Field & Cassel, 1997). Indeed, some of our attempts to improve the situation may be perceived as failures instead of valued learning experiences (Lynn, Schuster, & Kabcenell, 2000). We may struggle with inadequate compensation and become anxious when tasks are added to our already long list of "other duties as assigned." We may find ourselves suffering from survivor's guilt and develop hypersensitivity, hypervigilance, or a minimization of our own symptomology. And we may find ourselves facing unexpected (and perhaps unwelcomed) existential "meaning-of-life" questions.

We need to recognize the insidious nature of compassion fatigue and beware when our "escape strategies" increase (such as when we find ourselves taking more time for sick days). We need to be aware of our negative coping strategies and how our body experiences somatic symptoms of stress. Unaddressed, geriatric and other end-of-life care providers are at risk for emotional distancing or detachment, apathy, depression, increased sarcasm, a desire for distance or detachment, emotional numbness, hopelessness, helplessness, and generalized negativity, anger, frustration, and hostility, over- and undereating, substance abuse, self-flagellation, blame, guilt, and increasing fatigue. We are continuously being asked to do what we have not been prepared for. It is important that we develop robust self-care strategies to offset these risks for burnout and martyrdom.

MANAGING THESE CHALLENGES

Despite the risks, happiness in this work is not an oxymoron. Recognizing opportunities for vicarious learning, we are able to witness dying done by experts. This work is immensely rewarding, for what we offer is of great service (Egan & Labyak, 2006). Recognizing the privilege of sharing in this most profound and personal of journeys has transformative potential for all involved (Ersek, 2006; Faas, 2004). To sustain ourselves in this work and to maintain a healthy perspective we benefit from balance in our personal and professional life. We need an active commitment to rigorous self-care. Be gentle with yourself. Change is a process—it takes time, commitment, and much effort. We do well to recognize and celebrate our successes, for even if small, they're not insignificant. Determine which aspects of your work are energizing and which are exhausting and make decisions based on that. Reclaim responsibility for yourself and for your own growth (Sulmasy, 1997). It is vital to our long-term happiness that we consciously attend to all aspects of our quality of life, including our spiritual dimension (for meaning and purpose); our social dimension (with friends and family); our productivity dimension (through work and hobbies); our emotional dimension (with our feelings); our cognitive dimension (through thoughts and interests); and our physical dimension (through health and exercise) (A. R. Merrill & Merrill, 2003).

Attentiveness to the lessons learned from this work teaches us the importance of positive coping. Important personal coping strategies include physical self-care, exercising well, eating well, sleeping well, addressing our social needs, developing relaxation skills, using humor, and nurturing ourselves. In essence, we need to treat ourselves as if we were our own best friend, lover, or caregiver. We do best when we follow the strategies that we would offer to those who are dying: to reflect on our needs, to anticipate future challenges and to strive to be proactive versus reactive (E. T. Kramp & Kramp, 1998). It is wise to establish contingency plans, to know our priorities, and to live authentically and passionately.

We learn from this work that it is important to make peace with our mortality (Kemp, 2006). Indeed, working with those facing end of life reminds us that some come to life's close with tremendous grace and resilience while others are unable/unwilling to reconcile to the reality of their dying. Sitting at the bedside of those who are dying teaches us that if our own foundation premises and choices are not authentically made, our lives are more likely to be filled with guilt and regret. Emotional "stuckness" increases guilt and regrets, which is associated with lowered self-esteem and increased anger, depression, anxiety, and less pain tolerance.

We all have a normal tendency to postpone desired activities until things seem better or safer ("Not tonight, dear, I have a headache"; "I can't retire until the market comes back"; "We'll take that trip when the cancer is behind us."). Positive psychology informs us that this tendency is based on common myths about happiness (Seligman, 2002). Only rarely do we realize the fallacy of: "I'll be happy when . . ."; or "I'd be happy if . . . (I was richer, smarter, younger, older, skinnier, heavier, stronger, healthier)"; or "I'm too sick to be happy now."

Research informs us that happiness is a choice (Foster & Hicks, 1999). It is important for us to identify our intention to be happy, to consistently and purposefully choose happiness and to accept personal responsibility for our own happiness. We learn that we can ask, "What can I influence in this situation and what can I learn from this event?" This allows us to reframe our problems into opportunities. Working with those who are seriously ill reminds us of the wisdom in creating backup plans and then backups to our backup plans. We must choose if we believe that ultimately there is the potential for good to come from each difficulty (Borneman & Brown-Saltzman, 2006). Resiliency grows when we realize that we are strong enough to face times of challenge. We get to choose whether we perceive our "glass as half full or half empty." And perhaps it is this decision that ultimately matters the most. Optimism can be learned. We can increase our openness to new possibilities. If happiness is a choice, we can cultivate mindfulness in the moment so that we can be more authentically present with those we interact with.

Being fully present with those who are suffering teaches us to see that having our beliefs, values, and actions in harmony increases our sense of well-being and self-esteem (Stanley, 2002). We learn the importance in developing a generous spirit, for no matter our situation, we each have gifts that are only ours to give (Keyes & Haidt, 2003). And importantly, to the degree that we feel that we have used our unique talents and opportunities wisely, we minimize regrets. Victor Frankl's (1984) reflections from his experiences in a concentration camp in WWII remind us that purposeful lives are meaningful lives.

PROFESSIONAL COPING STRATEGIES

As professionals, we need to identify ourselves as lifelong learners who continually seek more education and skills training. To sustain ourselves in this work, it is essential that we cultivate our competence. We benefit from clarity regarding our job commitment so that we can maintain a long-term perspective of our priorities. To minimize later regrets, we need to routinely reconsider our true motivations for this work. Are we engaged in this work from authentic desire? Periodic review of our boundaries, personal limitations, and other responsibilities allows us to consider the resources we have at our disposal so that we can appropriately access community options and delegate duties as needed. Professional coping strategies include periodic and internally honest self-reflection regarding limit setting, a willingness to learn from mistakes, an ability to track the transmission of trauma, a commitment to build in periodic mini-timeouts, and a desire to develop a robust, vibrant, and resilient support network.

We regularly need to adjust our expectations, reframe, and reprioritize. We need to both seek and provide mentorship, to increase our network of support and clarify our commitments. We benefit from the use of stress relief skills, sharing praise, and appreciating team efforts. If we are to empower ourselves for the challenges we will inevitably face, then it is especially important that we both debrief and de-grief (memorialize our losses) and accept that things take as long as they take. We need to say "no" when appropriate and say "yes" when able. Sustainable career satisfaction increases as we learn to facilitate the development of coalitions and partnerships to achieve shared goals.

This work reminds us that we cannot do all that needs to be done. Dare to delegate. Consider who is the right person to do this task and be willing to creatively explore what other options might exist. Working with those who recognize that life is limited invites us to consider how well we are using our unique skills and gifts. If you knew that you were to die next year, what would you do differently now? Consider what truly matters and make choices accordingly to minimize future regrets. Work with the dying teaches us that it is vital to live an authentic life and to seize opportunities to make a meaningful difference.

PERSONAL COPING STRATEGIES

Acts of omission are more often a source of regret than acts of commission. Live life on purpose. Make meaning, create moments that matter . . . but take care of business along the way. If we recommend that those we see complete advance-planning documents, it is important that we consider them for ourselves. Complete a durable power of attorney for health care, consider estate planning, write a will, provide guardianship plans, and establish backup plans for those who will care for those whom you are responsible for, whether it be children, parents, pets, property, or possessions. Honor the ancient wisdom that reminds us to hope for the best, while preparing for the worst.

Live fully. Play daily. Learn new skills. Distinguish when good enough is. Learn to identify and then address your own unfinished business. Cultivate optimism—practice the art of making lemonade from life's lemons. Increase creative expression through music, art, and dance. Consider adding journaling, poetry, and storytelling to your self-skills repertoire (Davey, 2007). Make it a habit to use positive self-talk and deliberately reframe negative experiences into opportunities for learning. Weigh passion versus practicality and, when appropriate, pursue passion. Joy is a fabulous teacher and there are many more paths yet to be explored. Those who are facing the possibility of their own death encourage us to increase our self-awareness through listening to our intuition and using our own inner wisdom (Knight & Emanuel, 2007). They remind us to be open to the adventure of life and to breathe . . . deeply.

The conscious cultivation of various spiritual rituals and practices such as meditation, prayer, or mindfulness provides us with skills useful in addressing our own personal roadblocks, increasing our tolerance to ambiguity, and developing an appreciative attitude toward all of life's experiences (Dyer, 1998; Elgin & Ledrew, 2001). We are invited to enjoy the music and magic of each day and to reconnect with meaningful traditions (Puchalski, 2006). Periodically ask: "How has my faith tradition influenced my perspective regarding the meaning of suffering?" "What lessons can be learned from suffering and what is the meaning of death?" "What is the meaning of (my) life and what would make life even more meaningful?" Consider how your answers to these questions have evolved throughout your life.

Ancient practices such as walking a labyrinth remind us to cultivate faith in the process, seeking peace and inspiration amid apparent setbacks, maintaining perspective, and regularly asking "What matters the most right now?" Most of us will respond to that question in regard to relationships (Byock, 2004). Dying encourages us to communicate clearly and to surround ourselves with family, friends, pets, and plants. Sharing our hopes, our dreams, and our fears with our loved ones and our health-care team is vital, for this work teaches that we cannot assume that others know what our priorities are. Witnessing others facing end of life offers numerous lessons regarding the resiliency of the human spirit and the evolution of hope (Hedlund, 2007). Reviewing our life choices and consciously sharing lessons learned affirms the impact of our experiences upon others.

Living well increases the probability that we will have the skills we need to die well. Perhaps true wisdom lies in knowing what truly animates our existence and then living accordingly. This requires a commitment to regularly set aside time for self-assessment, introspection, reflection, meditation, prayer, and play. We need to reflect on what is most important to us and recognize that it is never too late to grow. But growth requires change and change is difficult, and can be exhausting. Great energy and courage are required for radical change, but these are in short supply when we're living with a serious illness. That's why we benefit from consideration of these matters while we are well and have the energy to make changes (Dolan & Vizzard, 2007; Ferrell & Coyle, 2008).

IMPLICATIONS FOR PRACTICE

Working with those who are facing the possibility of a limited lifespan invites us to celebrate opportunities to live an integrated life. As we have discussed, there are opportunities to apply the lessons learned from this work into our personal and professional spheres. The good news is that these principles all have implications for clinical practice. The patients and families that we see also benefit from learning strategies that enhance the likelihood of benefit finding, posttraumatic growth, resiliency, and growth through grief (Calhoun & Tedeschi, 2006). Clinicians are investigating the most effective means to incorporate existential concerns into therapeutic encounters (Breitbart, 2004; Chochinov, 2002; Hansen, 2009).

An example of such an effort was *Legacy Builders*, a psychoeducational support group for patients and loved ones facing a life-threatening illness offered through the *Transitions Program* at the City of Hope National Medical Center (Otis-Green, 2006a). The purpose of this pilot project was to explore the feasibility of offering a dedicated program that focused on consciously facing end-of-life concerns, addressing unfinished business, and building a positive legacy. Although there was legitimate concern about how best to market these activities and fear that patients may not attend, we found a strong interest in repairing and enhancing relationships and in discussions of medical, legal, and financial preparations. Consistent with the emerging literature in palliative care (Koenig, 2007; NCP, 2009; NQF, 2006) we found that whether God is perceived as a force without a face or a personally experienced entity, those living with a serious illness typically are very concerned about a myriad of spiritual and existential issues. Those in attendance worked to develop contingency plans and openly discussed strategies to increase their tolerance of ambiguity in order to obtain serenity regarding these mysteries. Participants offered one another guidance and support, mobilized their networks of support, and identified opportunities to address unfinished business and to address issues of forgiveness (Otis-Green, 2003).

We found that these powerful experiences deeply influenced our clinical practice with those who did not participate in the formal programs. *Transitions Program* staff began consciously exploring existential concerns of patients and their loved ones through encouraging life review (Riemer & Stampfer, 1994; Spence, 1997) with reflection on questions such as: “How can I find meaning in this experience?” and “How do I make sense of this suffering?” Our staff found that spiritual and existential coping was increased through the use of meditation, prayer, retreats, rituals, reading spiritual works, spiritual counseling, reflection and journaling, and use of the expressive arts. We encouraged family members to communicate their needs, to advocate for their loved one’s comfort, to network, to develop their resources, to learn more about their loved one’s illness and treatment, and to commit themselves to growth from the experience. We witnessed hope evolve and become increasingly contextualized.

A primary goal of the program was to provide culturally sensitive anticipatory guidance in an attempt to minimize regrets (Otis-Green, 2006b). We reminded distressed participants that they had made the best decision that they could with the limited information and resources available at the time and that knowing what they did now, they might make different choices. The best option at this point in time is to ask what they can learn from that experience that can guide them as they move forward and to be mindful that we can learn from past mistakes and be grateful for the opportunity to go onward now with greater wisdom and insight. The question then becomes: "What do I do now, knowing what I know now?"

This work reminds us that no matter what happens to the body, there are always opportunities for spiritual, psychological, and existential healing. We can encourage those we see to periodically participate in life review to reconsider priorities. Dr. Ira Byock (1997) wrote that there are five tasks that enhance relationships ("I forgive you"; "Please, forgive me"; "Thank you"; "I love you"; and "Goodbye"). These reflection questions ask our patients and families to weigh what they value most and provide guidance regarding steps to take to minimize future regret.

CULTIVATING A LASTING LEGACY OF LEADERSHIP

Those who are facing end of life or bereavement face a frustratingly fragmented system of care. Leadership is needed to advocate for improved delivery of care, equitable access to quality services, and the development of clinically meaningful research and educational programs that reliably transmit effective practice models. The population of older adults is increasing and their needs are great. Leaders are needed to mentor future generations of geriatric and end-of-life specialists in the provision of quality culturally sensitive services to our most vulnerable patients and their families. Professional leadership ultimately is a choice that we make and not a title that is bestowed (Maxwell, 1999; Steinbrecher & Bennet, 2003). No one's permission is needed to become a leader, just the courage of our convictions and the willingness to step up to the need. Professional leaders are needed who are willing to embrace the existential invitation to examine the needs of those facing end of life and to make a personal and professional commitment to excellence. Despite the real challenges of compassion fatigue, political fallout, misinterpreted motives, world-weariness, uncertainty regarding the outcome, and fear of failure, there is deep satisfaction in accepting the leadership challenge. The dying and the bereaved don't have time to wait. The time for bold leadership is now. We invite you to build an enduring legacy of leadership.

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