Counseling Strategies for the Dying and Their Loved Ones

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Although the majority of people in the United States die in hospitals and nursing homes (approximately 58%), there has been a shift in the places where Americans die, with more people dying at home (over 25%) and in noninstitutional settings (National Center for Health Statistics, 2011). Two major factors have changed the landscape of where people die in the United States. First, because most people die of chronic diseases (Xu, Kochanek, Murphy, & Tejada-Vera, 2010), a person's expected life trajectory is much more likely to involve a terminal period of physical decline and some anticipation of nearing the end of life. Second, the advent of palliative care as a formal medical specialty in 2006 (American Academy of Hospice and Palliative Medicine, 2013) and the proliferation of available hospice services have allowed more individuals to die at home. Based on data from 2011, the National Hospice and Palliative Care Organization (NHPCO; 2012) estimated that approximately 44.6% of all deaths in the United States were under the care of a hospice program.

As a result of these societal developments in medicine, counselors must be prepared to provide needed care to the dying and their families in a variety of venues. Besides traditional inpatient settings like hospitals, intensive care units, and nursing homes, the dying are increasingly seen for mental health services in outpatient clinics and offices as well as in private residences. These trends make it necessary for counselors in training who expect to handle problems across the lifespan to know something about compassionate care of the dying and their bereaved loved ones.

DEATH COMPETENCE

The Code of Ethics published by the Association for Death Education and Counseling (ADEC; 2006) includes basic tenets that codify practical competencies needed by grief counselors and those who care for the dying.

These basic tenets state first that professional work be "based upon a thorough knowledge of valid death-related data, methodology, and theory rather than stereotypes or untested hypotheses." This tenet speaks to the need for practicing from an evidence-based foundation. Second, grief counselors are exhorted to "understand [their] death-related feelings and experiences and the ways in which these may impact [their] thinking and work in the field." This second tenet prescribes self-awareness that is critical to the successful and ethical endeavor of counseling the dying and their loved ones. These two key points merit elaboration.

First, empirically based counseling of the dying and their loved ones demands that practitioners operate from a solid knowledge of theory and research findings that inform their practical interventions. As in other areas of counseling, this nexus of theory-research-practice constitutes a dynamic interplay whereby theory and research provide road maps for care of the dying person while observable events/responses in the counseling encounter generate ideas to be conceptualized into theory and/or tested with formal research designs. As psychologist Kurt Lewin is famously quoted, "There is nothing so practical as a good theory."

Second, counseling the dying carries unique challenges and rewards for clinicians willing to venture into this specialized treatment domain. Specifically, the counselor's own personal experiences with death and bereavement are important factors to consider when tackling professional work of this nature. Self-awareness of what drew one into the end-of-life field; how one has been affected by one's own losses or endings; what motivates an ongoing interest in grief; and how personal convictions around spirituality, faith, or life philosophy influence one's own beliefs and sensibilities are all part of a matrix of self-knowledge needed when dealing with death. So important is this element of personal experience when counseling the dying that it can be thought of as a fourth dimension. It consists of a dynamic interplay with the theory-research-practice triangle because what the counselor personally brings to the encounter influences how each of the other three domains are processed, and vice versa. This novel conceptualization, proposed previously by this author (Gamino, 2010), is illustrated in Figure 24.1.
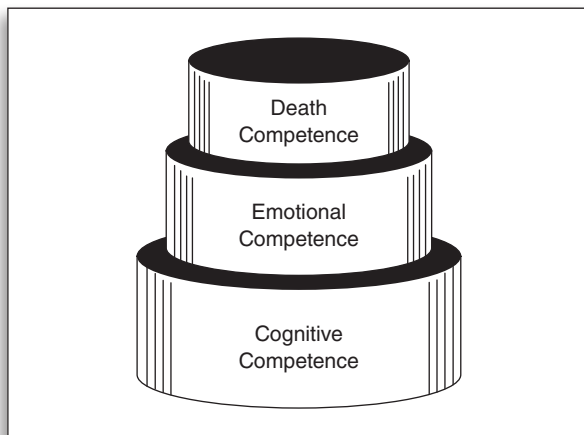
Gamino and Ritter (2009, 2012) coined the term *death competence* to describe specialized skill in tolerating and managing clients' problems related to dying, death, and bereavement. Conceptually, death competence is like the top tier of a three-layer cake in that it is undergirded by more omnibus competencies—cognitive competence and emotional competence—common to many forms of psychotherapy (see Figure 24.2). According to Pope and Vasquez (2007), cognitive competence refers to what the counselor *knows* from academic training and supervised field experience that is galvanized into a set of expert knowledge and skill, whereas emotional competence refers to the counselor's capacity to endure the emotional rigors of the therapy process with adequate psychological resilience. These two competencies are necessary foundational layers that, important as they are, are not by themselves sufficient for competent care of the dying and the bereaved.

Death competence goes beyond the cognitive and emotional competencies required by most forms of psychotherapy. Death competence certainly includes having domain-specific knowledge about grief and bereavement. It also subsumes the capacity to withstand the sights/sounds/smells of

Figure 24.1 Model for Integrating Personal Experience With Theory-Driven, Research-Informed Practice
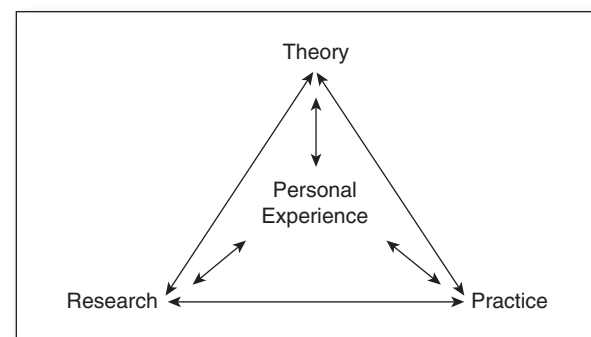
Figure 24.2 Hierarchical Model of Death Competence

in order to accomplish effective use of self when counseling the dying and the bereaved (Gamino & Ritter, 2012).

For those practitioners wondering whether they have "the right stuff" for counseling the dying, Gamino and Ritter (2009) identified four common impediments to death competence: unfinished business regarding the death of a loved one, inordinate levels of death anxiety, overgeneralizing from one's own loss experience to compensate for an insufficient knowledge base, and lacking a personal history of loss (sometimes a factor for entry-level professionals still in young adulthood). Gamino and Ritter also provided a self-assessment checklist for practitioners to gauge their levels of death competence, including honestly facing one's own mortality as evidenced by having a professional will that stipulates how to care for one's patients and one's practice in the event of untimely death or disability. Unfortunately, lack of death competence on the part of the counselor can lead to problems like empathic failure where the patient does not experience the counselor as understanding and compassionate, resulting not only in the treatment not helping but even making the patient worse (cf. Gamino & Ritter, 2012).

impending death; tolerate graphic stories of death, particularly when tragic/traumatic/horrific/gruesome/violent; manage one's own death-related feelings while maintaining therapeutic objectivity/perspective; and integrate one's own experiences

Case Examples

Having established a basis of death competence for proceeding into care of the dying, two case examples are described that, taken together, illustrate three major venues in which end-of-life counseling may occur.

Case 1

"Ruby" was an African American female in her 40s who had suffered with lifelong muscular dystrophy resulting in an inability to walk independently and a neurogenic bladder (i.e., inability to control voiding, so regular catheterizations are required), together with other physical conditions such as diabetes, high blood pressure, high cholesterol, and sleep apnea. She was hospitalized frequently throughout her life for complications of her conditions, particularly sepsis (widespread infection), and was hospitalized this time because of anemia (low red blood cell count). Tests run during her current hospital stay indicated a new and ominous diagnosis—acute lymphoblastic leukemia (ALL)—an incurable and terminal blood disease wherein immature white blood cells overproduce and crowd out normal cells in the bone marrow. Aggressive, experimental chemotherapies were available but with little, if any,

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hope of significant improvement. She was going to die in a matter of weeks. Ruby declined any further treatment and elected to receive hospice care.

Ruby was married and had two adopted children, a son aged 13 and a daughter aged 10. When told the diagnosis of ALL, Ruby requested to "talk with someone" *about how to break the news of her terminal disease to her children. A conference among her doctors resulted in a referral to a clinical psychologist with expertise in end-of-life counseling who was a member of the hospital staff.*

(Note: To perform professional work in a hospital setting and to charge for those services, the clinician would have to be an official member of the hospital staff approved to treat its patients. Such staff membership requires being licensed and in good standing in one's profession, free of ethical complaints or malpractice actions, and competent to deliver specific treatments, e.g., psychotherapy.)

When the clinician met Ruby at bedside, her opening remarks were "I have a strong [Christian] faith; I know where I'm going [heaven]. I've been sick my whole life so I'm not afraid to die. I just need to know how to tell the children and what to say."

Also at Ruby's bedside was her mother, and it was clear from the patient's body language that she wished her mother to stay during the consultation. After clarifying that it was indeed Ruby's preference for a joint meeting (i.e., obtaining informed consent), the session de facto became family therapy. Later, the patient's sister arrived and also joined the conversation at the patient's invitation. The clinician was aware of the strategic value of having these two close family members in attendance because undoubtedly they would play a major role in the subsequent lives of Ruby's children.

First, the clinician led a discussion of general principles about breaking bad news gently and progressively (Buckman, 1992). For example, finding out from the children what they have already been told or heard helps gauge where and how to start the disclosure. As with any difficult topic, the children's developmental levels need to be respected regarding use of language and technical concepts while remaining alert to cues of comprehension. Information can be given in stages, depending on receptivity. Monitoring for emotional overload is critical; the disclosure may take more than one conversation to allow the children an opportunity to process what has been heard and ask questions.

In addition, some principles from counseling children and adolescents were reviewed. These methods included using the "one-way conversation," wherein information is conveyed without requiring the listener to respond overtly, intuitively labeling emotion, and modeling constructive self-disclosure (e.g., "It makes me sad to know I won't be here with you . . . but I hope you'll always remember how much I love you"*).*

Ruby and her family were highly receptive to these initial remarks so the clinician pressed on with other concepts such as "gifting" the children with legacy keepsakes, heirlooms, or letters for future occasions such as graduation, marriage, or childbearing, and giving permission for tears, humor, and hugs (e.g., "I might be dying but I won't break!"*). The clinician reminded the patient that hospice can provide the children with emotional support during her decline and with bereavement programs after her death.*

As the meeting drew to a close, Ruby seemed empowered by the discussion: "I think I can do this." *The clinician suggested that the patient's mother and sister could serve as her proxies after her death and they each, in turn, promised Ruby to provide for the children's emotional as well as physical care in the future. The poignancy of the moment produced tears among all the participants, including the clinician. After handshakes and thank-you's from the family, the clinician discreetly left the room on an upbeat note, allowing Ruby and her family to craft the details of just how to apply these principles in breaking the news to her children.*

A post-session review of the medical record revealed that Ruby died at home approximately one month later. In retrospect, this consultation represented a "point in time" intervention consisting of a single session, albeit one with several pertinent themes developed and discussed. For the visit to be effective, the clinician used all three "layers" constituting death competence: (1) cognitive knowledge about how to break bad news, talk to

children/adolescents, incorporate legacy rituals, and work with hospice; (2) emotional resilience to orchestrate, with poise, an intense family meeting at the hospital bedside; and (3) death competence needed to talk candidly about dying with a terminally ill patient and her family.

Case 2

Kent was a White male in his 80s, a retired physician diagnosed with cardiac-renal syndrome, a progressive condition involving both congestive heart failure and kidney failure. In short, diuretics (i.e., water-reducing medicines) given to relieve fluid build-up around the heart put unsafe pressure for elimination on the already weakened kidneys. One organ system could not be medicinally supported without compromising the other, setting up a delicate balancing act that could only be sustained temporarily. Kent's initial prognosis was 1 to 2 years of life. He elected outpatient psychotherapy to address end-of-life concerns because "I'm becoming a crabby old man," *and he sought serenity and peace of mind rather than the bitterness he perceived was overtaking him.*

Subject to depression since his heart bypass surgery 20 years earlier, Kent took an augmented regimen of antidepressant medicines, Effexor and Celexa. In addition, Kent was no stranger to psychotherapy. He had been treated twice previously with moderate results. The primary focus of treatment had been enduring resentments toward his domineering mother, whose love had always been experienced as conditional, and toward his ex-wife (now deceased) who, in his estimation, had continued to harangue him after their divorce and negatively biased his children against him. As a result, Kent was estranged from his three natural children. However, he had a good relationship with his second wife of 27 years, a loving "earth mother," and his three stepchildren.

In the beginning, Kent came for psychotherapy about once a month over a period of 10 months. Whereas he seemed remarkably accepting of his terminal prognosis, Kent's distress was directed primarily toward his disappointing relationship history. Some of the therapy work focused on resolving his long-standing anger toward his mother. He decided to write her a letter (posthumously) enumerating his myriad complaints but, at the counselor's encouragement, agreed also to include acknowledgment of what she had done for his benefit. To his surprise, when he finished the letter and brought it to one of the sessions, the section on gratitude was far longer than the section on resentment! Kent also revisited the quiet conversation he had had with his hospitalized mother the evening before she died and noted that, in the end, they had softened toward one another. He concluded that his mother had done much to help him achieve his potential in life and that she had not been all bad as a parent. This revised assessment allowed Kent to release much of the resentment he had been carrying.

On the subject of estrangement from his children (who would not return his phone calls), Kent started to get some traction therapeutically with discussion of Ira Byock's (2004) ideas about the things that matter most at the end of life: forgiveness, gratitude, and love. Besides the letter to his mother, Kent wrote letters to his three natural children to be given to them after his death in which he asked forgiveness for any wrongs done to them, extended forgiveness to them, expressed gratitude, and affirmed his love for them. He also wrote a similar letter to his wife. These concrete actions gave Kent some sense of contentment that, combined with a sober realization that not all conflicts have a storybook ending, allowed him to conclude that he had tried to bridge the gulf from his end and that things were "as good as they are going to get" *regarding his estranged children.*

Kent's condition worsened. He became housebound and went on hospice care. At that point, the clinician shifted to making home visits during the last 3 months of Kent's life.

(Note: This change of venue requires conducting oneself with the same commitment to confidentiality employed in hospital or clinic settings, albeit carried out under different circumstances where the clinician is, in effect, a "guest" in the patient's home and follows rules of decorum appropriate to that status; cf. Gamino & Ritter, 2009.)

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Kent became increasingly depressed as his health deteriorated and declared at one point, "I just want to get it [dying] over with."

In this penultimate session, the clinician first inquired whether Kent thought of himself as "living or dying." When Kent endorsed the latter (i.e., dying), the clinician focused on the possibilities for self-determination between the present and whatever future time proved to be Kent's moment of death. He retained control of his thinking and of how he spent his day. Gratitude proved to be the central theme: appreciating his clear mental faculties, acknowledging his full self-awareness, being a companion to his wife, enjoying special foods, and even playing with his dog.

The turning point in the meeting occurred when Kent began describing in great detail his fondness for the homemade gumbo prepared for him by his stepdaughter. He waxed on about the delicacy of the roux, the tangy seasonings, and the assorted meats and seafood she included. It was enough to make the clinician's mouth water and he responded, "Do you hear yourself? Enjoying that gumbo and eating it with gusto—that's living!" *Kent immediately retorted,* "But I'm supposed to be dying." *The ironic humor of the exchange was not lost on Kent. He seemed to internalize the lesson that he had the choice to live each day fully until he died and to do so with a sense of gratitude for all he still had.*

The clinician's last meeting with Kent was about 2 weeks later and he was much more serene and accepting. Not long after that session, Kent died quietly at home with his wife at his bedside. At the family's request, the clinician made a condolence call the next day, and Kent's wife and stepchildren seemed very comforted by the clinician's presence given how much the therapy appeared to have helped Kent come to some peace of mind and heart about his life before he died. The clinician also attended Kent's funeral a few days later.

An unexpected and touchingly personal form of follow-up occurred about 1 month after Kent's death when a thank-you card arrived in the office mail from Kent's widow. Along with her note was a typed "Byock letter" to the clinician written by Kent before he died. The following excerpt from that letter sums up the conclusion of this case: "What a remarkable change you made in my life. I was depressed so that life wasn't worth the trouble, I felt. . . . I always felt excited to see you, because I was going to find something different to free me from the depression, and get some homework . . . It was the most fruitful experience that I ever had in a therapeutic setting."

Not all counseling work ends with this kind of positive outcome, much less the subsequent confirmation of helpfulness via letter or follow-up. Clearly, the patient was highly motivated to receive help. Yet, the clinician in this scenario adroitly combined fairly standard therapeutic techniques (e.g., addressing perceived past abuse by the mother) with more specific end-of-life work, such as seeking reconciliation with his children and confronting the existential complexity of how to "live until you die."

SELECTIVE LITERATURE REVIEW

The remainder of this chapter consists of a strategic review of scholarly literature, both theoretical and research based, pertinent to counseling the dying and their loved ones. Particular attention is paid to sources informing the actions of the clinicians in the two case examples, which are referenced frequently throughout this section, to illustrate integration of theory-research-practice in compassionate care of the dying.

How does one even begin approaching this delicate and daunting task of counseling the dying person? Any sound clinical interview is based on an overarching rationale leading to a plan of action, and counseling the dying is no exception. Generally, an initial evaluation with a patient facing the end of life includes eliciting some biographical history in order to know something about the person with whom one is speaking as well as inquiring about the individual's specific experience approaching the end of life. Thinking of the

patient's descriptions as narrative accounts, these parallel endeavors can be conceptualized as getting the patient's stories, both the *life story* and the *end-of-life story*. Table 24.1 contains a breakdown of content areas typically probed in each of these two major domains. Counselors can easily recognize the elements of the life story as standard components of an intake interview. The following subsections provide elaboration and illustration of how counselors go about eliciting material pertaining to each of the eight elements of the end-of-life story.

Diagnosis and Prognosis

Understanding the patient's subjective sense of the diagnosis and prognosis provides a natural starting point for a conversation about end of life. The biological aspects of the disease process and its implications are usually in the forefront of the patient's mind, and grasping those realities helps the counselor empathize with the seriousness and urgency of the situation. Also, the patient's perspective can be compared objectively with medical facts provided to the counselor prior to the interview in order to gauge the patient's level of comprehension about the disease. For practitioners or trainees uncertain how to open a session of this nature, a sample approach using a psychoeducational style is provided.

Table 24.1 Getting the Patient's Stories

Life Story	End-of-Life Story
• Family of origin	• Diagnosis and prognosis
• Medical status	• Primary emotions
• Psychiatric history	• Grieving styles
• Education/occupation	• Attachment patterns
• Family of procreation	• Leave-taking
• Social support	• Faith and spirituality
• Turning points	• Final arrangements
• General adaptation	• Legacy

I understand that [you're here because] you have very serious health problems. I'm hoping you can fill me in a little bit on your medical condition and what this means for you. As a [counselor], it would be my intention to try to help you and your loved ones cope with what's happening and be prepared to deal with whatever is required of you at this time.

Besides the careful wording, a delivery style that is clear and direct, yet inviting, goes a long way toward conveying a spirit of "rational confidence" so necessary for communicating competence and putting the patient at ease (Roos, 2002). Rational confidence means an attitude of positive expectancy on the part of the counselor, a grounded personal sense of "I can do this," connoting a conviction of authoritative know-how.

Primary Emotions

Most readers who have had any exposure to end-of-life literature will have heard of Elisabeth Kübler-Ross's (1969) seminal work, *On Death and Dying.* Originating in a patriarchal era in medicine and situated in the context of a medical-surgical hospital where dying patients were not always told directly about their diagnoses, Kübler-Ross's stages of dying (i.e., denial, anger, bargaining, depression, acceptance) have been both hailed for their genius and criticized as too simplistic, lockstep, and prescriptive (Corr, 2011). Whichever view of her work the reader takes, there is no disputing that Kübler-Ross's conceptual framework for understanding the dying patient has been widely disseminated and broadly applied as a psychological model for adapting to grief and loss of many kinds.

Perhaps the most important heuristic value of Kübler-Ross's work has been to identify key human emotions central to the experience of encountering the prospect of one's own death. Indeed, if one considers her findings not as sequential stages in an invariant, linear process but rather as "affect states" common to those facing death, Kübler-Ross's theory becomes a valuable road map for exploring that arduous emotional landscape. The truth is that many patients, no matter how insightful, often

do not fully recognize or understand their own strong emotions when approaching the end of life. Therefore, a basic and helpful step by the counselor is guiding patients to accurately "read" their own feelings, enabling them to delineate some sense of internal order amid the confusion and the fear.

In the case of Ruby, she decried the idea of being afraid of death herself. Nonetheless, her anxiety over her surviving children—what to say to them and how they would fare without her—constituted a derivative form of death anxiety. In many ways, the bedside consultation bolstered Ruby's courage to where she was no longer so afraid of confronting the specter of death when breaking the news to her children. The other prevailing emotion in the room was an unspoken sense of sadness, particularly evident in the "relational space" between Ruby and her mother and sister, all of whom realized that the cancer would separate them.

With Kent, the retired physician, anger and guilt were the predominant affective themes. His anger primarily targeted his mother and ex-wife, but frustration smoldered over his natural children's nonresponsiveness to his overtures to reconnect with them. He was also angry with himself. Kent's exasperation over his shortcomings in some of the major interpersonal relationships in his life was augmented by a nagging sense of guilt. The estrangement from his children reflected badly on his performance as a father. The pervasive anger and guilt initially blocked his efforts to find joy in everyday life even during his physical decline.

An innovative concept from the bereavement literature, the dual process model (Stroebe & Schut, 1999, 2010) purports a kinetic dimension to how individuals can be expected to respond affectively and behaviorally to their own imminent deaths. The dual process model suggests that individuals "oscillate" between loss-oriented and restoration-oriented modalities. At times, the dying patient and the loved ones may be actively grieving over the impending death, whereas at other times their focus is away from the grief and may involve activities concerned with surviving, even thriving, despite the loss. Clinical lore among those who counsel the dying and the bereaved translates this concept

colloquially as either "leaning *into* the pain" or "leaning *away from* the pain." Said differently, there is a time to grieve and a time to take a break from grieving. Knowing how to shift between these two modalities according to an intuitive personal rhythm can aid adaptation both for the dying patient and the loved ones in attendance. This need for oscillation is hypothesized as one of the reasons why there is frequently both laughter and tears expressed by grievers at moments of high sorrow, whether at the bedside of a dying person or later at funeral and memorial services (cf. Kunkel & Dennis, 2003). Such behavior, properly understood, is not disrespectful but needed and normative.

Grieving Styles

Another recent development in the bereavement literature codifies the long-standing commonsense notion that not everyone grieves alike and that individual differences are to be expected. Doka and Martin (2010) proposed two somewhat distinct grieving styles, intuitive and instrumental. Intuitive grievers are those who respond to loss and grief in a strongly emotional manner and experience significant relief from an opportunity to express those strong emotions, for example, by "talking it out" or "crying it out." Not surprisingly, these intuitive grievers are among those more likely to seek counseling. They appreciate someone listening to and giving witness to their pain, benefit from cathartic release, incorporate insight about what they are feeling and experiencing, and derive reassurance from connecting with others through their grief.

By contrast, instrumental grievers more often exhibit their grief through cognitive and physical responses. Loss provokes a mental conundrum to be solved and/or produces somatic symptoms and ailments that need to be alleviated. Instrumental grievers are disinclined to share their feelings or focus on emotion. For them, adaptation involves thinking and doing. Their perception is that traditional psychotherapy, with its emphasis on elicitation of affect, is "not for me." Instrumental grievers are much more likely to respond favorably to psychoeducation about loss because they need

information to process their experience. They will consider changes, assess impact, and weigh consequences. Therapeutic suggestions in the form of directives for ritual, projects, or memorializations, that is, "grieving in action," are usually well received. Pressing instrumental grievers to express affect may be not only counterproductive but also off-putting.

Finally, Doka and Martin (2010) caution that there are not merely two categories of grievers and that many people exhibit mixed styles. Their take-home lesson for counseling the dying and their loved ones is that individuals express their grief differently and that sensitivity to stylistic differences can help the clinician to better assist those in sorrow and in pain, whether it is the dying patient or associated loved ones.

Attachment Patterns

Much has been written about the possible correlations between a person's preferred attachment pattern and the manner in which grief may express itself. Based on Bowlby's (1980, 1988) groundbreaking work with children orphaned after World War II and subsequent empirical investigation (Ainsworth, Blehar, Waters, & Wall, 1978), clinical interest focused on children who displayed other than a *secure* attachment pattern. Variations of *insecure* attachment include anxious-ambivalent, dismissive-avoidant, and disorganized-disoriented patterns. Formative developmental experiences with primary caregivers are thought to lay down the templates for later attachment behavior demonstrated in significant personal and love relationships. Such patterns are not invariant, however, and modulation/adaptation can occur subsequently.

How do these attachment patterns come into play when counseling the dying? Practically speaking, as in the case of the bedside consultation with Ruby, there may be precious little time for assessing such factors via detailed interviewing about her early life. Immediate evidence (e.g., presence and inclusion of her mother and sister, descriptions of ties to her children) suggested that Ruby's significant relationships were close and strong (i.e., they reflected a secure attachment pattern). Counseling Ruby could proceed assuming understandable sadness about impending termination of her key relationships.

On the other hand, understanding early relationship formation and how stylistic patterns may have influenced adult relationships for Kent was a different scenario altogether. With Kent, the clinician had the luxury of time to assess his upbringing and identify the difficult dynamic between him and his mother. Kent was distrustful and cautious as a result, and his former relationship with his ex-wife and his estrangement from his natural children were characterized by distance, suggesting a more dismissive-avoidant attachment pattern. Although Kent seemed to have "mellowed" in that he had a much closer relationship to his current wife and stepchildren with whom he had no conflict, his avoidant style made it difficult even to consider how to engage his natural children as he approached the end of his life.

Mikulincer and Shaver (2008) hypothesized that attachment patterns have implications for how grief may be expressed. Those with secure attachment will likely display "normal" or uncomplicated grief with attendant sadness that usually resolves on its own (cf. Worden, 2009). Individuals with insecure attachment patterns may show problematic variations: Anxious-ambivalent attachment leads to clinginess that can result in prolonged or chronic grief; dismissive-avoidant attachment with its distancing may manifest as delayed or inhibited grief; disorganized-disoriented attachment may engender unresolved grief due to the complexities inherent in such a conflicted pattern. Counselors are well advised to keep these possibilities in mind when encountering the dying patient and the loved ones closest to them.

Recent revisions in the diagnostic nomenclature (American Psychiatric Association, 2013) help differentiate between uncomplicated grief and more serious clinical depression, a possible derivative of difficulty in grieving, especially when an insecure attachment pattern is involved. Individuals who suffer from serious depression often fare poorly during bereavement in general and may be even

more distressed during acute grief. Specific diagnostic markers can help counselors more accurately detect when underlying depression accentuates grief intensity. These diagnostic differences are summarized in Table 24.2. Counselors should be attentive to these distinctions, particularly during the assessment phase of clinical work.

Leave-Taking

The work of Ira Byock (1997) has been quite instructive in identifying "developmental milestones" within the context of the dying experience. In other words, there are recognizable landmarks in the psychological/emotional processes displayed by individuals approaching the end of life, which can be thought of as the "work" of dying. Some of the major milestones at the end of life include the following processes:

- Completing one's worldly affairs, such as finances, estates, wills, business, property
- Finding a sense of meaning about one's life, accomplishments, choices, destiny
- Experiencing the love of others who are important in one's life
- Completing one's relationships with family, friends, community
- Accepting the finality of life
- Surrendering to the transcendent, to the "unknown," by letting go

Counselors who know these milestones will more accurately understand the dying patient's

Table 24.2 Diagnostic Differences Between Uncomplicated Grief and Clinical Depression

Clinical Sign	Uncomplicated Grief	Clinical Depression
Onset	Death of loved one	May or may not have an identifiable psychosocial precipitant
Predominant affect	Feelings of emptiness Sense of loss	Depressed mood Inability to anticipate happiness or pleasure
Course of dysphoria	Wave-like, decreases over time	Persistent, nonspecific
Capacity for humor or positive emotions	Yes	No
Thought content	Preoccupation with deceased	Self-critical Pessimistic Ruminative
Self-esteem	Preserved Sense of failure specific to relationship with deceased	Generalized worthlessness; self-loathing
Thoughts of dying or death	Focus on deceased Anticipate reunion	Ending own life due to feeling worthless, undeserving, or intolerable psychic pain

SOURCE: Adapted from American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

phenomenological experience and more adroitly guide their conversational interventions toward therapeutic work remaining to be done.

Byock (2004) later elaborated what was embodied in the concept of "completing" relationships with family and friends identified in his earlier writing. From his work as a physician, both in emergency medicine and in palliative care, Byock found himself in a position to influence end-of-life discussions between dying patients and their loved ones when medical cure was no longer possible. For Byock, completing does not mean finishing per se, but rather accomplishing a series of crucial steps in order to arrive at a level of mutual understanding and peace about what individuals have meant to one another during the course of their shared life experiences. Specifically, he posited four things that matter most before saying good-bye—*Please forgive me; I forgive you; Thank you; I love you.*

According to Byock (2004), finding the courage to say these four things in an authentic, heartfelt manner is the essence of completing a personal relationship before death and is the only remaining tonic that can give either party—the dying person or the surviving loved one—any genuine sense of peace before parting permanently in this life. As mentioned in Kent's case narrative, writing letters to his estranged natural children following Byock's prescription gave him some modicum of comfort that he had done what he could to reach out and be on the best possible terms with his children before he died. He hoped the letters might give his children some sense of peace as well. Additionally, because Kent was probably an instrumental griever, this specific assignment gave him a conceptual pathway to think about their relationship history and provided a concrete action plan, which he readily embraced.

The theme of gratitude is particularly important. Empirical research shows that actively cultivating gratitude awareness (e.g., grateful contemplation) and expressing gratitude by regularly thanking others is associated with better self-report of mental and physical health (Emmons & McCullough, 2003; Ruini & Vescovelli, 2013; Wood, Froh, & Geraghty, 2010). These findings support Byock's (2004) conceptualization of the four things that matter most at end of life.

Faith and Spirituality

In Rando's (1993) impressive tome on complications in grief, she articulates how having an "explanatory framework" for understanding death, what it means, and how it fits into the natural life cycle lends resiliency to the grieving person when confronting the end of life. For many people, codified faith beliefs, intrinsic spirituality, or an ethical life philosophy constitutes that explanatory framework.

Gamino, Easterling, and Sewell (2003) described how the end of life may create a "reachable moment" wherein individuals may be able to access and activate their faith or spirituality, even when previously dormant, to help them cope with the prospect of death, whether their own or someone else's. To substantiate their assertion, they presented empirical data showing that grieving persons who endorse higher levels of intrinsic spirituality—defined as a personal conviction about the existence of God or a higher power as well as some type of personal relationship with that higher power—and who practice their beliefs in a faith community report correspondingly lower levels of grief distress during bereavement.

Therefore, incorporating faith and spirituality into an end-of-life conversation may potentially be very therapeutic for some dying patients. It may also be not applicable or even unwelcome for others. Gamino et al. (2003) recommend that interviewers first inquire carefully whether the topic of faith or spirituality is appropriate before charging forward with a universal assumption that discussing it will help everyone. Questions designed to gauge the patient's receptivity may include queries such as "Does faith or spirituality affect how you approach this time in your life?" or "How inclined are you to think about God, or a higher power, at a time like this?"

Inquiring if faith or spirituality is important and/or listening for its spontaneous emergence in the dialogue are salient tasks for anyone attempting to work with the dying and their loved ones. In the case of Ruby, she declared her Christian beliefs in God

and the afterlife without any prompting whatsoever from the clinician. Ruby's disclosure helped establish immediately her explanatory framework for thinking about death and gave context for her reported lack of fear and high level of acceptance. Yet, not every counselor may feel adequately prepared for a discussion about this topic with a dying patient. If the resulting theological/philosophical discussion seems too complex for the clinician, beyond one's range of competence, or so different from the clinician's own beliefs and sensibilities so as to be compromised by lack of empathic understanding, patient advocacy in the form of a referral to a chaplain or a faith representative is always an option (cf. Sue & Sue, 2008).

No one can be reasonably expected to know everything about all possible faith traditions. However, Griffith (2010) proposed that clinicians need to listen openly and empathically when encountering patients whose faith or spiritual beliefs seem radically different from one's own in order to promote a solid person-to-person connectedness that can transcend differences. Even listening from the "outsider" position can yield an empathic connection from which useful discussion can occur, particularly when counseling the dying and the bereaved. Graybar and Leonard (2005) suggested that listening is the "mortar" that binds together the clinician and the patient into the therapeutic relationship that is the foundation of successful psychotherapy.

> Ideally as clinicians, listening is at the core of who we are and at the center of what we do. Listening and being listened to are the cornerstones of psychological development, psychological relatedness, and psychological treatment. It is hard to imagine an intimate, close, or curative relationship where listening does not occur, or where one does not feel seen through the process of being heard. The need to be listened to is never outgrown. Being listened to allows us to be understood in all our complexity. It allows our experiences to count and ourselves to matter. (p. 3)

Final Arrangements

Consistent with diversity among people, viewpoints toward making final arrangements vary widely. Counselors should not be surprised that dying patients and their loved ones show parallel variability in their willingness to openly discuss such matters at the end of life. For some families, such conversations can be consoling and even healing in coming to terms with inevitable death, knowing things are settled, and resting assured that surviving loved ones have the direction they need to follow through with decisions made and wishes expressed. Yet, for other families, such talk about final arrangements is essentially verboten (i.e., forbidden). Discussing things like cremation/earth burial, funeral/memorial services, location of burial/interment, or matters of estate/legacy seems disrespectful to the dying person who is still alive, or even offensive due to cultural or faith traditions, superstitions, or fears. A simple question such as "Would it be helpful to you to discuss what happens after death [or after you are gone, or after he/she is not here], or not so helpful?" usually will elicit a basic direction for the counselor, often on the basis of nonverbal signals (e.g., affirmative nod of the head, or pursed lips/brow and frown). The response to such an inquiry aids the sensitive counselor in the timing of any therapeutic intervention around final arrangements.

Fortunately, once the subject is broached, there are some excellent and accessible resources available to assist dying patients and their loved ones in discussing these matters and making satisfactory decisions. For example, Harvard Medical School (2008) published a monograph specifically for educating the general public about advance directives for health care decision making at the end of life and the role of proxy or surrogate decision makers if the patient is too medically compromised to decide autonomously.

Another helpful tool, the *Five Wishes* document, is available on the Internet through an organization called Aging With Dignity (2013). This accessible brochure walks the reader through a series of steps designed to address various medical, personal, emotional, and spiritual options for care at the end of life. The *Five Wishes* include who will be the proxy decision maker in the event of incapacity, what medical treatments are desired/not desired (e.g., CPR, artificial ventilation), how

to be kept comfortable, how one wants to be treated by others when nearing death, and what messages there are for loved ones regarding final arrangements and legacy. Because discussing final arrangements sometimes can become technical and controversial, the counselor needing additional information for facilitating such a conversation can consult ancillary resources (e.g., Gamino & Bevins, 2013; Gamino & Ritter, 2009).

Throughout human history, funerals have played an important sociological function for survivors to honor the deceased, express grief, garner social support, enact religious or cultural traditions, and dispose of human remains (Fulton, 1995; Hayslip, Sewell, & Riddle, 2003; Irion, 1990–1991). Because feelings of sorrow and sadness can be so overwhelming around the time of death, ritual actions performed during funeral or memorial services provide a vehicle to "walk out what you cannot talk out" as a vital coping strategy (Hoy, 2013). Additionally, active participation in planning and carrying out funeral or memorial services has been shown to be associated with better subsequent adaptation during the bereavement trajectory (Gamino, Sewell, Easterling, & Stirman, 2000). For all of these reasons, counselors are well advised to encourage dying patients and their loved ones to embrace the requirements inherent in making and executing final arrangements.

Further on the subject of funeral and memorial services, some loved ones of dying patients may be tasked with eulogizing them but may not have any systematic idea of how to go about composing a fitting eulogy. Counselors involved in end-of-life discussions may be in a position to offer helpful suggestions and can refer interested individuals to appropriate resources. Specifically, Kunkel and Dennis (2003) wrote a very informative article about what makes eulogies comforting, based on a critical analysis of their content as a form of rhetoric. Key elements in effective eulogia include establishing the credibility of the speaker, praising the deceased, affirming a vivid past relationship, disclosing grief emotions, employing positive reappraisal, calling for action-based coping (cf. Lazarus, 1991), and invoking continuing bonds with the deceased (cf. Klass, Silverman, & Nickman, 1996). The authors include examples of well-received eulogies. Intuitive validation for the efficacy of these elements comes from their obvious similarity to proven therapeutic techniques in grief counseling (cf. Worden, 2009).

Legacy

Recently emerged in the field of end-of-life counseling is dignity therapy, an empirically validated psychosocial intervention for the dying pioneered by Harvey Chochinov and colleagues (Chochinov, 2012; Chochinov et al., 2005; Chochinov et al., 2011). Designed for the terminally ill who are being served with palliative care in lieu of any curative treatments, application of dignity therapy has been shown to be associated with better perceived quality of life, greater sense of personal dignity, positive changes in how families saw and appreciated the patient, improved sense of spiritual well-being, and decreased sadness and/or depression.

Dignity therapy itself consists of a four-step protocol. At the initial visit, the process is introduced and the patient's permission and cooperation are secured. Some questions are left behind for the patient to ponder as "pump primers" for the subsequent inquiry. At the second visit (ideally, within a day or two), the patient is interviewed with the formatted prompts, for example, "Tell me about your life history and what you think is most important." "What are the most important roles you have played in your life?" "What are your hopes and dreams for your loved ones?" "What have you learned about life that you would like to pass on to others?" "Are there words of instruction, guidance, or comfort for your family?" An audio recording of the interview is made and transcribed immediately. Following some judicious editing by the interviewer, the transcript is then read back to the patient at the third visit. This rendition allows for correcting, affirming, reflecting, and summarizing as well as giving a "title" to one's life story. At the fourth and final visit, a bound copy of the polished dignity therapy interview is presented to the patient and family as a legacy gift.

One impressive strength of the dignity therapy protocol is its empirical validation when carried out according to its intended sequence. Unfortunately, not every end-of-life situation is sufficiently anticipated or orderly enough to accommodate such an elegant four-step process. Counselors and therapists working with the dying and their loved ones may be forced by circumstances to improvise or adapt dignity therapy principles to the unique needs of the patients whom they encounter. The core ideas of dignity therapy—that is, specific interrogative prompts to elicit end-of-life reflections and transcribing and preserving the words and observations of the dying person—merit serious consideration for implementation when clinical circumstances allow.

In the case of Ruby, the one-time bedside encounter at a geographically remote (from her home) hospital did not lend itself to incorporating the formal four-step procedure of dignity therapy. However, the clinician utilized some of the dignity therapy concepts, especially when extending the discussion beyond the presenting question of "How do I break the news to my children?" to related topics of legacy letters, verbal instructions for the future, and transmission of symbolic keepsakes. The goal was for Ruby to leave behind something of herself for her children—tangible and intangible—to embody and represent the love she had for them during her foreshortened time in their lives.

ETHICAL CAVEAT

One potentially hazardous dimension in end-of-life counseling concerns appropriate boundary regulation. As is evident from the case examples, the nature of end-of-life work requires a certain level of finesse when it comes to maintaining confidentiality, managing physical contact with the patient (or loved ones), using self-disclosure, and leveraging the relationship dynamic to have the optimal therapeutic impact. Table 24.3 displays key concepts intended to help the reader see how common practices in counseling the dying may differ from typical office behavior (Gamino & Bevins, 2013). Being well-grounded personally and professionally

is absolutely essential to making intentional decisions as to when such procedural or philosophical variances are indicated and advantageous. As in all clinical decision making, welfare of the patients and their loved ones is the highest priority so that any boundary "crossing" made for therapeutic reasons does not become a problematic boundary "violation," which could harm the patient or compromise the clinician's objectivity (Gamino & Ritter, 2009).

With Ruby, the clinician utilized greater than usual physical proximity in talking with her at bedside, a move that increased familiarity and emotional intimacy. Family members in attendance were brought into the exchange so that ideas and information flowed freely back and forth, much like a problem-solving "kitchen table" meeting at home. In the process, the clinician was taken into the family's confidence much like a blood relative, at least for purposes of addressing the children's needs. Even the clinician welled up with tears during part of the discussion about how to help the children not just survive, but thrive, after the patient's death. An argument could be made that any stance by the therapist that was more aloof or formal would not have yielded the same heartfelt resolutions.

In palliative medicine, the family is considered the "unit of care," and sharing information about the dying patient with loved ones in attendance is considered normative (cf. Gamino & Bevins, 2013). For counselors coming from a tradition of protecting the privacy of the individual being counseled, it is important to verify with the patient that others are to be included in the session and that information can flow freely. In Ruby's case, the clinician confirmed her wish to include her mother and sister in the discussion. Because this was a one-time bedside visit, there was no "prior information" from previous sessions to be protected; rather, the patient remained in charge of what she chose to disclose in the presence of her relatives.

With Kent, physical touch and hugging were important aspects of the home visits, a tangible connection he seemed to need to counter increasing fears of death. The therapist employed self-disclosure of life values (e.g., "It's what you do between now and the time you die that counts").

Table 24.3 Reconsiderations of Provider-Client Boundaries in End-of-Life Counseling

Typical Office Behavior	Topic	Common Practice in End-of-Life Counseling
No disclosures beyond consultation session without specific written/ oral permission.	← Confidentiality →	Discussion of client information with family & loved ones, especially when client's consciousness is compromised.
Handshakes at greeting or parting; perhaps occasional hug; rare contact during Gestalt/ psychodrama maneuver.	← Physical Contact →	Sitting/standing close; holding hands; touching limb/shoulder; hugging (patient/family); assisting with physical care.
Selective/strategic self-disclosure that advances "process" discussion of "here-and-now." Emotion *described* but generally *not displayed*.	← Self-Disclosure →	Greater demand to be "in the moment" of liminal period of dying. More disclosure of personal thoughts, feelings, beliefs (e.g., religious convictions). More permissive approach to display of emotion.
More formal, more "vertical" relationship, with power differential favoring the provider. Friendly, but not friend.	← Relationship Dynamic →	Less formal, more "horizontal" relationship, with more equalized power. More "friend-like" or "honorary family."

SOURCE: Ethical Challenges with Counseling Clients Nearing the End of Life. In J. Werth (Ed.), "Counseling clients near the end of life: Practical perspectives on fundamental issues" (pp. 3-24). Reproduced with the permission of Springer Publishing Company, LLC, New York, NY 10036.

The honorary family status of the therapist was evident during the condolence visit in the home after Kent's death and by the therapist's presence at the funeral. However, despite a sincere invitation to return to the patient's home for the customary bereavement meal after the funeral, the therapist chose to reestablish the boundary of "outside the family" and politely declined. When in doubt about decisions such as these, the conscientious clinician turns to trusted colleagues or a supervisor to ensure an objective "reading" of the circumstances and to avoid behaving inappropriately as a result of a "blind spot" (Gamino & Ritter, 2009).

CONCLUSION

It should be abundantly clear to the reader at this juncture that compassionate and clinically effective care of the dying and their loved ones can be both challenging and immensely rewarding for those counselors who possess death competence as well as the requisite therapeutic skills. The eight domains pertaining to end-of-life care—diagnosis and prognosis, primary emotions, grieving styles, attachment patterns, leave-taking, faith and spirituality, final arrangements, and legacy—constitute important areas of inquiry, and their pertinence is supported by theoretical and empirical findings that give an evidence base for employing them.

The two case examples provided in this chapter illustrate some of the existential uncertainties of counseling dying patients. No two persons are alike, and each therapeutic dyad of clinician and patient is unique. These truisms apply to counseling endeavors in general and certainly apply to end-of-life counseling with the dying and their

loved ones. Practitioners who prepare themselves emotionally, equip themselves with concepts and techniques from the scholarly literature, seek appropriate guidance and supervision, and reflect thoughtfully about their work will be well positioned to provide compassionate and effective care to the dying and the bereaved.

DISCUSSION QUESTIONS

1. What personal experiences have you had with death or loss, and how do these experiences sensitize you, positively or negatively, toward counseling the dying?

2. To better explore your own level of death competence, what areas of counseling seem most "natural" or comfortable for you, and what areas seem more challenging or difficult to undertake? How comfortable are you with the prospect of counseling the dying?

3. Which grieving style, intuitive or instrumental, better describes your personal inclination? (The *opposite* style would be the one you would need to explore and study further in order to be prepared to help grievers from that standpoint.)

4. What kind of attachment style was modeled in your family of origin, and how does that experience influence your personal style in friendships and love relationships as well as in counseling relationships?

5. How open are you to accommodating spiritual belief systems and cultural practices around dying and death, including final arrangements, that are different from your own?

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