Preparation for Counseling Adults With Terminal Illness: Personal and Professional Parallels

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This article presents a review of the literature on counseling adults with terminal illness, particularly the literature on the nature of preparation that counselors and other professionals who attend to the needs of adults with a terminal illness require. The authors review information and findings from philosophical, psychological, practical, and spiritual works. It is evident from these readings that a personal and professional examination of making meaning of life and death is integral to the performance and personal well-being of professionals who take this caregiving role.

A review of the professional literature on counseling adults with terminal illness yields fascinating information. Almost invariably, discussions about theory and practice are preceded or intertwined with philosophical discussions about death and about how it is and how it ought to be viewed by individuals and groups. It is evident from these discussions that a personal and professional examination of how counselors make meaning of life and death is integral to preparing to counsel adults who have a terminal illness.

In this article, we provide a review of pertinent literature—primarily but not exclusively from the counseling field—that shows that there are parallels between the experiences and preparations of both the counselor and the client as they seek to address the client's concerns. Starting with the philosophy of life and death and the mindfulness of meaning needed by all who are facing death, we find that the potential for increased awareness is high for both client and counselor. Recognizing this potential, we suggest that integrating spirituality and interacting fully with the client and the reality of life and death are critical in the support process through the various coping phases.

Mindfulness of Death and Meaning

Life and death are often juxtaposed as polar opposites. Simplistically, life is viewed as a beginning and a cause for celebration, whereas death is viewed as an end to be feared and a cause for mourning. Yalom (1998), an existential psychotherapist, offered an illuminating analysis of how this polarization develops in his writings on death anxiety, or fear of death. Yalom identified...
death anxiety as a universal human phenomenon. He theorized that death anxiety plays a major role in individuals' internal experience. He explained that a major early developmental task for children is dealing with a fear of obliteration and that in order to cope with that fear, they erect defenses against death awareness. In essence, they cope by denying the possibility of death. He further explained that they do this in one of two ways. They may develop a belief in their own specialness and personal inviolability, or they may put faith in the existence of an ultimate rescuer. Confrontation with a terminal illness is a direct challenge to the defenses an individual has constructed against death awareness (Garrow & Walker, 2001; Yalom, 1998).

It is worthy of mention that Yalom (1998) suggested that the concept of death awareness is not only helpful in counseling adults who have a terminal illness but that "a robust and effective approach to all psychotherapy may be constructed on a foundation of death awareness" (p. 184). Yalom's work is rooted in philosophy from which he crystallized the impact of the interconnectedness of life and death awareness for all of us:

A venerable line of thought, stretching back to the beginning of written thought, emphasizes the interdigitation of life and death. It is one of life's most self-evident truths that everything fades, that we fear the fading, and that we must live, nonetheless, in the face of the fading, in the face of the fear. Death, the Stoics said, is the most important event in life. Learning to live well is to die well; and conversely, learning to die well is to learn to live well. (p. 185)

Not surprisingly, the work of others in the field of death and dying, such as the field's pioneer Elizabeth Kübler-Ross, also emphasizes the ideas that life and death are inextricably connected and that maintaining an awareness of death presents challenges that offer the potential to enrich life. Clearly, a diagnosis of a terminal illness is a catalyst for reflection on existential meaning or the "ultimate concerns" as Yalom (1998) referred to them.

A variety of professionals whose work brings them into contact with dying people have reported personal and professional challenges. For example, family lawyers have recognized that their work with dying clients forces them to face their own mortality, and they refer to themselves as "hidden victims of every dying client's death" (Kliman, 1980, p. 15). In addition, rehabilitation counselors have recognized that their work and home lives are affected by the deaths of clients (Hunt & Rosenthal, 2000). Recognizing his own personal involvement in the tragedy, Weinrach (1988), in an essay about critical incidents in counselor development, reflected on his own countertransference while counseling a family with a dying child. Clearly, the challenges faced by the professional caregivers parallel the process experienced by the clients.

Everyone, including counselors and clients, lives along a continuum of death anxiety and death awareness. As part of the process of preparing to work with clients, counselors should recognize their own position along the continuum, and, similar to racial identity issues in multicultural counselor education (Helms, 1995), counselors need to be aware of both their own and their cli-
ents’ level of death anxiety and death awareness. Although research specific to counseling is scarce in this field (Becvar, 2003; Werth, Gordon, & Johnson, 2002), one study (Kirchberg, Neimeyer, & James, 1998) indicated that counselors with lower levels of death anxiety corresponded to higher levels of empathy toward the client and lower levels of secondary trauma experienced by the counselor. Individuals with a terminal illness, their families, and their counselors inevitably experience a shift in where they are along this continuum. Understanding and managing these shifts are further “illuminated by Pattison’s crisis model” (Rando, 1984, p. 200), which bridges the sense of both danger and opportunity of continuum shifts.

An examination of the meaning of the word *crisis* serves to reinforce the idea that the knowledge of death has the potential to enrich life by inducing a state of mindfulness of being. Greenstein and Breitbart (2000) traced the word *crisis* to the Greek root, *krisis*, which literally means turning point, and to *krinein*, which means to separate or decide. Yalom (1998) considered the word *crisis* in terms of its Chinese pictogram, which “is a combination of two symbols: ‘danger’ and ‘opportunity’” (p. 190).

A psychological characterization of a diagnosis of terminal illness as a crisis that can trigger continuum shifts similarly points to the inherent dangers and opportunities. Rando (1984) summarized five aspects of this crisis: It is not solvable, clients have no prior experience coping with terminal illness, it threatens life goals, it builds tension and anxiety that can be integrative or disintegrative, and it brings unresolved problems to the forefront.

**Theoretical Constructs of Death and Dying**

**Phases of the Living–Dying Interval**

The “living–dying interval” (Rando, 1984, p. 209) describes the phases between a diagnosis of a terminal illness and physiological death. These phases are identified as the acute crisis phase, the chronic living–dying phase, and the terminal phase. Naturally, the tasks for the client and counselor are different at each phase.

**Acute crisis phase.** Because the phase of acute crisis is predominantly marked by anxiety, the proper focus of the counselor is on the reduction of anxiety. It is important for the counselor to maintain this focus rather than responding to the client’s defenses, which in any other case could be considered pathological. The key to reducing anxiety is to help the client “delineate his specific fears and concerns” (Rando, 1984, p. 232) and address each fear and concern individually.

Rando (1984) suggested that familiarity with common fears is useful in assessing a particular client’s fears. These include fears of the unknown, loneliness, loss of family and friends, loss of self-control, disability, suffering and pain, loss of identity, sorrow, regression, mutilation, and premature burial.

**Chronic living–dying phase.** The reduction of anxiety helps the client to move into the second phase, the chronic living–dying interval. The tasks of the counse-
lor at this stage center on helping the client with adaptive issues that arise through integrating living and dying. An understanding of the basic adaptive tasks that confront an individual who is seriously ill, especially someone who is terminally ill, helps the counselor when working with a client during this phase.

The basic adaptive tasks, attributed to Kalish (as cited in Rando, 1984), that confront a person who is terminally ill are (a) arranging a variety of affairs; (b) coping with loss of both loved ones and self; (c) arranging medical care needs; (d) planning the future; (e) anticipating future pain, discomfort, and loss of abilities; (f) coping with the death encounter, deciding whether to attempt to slow down or speed up the dying process; and (g) dealing with numerous psychosocial problems (Rando, 1984). Another framework for understanding the client's needs in terms of psychosocial issues was presented by Werth et al. (2002). They advocated for awareness of issues including autonomy/control, decision-making capacity, dignity, existential and spiritual beliefs, fears, hopelessness, being a burden, and absence of significant others in the counseling process.

The terminal phase. The final task of the counselor is to help the client move into the terminal phase when it is appropriate. This phase is typically marked by the client's withdrawal into self. Rando (1984) noted that the family should be prepared for this withdrawal, because it is natural at this stage, but stressed that it is important to ensure that the client does not withdraw during the earlier phases. During the terminal phase, the counselor's tasks focus primarily on facilitating an "appropriate death." Rando presented the criteria for an appropriate death as follows: Conflict is reduced, compatibility with the ego ideal is achieved, continuity with important relationships is preserved or restored, and consummation of a critical wish or concern is brought about.

Individual factors. Although the framework of phases is useful, Rando (1984) and Werth et al. (2002) reminded counselors that individual factors should also be taken into account in considering an individual's response to terminal illness. These factors include personal characteristics; interpersonal relationships; cultural, spiritual, socioeconomic, and environmental factors; and the characteristics of the specific illness. Clearly, maintaining a multicultural perspective is as important to counseling adults with terminal illness as it is to any other type of counseling.

The psychological perspective that Rando (1984) provided regarding crisis resonates with the philosophical perspective in recognizing the potential for both danger and opportunity, that is, the mobilization of integrative or disintegrative mechanisms that takes place for an individual with a diagnosis of terminal illness. It also provides counselors with a framework for conceptualizing the gravity and enormity of the physical, intellectual, emotional, and spiritual work with which an adult with terminal illness is challenged. Rando emphasized the personal and professional importance of balancing the goal of helping a person with terminal illness to seize the opportunities inherent in the crisis in order to live as fully as possible with the knowledge that dying is a painful process that is not to be romanticized. This counseling process of supporting the client in developing a balance, which in itself can be a continuum shift of death awareness and anxiety, can also serve as a catalyst for a continuum shift in the counselor.
The Five Stages of Death and Dying

Although the living–dying interval is particularly helpful in conceptualizing the tasks facing both counselor and client, Kübler-Ross's (1969) well-known five stages of death and dying are helpful in conceptualizing the feelings experienced by adults during the living–dying interval. These stages are denial, anger, bargaining, depression, and acceptance. Callanan and Kelley (1992) demonstrated the usefulness of this paradigm for both lay and professional caregivers. They suggested that imagining the five stages of dying also helps caregivers to better understand the feelings of people with terminal illness and thereby better prepare themselves for talking with a dying person.

Callanan and Kelley (1992) clarified that although denial, anger, bargaining, depression, and acceptance are called stages of dying, they are not necessarily progressive, unlike the phases in the living–dying interval. They are also not exclusive to dying but may be associated with any type of loss. Callanan and Kelley indicated the feelings that accompany each stage are easier to understand if we see them in the context of what dying people are trying to accomplish [the living–dying interval]: they're struggling to accept the reality of their diagnosis, to adjust to life with illness, and to prepare for approaching death. These are enormous tasks; it's no surprise that the emotions accompanying them are varied and painful, sometimes difficult to understand, even overwhelming. (p. 44)

Denial. In the case of denial, Callanan and Kelley (1992) echoed Kübler-Ross (1969), suggesting that caregivers should neither challenge nor encourage denial. Instead, they recommended seeking and recognizing the desire behind the denial, which is frequently self-protection and buying time to adjust to the new reality of a terminal diagnosis. Although the literature on death and dying is permeated by the message that the crisis posed by terminal illness is ripe with opportunity, Callanan and Kelley were careful to remind caregivers that some people who have a terminal illness remain in denial throughout their illness.

Anger. In their discussion of anger, Callanan and Kelley (1992) observed that the anger is typically directed at those closest to the dying person. They advised it is more useful to look for the cause. . . . In people who are terminally ill, the roots of anger often are frustration, resentment or fear. Frustration can stem from helplessness at losing control and becoming dependent on others; resentment, from seeing others' lives go on; fear, from uncertainty about what dying is like. (p. 47)

Kübler-Ross (1969) described this stage as arising from the question, “why me”? Bargaining. In order to describe the bargaining phase, Callanan and Kelley (1992) used the metaphor of a child at bedtime who asks for one more story, a glass of water, or one more trip to the bathroom. Dying people in this stage are trying “to postpone the inevitable.” They noted that most “dying persons' deals go unnoticed; the bargains usually remain secret” (p. 50). They advised that “if a dying person does bring up the subject [one should] listen with respect and say something like ‘Wouldn’t that be great!’ or ‘We’ll help in any way we can’” (p. 50).
Depression. Callanan and Kelley (1992) explained that a dying person's depression stems from grief and that the grief has two parts. "They're mourning what's lost already to illness—health, family role, job, independence—but also for what will be lost when they die—personal relationships, life itself, and the future" (p. 54). Kübler-Ross (1969) characterized the two parts as reactive depression and preparatory depression. She noted that these two parts are quite different from one another and should be dealt with as such. If a client experiences reactive depression, often the task for the caregiver is to help relieve unnecessary guilt or shame. If a client experiences preparatory grief, then Callanan and Kelley recommended that the task for the caregiver is honoring the client's feelings by simply listening and trying to understand.

In his personal reflections, Thomas (2001) spoke to this stage as presenting the most challenging aspect of his experience with dying, particularly coping with the preparatory or anticipatory grief.

I believe that my worldview, developed over a lifetime of reading and personal seeking, has made my terminal illness experience easier. . . . But this, I find, is only half the task. The other step in the tango of death, the emotional work involved in facing the ending of relationships, I have found remains to be dealt with, whatever one's worldview. (p. 121)

He clearly articulated what Callanan and Kelley (1992) observed—that the work at each stage on the path toward acceptance of death is challenging and the path will be different for each individual.

Acceptance. The final stage of death and dying is acceptance. Callanan and Kelley (1992) described acceptance as "a feeling of peaceful resignation that usually doesn't come to stay until death is very close" (p. 55). They noted that it is common for people who have a terminal illness to "experience interludes of acceptance and then, in one day, in one conversation, in one sentence, slip into another emotional stage" (p. 55). Kübler-Ross (1969) was careful to explain that acceptance "should not be mistaken for a happy stage. It is almost void of feelings" (p. 113).

In gaining an understanding of the client's experience and the potential of crisis, it becomes clear that the process of counseling and the preparation for the counselor are critical. It is essential for the counselor to be aware of his or her own place along the continuum of death awareness and anxiety and to support the client's movement through phases and stages. To accomplish this, the counselor needs to integrate meaning and spirituality into the counseling relationship.

The Counseling Relationship

The concept of impending death as a catalyst points to a major, if controversial, role of the counselor, namely facilitating the exploration of existential or spiritual meaning as a vehicle for helping the client to live the remaining time as fully as possible. Lair (1996) articulated this clearly in his description of the counseling process with adults who have a terminal illness as one that facili-
tates a shift from one mode of existence to a higher one. On the basis of his personal experience with counseling individuals who had a terminal illness, he described the process as different from psychotherapy, as it is commonly known, and indicated that the importance of a genuine and egalitarian relationship is extremely critical because it is depathologizing for the dying client.

Lair (1996) clearly and deliberately emphasized the Rogerian nature of the therapeutic relationship. He stressed the role of counselor as facilitator, the positive potential for growth, and the primacy of the relationship. Kübler-Ross (1995) described the proper posture of caregivers similarly:

What I am trying to say to you is that knowledge helps, but knowledge alone is not going to help anybody. If you do not use your head and your heart and your soul, you are not going to help a single human being. In all my work with patients, I learned that whether they are chronic schizophrenics, severely retarded children, or dying patients, each one has a purpose. Each one cannot only learn and be helped by you, but can actually become your teacher. (p. 6)

In her work, Kübler-Ross consistently emphasized the authenticity of the relationship and counselors' responsibility, not only to themselves but also to those they seek to help, to rid themselves of negativity and, thereby, to become more intuitive. When counseling clients who are terminally ill, counselor anxiety regarding death is a clear form of negativity. Increased intuition can help counselors understand the client's experiences and communication. Kübler-Ross (1995) stressed that this is particularly important when counseling adults who have a terminal illness because their physical ability to communicate may be hampered as their disease progresses and their style of communication may shift. Callanan and Kelly (1992) discussed this at great length, describing the "special communication" of people who are dying. They explained that "dying people communicate in wondrous but sometimes strange ways, and it takes persistence and insight to catch and decipher their messages—which come by gesture, by facial expression, by allegory or symbol" (p. 34).

**Integrating Spirituality With End-of-Life Care**

There is no doubt that Kübler-Ross is largely responsible for the growing recognition among medical and mental health professionals that reframing the way death and dying are viewed is critical personally, professionally, and culturally. Puchalski (2002) echoed the groundbreaking message that Kübler-Ross delivered decades ago: that death is treated as an illness, not as a natural process. This "medicalization" of death is detrimental to the relationship between caregivers and the dying. It promotes a focus on curative rather than palliative care. It also casts healing in terms of recovery so that dying patients are viewed as medical failures. Sadly, their needs go unrecognized and unfulfilled as they prepare to journey between life and death.

Puchalski (2002) challenged caregivers to face their own mortality as a vehicle for personal and professional development:
All of us, whether actively dying or helping care for the dying, have one thing in common: We will all die. The personal transformation that is often seen in patients as they face death can occur in all of our lives. By facing our inevitable dying we can ask ourselves the same questions that dying patients face—what gives meaning and purpose to our lives, who we are at our deepest core, and what the important things are that we want to do in our lives. By attending to the spiritual dimensions of our personal and professional lives, however we express that, we can better provide care to our patients. (p. 810)

This passage underscores the message of the existential philosophers, namely that living with the knowledge of death is potentially enriching for every individual. It is also essential preparation for counselors and other caregivers of adults who have a terminal illness. In order to be able to help a client come to terms with dying, counselors must have contemplated these questions and be reasonably comfortable with the knowledge of their own mortality (Wass, 2004).

Helen Farrar (personal communication, October 7, 2003), a licensed clinical social worker at the Rockbridge Area Hospice in Lexington, Virginia, aptly captured the need for such personal preparation. She described counseling adults with a terminal illness as bringing the counselor face-to-face with profound and painful experiences on a regular basis. Counselors must be prepared for the questions and emotions that will confront them as well as their clients if they are to be fully present for their clients and preserve their own sense of well-being.

Callanan and Kelley (1992), who have worked as hospice nurses, further underlined the benefits of integrating spiritual or existential exploration into the preparation to be caregivers. They wrote,

The truth is that our work brings tremendous satisfaction, fulfillment, and even joy...we have come to recognize the parallels between being born and dying—between entering this world and leaving it—and this understanding helps us to define our function and rewards. (p. 28)

It is evident from their observation that the way they frame death is key to their ability to sustain themselves in the face of death, as well as key to finding satisfaction, and even joy, in their work.

This type of personal examination not only prepares caregivers for the existential challenges associated with being with people as they confront their mortality but also positions professionals to assist clients with their own process of coming to terms with mortality in a way that fosters growth. Shepherd Johnson (2003) emphasized the “pivotal position” of counselors to help adults with terminal illness “more fully experience their spirituality as part of fully living through the end of life” (p. 233). She gave special attention to this because there is a historical tendency to view counseling work in the spiritual domain as out-of-bounds. It is interesting to note that Puchalski (2002) also alluded to this tendency, suggesting that both the physicians who care for adults with a terminal illness and their patients would benefit from attending to the spiritual domain.
The recorded experiences of two teachers with terminal illness offer vital examples of how to find opportunities in a diagnosis of terminal illness. Their personal reflections offer motivation, hope, and sustenance for individuals confronting death, as well as for their caregivers. L. Eugene Thomas (2001) reported experiencing a shift in his creative energy during his own terminal illness. He explained that Peter Koestenbaum (as cited in Thomas, 2001) referred to this as the "vitality of death" (p. 123). Thomas wrote of his own experience, not "only did creative ideas related to my research and professional activities tumble out, but also ideas related to past relationship problems. . . . It was hard to keep up with the rush of ideas" (p. 123).

Albom's (1997) Tuesdays With Morrie also captured the experiences and wisdom of a man who fully availed himself of the opportunities intrinsic in coming to terms with his death. On one of their Tuesday afternoons together, Morrie, Albom's former professor, explained,

most of us all walk around as if we're sleepwalking. We really don't experience the world fully, because we're half asleep, doing things we automatically think we have to do. And facing death changes all that? Oh, yes. You strip away all that stuff and you focus on the essentials. When you realize you are going to die, you see everything much differently. . . . Learn how to die and you learn how to live. (p. 83)

Albom (1997) described his own continuum shifts away from and toward mindfulness:

I cannot tell you why he received me so warmly. I was hardly the promising student who had left him sixteen years earlier. Had it not been for "Nightline," Morrie might have died without ever seeing me again. I had no good excuse for this, except the one that everyone these days seems to have. I had become too wrapped up in the siren song of my own life. I was busy. What happened to me? I asked myself. Morrie's high, smoky voice took me back to my university years, when I thought rich people were evil, a shirt and tie were prison clothes, and life without freedom to get up and go—motorcycle beneath you, breeze in your face, down the streets of Paris, into the mountains of Tibet—was not a good life at all. What happened to me? The eighties happened. The nineties happened. Death and sickness and getting fat and going bald happened. I traded lots of dreams for a bigger paycheck, and I never even realized I was doing it. (p. 33)

Albom's reflections aptly illustrate his own unrecognized continuum shift away from mindfulness as well as how a confrontation with death served as a catalyst for another shift toward greater awareness and appreciation of truly, and perhaps spiritually, meaningful experiences.

Yalom (1998) also offered his observations of the number of ways in which people with a terminal illness experience a continuum shift and thereby use their crisis as an opportunity for growth. He wrote that his patients "report startling shifts, inner changes that can be characterized in no other way than 'personal growth'" (p. 190). He went on to list these changes and shifts:
a rearrangement of life’s priorities: a trivializing of the trivial; a sense of liberation: being able to choose not to do those things that they do not wish to do; an enhanced sense of living in the immediate present, rather than postponing life until retirement or some other point in the future; a vivid appreciation of the elemental facts of life: the changing of the seasons, the wind, falling leaves, the last Christmas, and so forth; deeper communication with loved ones than before the crisis; fewer interpersonal fears, less concern about rejection, greater willingness to take risks, than before the crisis. (p. 190)

It is important to temper the potential for growth and enrichment with the recognition that a permanent state of mindfulness is not a realistic goal. Balanced expectations on the part of the counselor are critical for the client. Thomas’s (2001) personal reflections remind counselors of this, as do Morrie’s (Albom, 1997). Thomas noted ebbs and flows in his level of creativity and the level of urgency with which he worked at various times during his illness. He concluded that

Koestenbaum and the existentialists are right about the importance of facing death in leading an “authentic” life. But I suspect they are wrong when they seem to imply that it can become a permanent state. My experience has been that it is a powerful state, but, to use psychological jargon, it is not a permanent trait. (Thomas, 2001, p. 124)

Conclusion

The professional literature on death and dying is richly textured with philosophy, spirituality, psychology, and personal reflections. A review leads to the conclusion that counseling adults who have a terminal illness will be most rewarding for the client and counselor if it is nondirective, genuinely compassionate, and informed by an understanding of the potential for continuum shifts and the psychological and personal factors that underpin the experience. Counselors understand that clients’ developmental experiences are not unidirectional and that they should not expect their own development to be so. As counselors experience the challenges and benefits that personal awareness and development entail, they have the potential to grow both personally and professionally. Ideally, counselors and counselor educators need to attend to both areas of development in preparing for grief work. The parallel processes between counselor and client provide a window that counselors would not otherwise have on the client’s experience, which is, in truth, also their own future.

References


