



Helping Patients, Families, Caregivers, and Physicians, in the Grieving Process

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Physical experiences of the body and those that are emotional, cognitive, and spiritual are inextricably related. The author, a hospice bereavement coordinator and counselor, discusses how medical professionals can become personally prepared to assist in the often intense and intimate passage of life into death and later through both didactic and personal preparation. She also describes the major models of grief processes and illustrates the power a caring professional can have during the dying process and in the aftermath of a patient's death by relating personal case scenarios.

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When addressing pain, it is important to recognize an inextricable relationship between physical experiences of the body and those that are emotional, cognitive, and spiritual. Feeling pain is paradoxical: both undeniably real and exclusively subjective in measurability. Whether specific physical contributors to a given experience of pain can be judged to be neuropathic, nociceptive, or visceral in origin, all psychogenic components of pain—psychological, social, spiritual, and emotional—will be added to the physiologic register and mediated through the central nervous system. The effect will be reverberating, greatly influencing the ability of patient, family, and the caregiving team to cope with the patient's illness and gain the comfort and hope that is so necessary to maintaining quality of life. The pain of grief is no exception, and can be a powerful factor in the total pain experience that must be managed

not only by the patient, but also by all those involved in the patient's care.

Grief can be defined as the neuropsychobiological response to any kind of significant loss, with elements both typical and unique to each individual or situation. The grief response is generally associated with degrees of suffering, at times intense or even unbearable, and of widely variable duration. *Grief* is a systemic event, whether the system is an individual or a larger group of individuals thrown out of equilibrium through changes brought on by loss.

Mourning is the shared expression of a grief experience, important in gaining a new equilibrium following any manner of deficit, including decreased function or role, loss of assumed health, and diminished dreams of the future. Grief and mourning together constitute the grief process, representing movement from life through death and back into life again. A grief

process for the patient with cancer and all those related in the system of care may begin at the time of a prognosis of terminal illness, but more often even before that point, at the onset of any life-limiting or life-altering condition. Every change in status will alter the ensuing grief trajectory to some degree.

In the medical arena, the team that has focused its efforts on healing often drops out when a patient becomes terminally ill. Patients and family members may experience this "dropping out" as abandonment at the moment of their greatest need by the experts to whom they have entrusted their hope. They are left to traverse the landscape of approaching death on their own, with all its emotional intensity, often without knowing what to expect or how to interpret what is happening to the patient physically. How can medical professionals become personally prepared to assist in this often intense and very intimate passage of life into death and in its aftermath? The best preparation is both didactic and personal.

Knowledge About Grief

Specifics of the grief process are being widely investigated today as health professionals attempt to delineate "normal" grief from that which is "complicated or prolonged," qualifying for intervention as a clinical condition. Complete understanding of this profound experience will better prepare all care providers to offer the most effective intervention(s) under given circumstances. Such knowledge may also assist those working through this very natural, necessary feature of human life to progress to a more positive outcome.

Modern psychology, from Sigmund Freud forward, has offered models of the grief process—both descriptive and task-oriented—that serve to define "appropriate, healthy, normal" sorrow and provide guidance through what is often called "the journey of grief."¹

The anguish of loss is a universal phenomenon, whereas mourning prac-

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tices vary across cultures; mourners bring their own respective life histories and context to the grief experience. Therefore, amid the diversity of approaches to grief, three attitudes remain the basic foundation for healing practice: empathy, attentiveness, and respect.

■ *Empathy* springs from simultaneous awareness both of oneself and of another person.

■ *Attentiveness* requires a level of personal comfort sufficient under extreme circumstances to remain “tuned in”—cognitively, emotionally, and spiritually “present.”

■ *Respect* entails cultural sensitivity and openness.

Case Scenario

A significant event in the life of my father, a physician, illustrates the principles of empathy, attentiveness, and respect. That event was his first encounter with the death of a patient.

As a first-year medical student at Pennsylvania State University in 1943, he had been designated on a Friday afternoon to work in the emergency room. Around 4:30 PM, a 25-year-old woman, the mother of two young children, was brought in and assigned to him. She was several hours into the sudden onset of respiratory distress of unknown cause. As my father began to take a careful history, he could see that this woman's life was ebbing away. He brought in the resident and called for the chief physician; no one knew what was happening except that her pericardial sac was filled with fluid, which they aspirated to no great effect. The hours passed and at 3 AM, despite efforts of the staff, she continued to decline. At that time in medicine, there was nothing more that the hospital staff could do for this woman.

My father stayed with her, though the shifts came and went. In my father's own words:

I couldn't leave her, and no one knew what was wrong except that her heart and lung systems were all messed up. So in my very unprofessional and naive way, I just sat and held her hand. I never left her—I couldn't leave her. Her life was slipping away. She kept saying, 'I'm going to die, doctor,' and I kept telling her, 'We're going to do everything we can for you, and every time you have any pain or discomfort,

you let me know and I'll have the nurses do something about it.'

During the night, my father was given the task of informing the patient's husband that his wife was dying. Although it was not a part of standard medical protocol at the time, it occurred to my father to inquire of her husband about her spiritual affiliation. The man responded that they were Catholics. Acting on instinct, my father called for a priest and participated in the ritual of extreme unction with the patient and family. At 5 AM, approximately 12 hours after the young woman's admission to the emergency room, the patient died. A postmortem examination revealed that she had died of Ayres disease, a hereditary pulmonary stenosis for which there was no known intervention six decades ago.

The next day, the patient's husband called the hospital to obtain the name of the medical student who had stayed up all night. The family invited my father to the home for the wake, grateful to him as the “doctor” who had cared for their family member in her dying hours, and grateful for his sensitivity to the family's emotional and spiritual needs. His participation in the end-of-life story of this patient and her family would become a foundation of healing for them in the aftermath; for my father, it was an unforgettable lesson in the power of a caring professional.

We live in a grief-saturated world. More than 2 million individuals die in the United States each year. It is difficult to estimate how many others are directly affected by these deaths, and it is even more complex to estimate how many will have compromised health due to bereavement. Healthcare institutions may fail to address the needs of the bereaved. Although the primary responsibility of healthcare providers is to the patient, the well-being of the family and others close to a dying person is also part of terminal illness. Even practitioners who perceive these needs may have trouble addressing them when third-party payers refuse to reimburse bereavement services. Grief affects not only individuals and communities; but it is also a significant public health issue of concern to employers, policy makers, healthcare providers, and managed care administrators.²

Grief as a Natural Response

Although grief can become prolonged

or complicated, it is not an intrinsically pathologic state, but rather, a normal and needful adjustment response. What are some common, predictable grief reactions? Every one of us has experienced them to some degree in the face of loss. In the cognitive-emotional realm, there may be disbelief, sadness, anger, guilt, and self-reproach, panic, anxiety, loneliness, listlessness, and apathy, shock, yearning, numbness, depersonalization, and, depending on the circumstances, relief.

Grievors may become preoccupied with their loss, and their thought processes can become confused. There may be a sense of timelessness. If someone has died, there is often a sense of presence, or of seeing or hearing the deceased. Physical sensations might include muscular weakness, fatigue, tightness in the chest and throat, dry mouth, nausea, and sensitivity to noise. There may be sleep and appetite disturbances, social withdrawal, sighing, searching, and crying, restless overactivity, reminiscing, and laughing, treasuring objects that belonged to the deceased, or avoiding such reminders.³

However it proceeds, the grief process poses a challenge to human systems at each level—through personal, interpersonal, family, and caregiver systems. Inherent in this process is the demand for change and substantial potential for growth—and/or decline. Loss disrupts equilibrium, and subsequent readjustments are multifaceted and complex involving somatic, psychological, social, cultural, spiritual, and historical components. Practically speaking, this means that besides somatic changes due to illness, one must be aware of a patient's grief-associated symptoms. The impact of disease or loss on total functioning of a patient or family system must be considered. How is self-concept affected? Identity, expectations, and sense of the future all may need adjustment. What is—or was—the role of the patient in the family system? This role may change. There may be a loss of roles, of accustomed activities, capabilities, and personal dignity. In a culture that strongly emphasizes health and youth, disease and demise are isolating.

Many people see suffering and loss

as spiritually related. There may be a feeling of being punished or forgotten by the Deity, or of being purified and strengthened. Since there is a strong connection between spirituality and well-being, it is important to allow or provide for spiritual exploration and support during grief. It is also important to ask what personal history of losses provides the context or foundation for this one. What is the family context, community context, or racial-ethnic context? What “undigested” grief is there that will become a part of the matrix for this new experience?

Other contributing factors to the grief process include suddenness versus expectation of loss, causes and course of the illness, and whether there is a sense of hope and purpose through it all. Especially difficult is “ambiguous loss,” essentially living with frozen grief, as in brain injury, dementia, serious addiction, or mental illness. Since the person being lost is neither clearly absent nor clearly present, it can be difficult for survivors to know how to move through the grief.⁴

Major Models for Grief

Various models for the grief process have been proposed and used over the past half century as thanatology has developed as a field of study. Most notable have been the works of Kübler-Ross⁵; Bowlby⁶ and Parkes⁷; Worden⁸; Wolfelt^{9,10}; and Neimeyer.¹¹

Kübler-Ross's Five-Step Paradigm for the Grief Process

Elisabeth Kübler-Ross, MD, psychiatrist and internationally known thanatologist, published her seminal study in 1969, titled *On Death and Dying*.⁵ The cover to the first edition included the explanatory subtitle, “what the dying have to teach doctors, nurses, clergy and their own families.” The work was the result of a seminar that began in 1965 at the University of Chicago Billings Hospital, when four theological students approached Kübler-Ross for assistance in a research project on “the crisis of death in human life.” Together they determined that the best way to study death and dying was to ask terminally ill patients to be their teachers, through observation and interview.

Kübler-Ross's observations now form the classically regarded five-step paradigm for the grief process: denial, anger, bargaining, depression, and acceptance. She described the five stages as “coping mechanisms” that people go through to deal with extremely difficult situations.⁵ These stages were at times overlapping or coexisting, but, in her model, they are progressive. In addition to these central stages, the model included stage-bridging mechanisms of partial denial and preparatory grief. Included in the acceptance stage were Freudian concepts of *decathexis*, or withdrawal of emotional energy from the lost object, and *recathexis*, or reinvestment of that energy. In regard to the dying patient, this withdrawal signaled the end of the struggle to sustain bodily life and the investment of energy in letting go and moving on.⁵

Kübler-Ross further observed that “the one thing that usually persists through all these stages is hope.... It's this glimpse of hope which maintains them through days, weeks or months of suffering.”⁵ She defined *hope* as “the feeling that all of this must have some meaning, and will pay off eventually if they can only endure it for a little while longer.”⁵

Interestingly, the patients that Kübler-Ross interviewed showed the greatest confidence in those physicians who allowed them to express and maintain their hope, in whatever form.⁴ Even with acceptance of a diagnosis of terminal illness, one can hold hope of continuing to live to the end in a meaningful, zestful way, relating to life, and being a unique personality through the moment of death.

Bowlby and Parkes' Four Phases of Grief

British psychiatrists John Bowlby, MD, and Colin Murray Parkes, MD, collaborated on the grief process in the 1980s, bringing together insights from Bowlby's “Attachment Theory”⁶ and Parkes' studies of human information processing.⁷ Together they reformulated Kübler-Ross's five stages into four phases of grief, and observed that these stages were not always linear but could recycle through recollection, or some triggering experience or anniversary reaction. One

who grieves can travel around and around the process before emerging, so sustained care giving is needed rather than viewing grief as a series of progressive stages with a predictable and orderly end.⁷

The initial phase of their model, *shock and disbelief*, discards the term *denial* with its pathologic connotations. Instead, there is insight that the human organism does what it needs to do to cope with reality. Body, mind, and soul adjust to the distressful situation by closing down to protect and rebuild in small increments. Reality is set aside, in part, and allowed slow entry into the self-system. In this stage, there is a strong, but adaptive, need to withdraw, to be numb and unresponsive.⁷

During the second phase, *searching and yearning*,⁷ a person will attempt to undo or retract the distressful reality with thoughts such as “This couldn't have happened!” “Why this?” “Why us?” “Why now?” “If only...!” The affect is angry, agitated, and frantic.

The third phase, *disorganization and despair*, represents full penetration of the distress, and of facing the loss.⁷ Here, one could hear statements such as “My life is over. I just don't care anymore. I can't go on.” There is depression, disorganization, absentmindedness, and apathy. These responses, normal signs of separation distress in this phase of grief, should be supported and not confused with a pathologic state.

The final phase is that of *rebuilding and healing*, in which the grieving person will begin restructuring and reorganizing to proceed.⁷ One begins to take on the changes and move forward in life; the loss is no longer defined in terms of the self. Rather, the grieving one has a renewed sense of identity, which goes beyond—and is greater than—the loss. The grieving person will have more energy and sociability, and an ability to view his or her grief in a larger perspective.

Worden's Four Basic Tasks for Adapting to Loss

J. William Worden, PhD, psychotherapist and researcher in the field of terminal illness and suicide, holds academic appointments at Harvard Medical School

and the Rosemead Graduate School of Psychology in California. He is also co-principal investigator for Harvard's Child Bereavement Study. His research and clinical work spanning 30 years has centered on life-threatening illness and life-threatening behavior. His text, *Grief Counseling and Grief Therapy*,⁸ grew out of this project and his own clinical practice. Worden views mourning—the adaptation to loss—as involving four basic tasks, the completion of which are essential for a person and/or family system to return to equilibrium and complete bereavement by

- accepting reality of the loss,
- experiencing the pain of grief,
- adjusting to an environment in which the deceased is missing, and
- withdrawing emotional energy and investing it into another relationship.

These four undertakings need not follow a specific order; they can be concurrent, cyclical, or overlapping, and the grieving person will work on them with effort until regaining balance.

Worden speaks of particular difficulty with the fourth task. It is here that grief most often remains unresolved, as the mourner continues to hold onto a past attachment rather than form new ones. In doing grief therapy within this model, it is important to facilitate emotional reconceptualization of a lost love into memory so that emotional space will be created for new relationships. Worden's expected time frame for full resolution of grief is 1 to 2 years, a projected point where natural sadness of having loved and lost will no longer have the initial wrenching quality. If progress through these developmental tasks is arrested at some point, the grief experience will become intensified such that the grieving person becomes overwhelmed; a pathologic condition then appears.⁸

Wolfelt's "Companioning" Approach to the Bereaved

Alan Wolfelt, PhD, a major voice in the field of thanatology, is founder and director of the Center for Loss and Life Transition in Ft Collins, Colo (*Figure*); he is known internationally as a grief educator and care provider.

Whereas previous models have emanated from the modern perspective

Resources

- **www.adec.org**
Association for Death Education and Counseling (an interdisciplinary organization formed to assist professionals and lay people in the field of dying, death, and bereavement)
- **www.centerforloss.com**
Alan Wolfelt's organization
- **http://cancernet.nci.nih.gov**
National Cancer Institute
- **www.aarp.org**
American Association of Retired Persons (has useful self-help information about grief)
- **www.nhcpo.org**
National Hospice and Palliative Care Organization.

Figure. Useful Web sites.

that if we know what is wrong, we can fix it, Wolfelt's approach is much more postmodern, that is, each person's grief experience is unique and no predictable or orderly stages exist. The mourner is the teacher, rather than the recipient of another's expertise; mourner and supporter go together on a journey of discovery.

Wolfelt's approach is therefore much more experiential and narrative; he teaches that caregivers to the bereaved should "companion," rather than treat those in grief. In his words,⁹

'Companioning' is about honoring the spirit, being curious, learning from others, walking alongside, being still, listening with the heart, bearing witness to the struggles of others and being present to their pain, respecting disorder and confusion rather than imposing order and logic. Companioning is about going to the wilderness of the soul with another human being; it is not about thinking you are responsible for finding the way out.

"If you love, you will mourn," is a foundational understanding in Wolfelt's

philosophy. Rather than viewing grief as a disease state from which to seek recovery, he sees the pain of loss as an inherent part of life resulting from the ability to give and receive love. Since everyone is changed forever by their grief journey, concepts like *reestablishment*, *recovery*, and *resolution* are not adequate to describe what needs to happen in grief. One does not "get over it," but learns to live with it and reconcile oneself to it. In Wolfelt's grief process, one moves toward the pain in order to *walk* through it (vs *work* through it).

Wolfelt sees six central needs of grief (cf Worden's four central tasks⁸) that are more experiential than task-oriented, and with a more relational, tribal, systemic view of the self. Four are familiar:

- to inwardly experience and outwardly express the reality of loss through mourning;
- to tolerate the pain of grief while caring for oneself;
- to convert the relationship with the lost person from presence to memory (relocation of the relationship in the heart of love versus *decathexis* or withdrawal); and
- to develop a new self-identity based on life without the person who died, taking on new roles, and exploring positive aspects of oneself in the change.

Added to the process are

- to relate the experience of loss to a context of meaning, telling a story about the loss until it becomes "the story" that makes some sense of it all, teaches some lesson, or provides some doorway to continuance; and
- to develop an understanding, enduring support system that will provide a strengthening brace while healing takes place in the months and years ahead. These are fellow human beings who will companion the mourner and encourage self-compassion whenever a normal resurgence of intense grief occurs.¹⁰

Neimeyer's Narrative and Constructivist Approach

An important contribution to thanatology comes from Robert A. Neimeyer, PhD, professor of psychology at the University of Memphis in Tennessee. A prolific author, theorist, and clinician in the fields of psychology and bereavement, he has

conducted extensive research on the topics of death, grief, loss, and suicide intervention. He is currently working to advance a more adequate theory of grieving as a meaning-making process. As a narrative-constructivist, Neimeyer¹¹ approaches human experience from the view that people co-construct reality together, continually updating their perception of it as they write and rewrite their life stories in the center of their beliefs; developing an ongoing sense of identity, purpose and belonging. Neimeyer elucidates *six key realities influenced by death*, derived from constructivist thought, namely:

■ Particulars of a loss can validate or invalidate one's core assumptions about how life should work, or they may encompass a novel experience for which one has no framework of assimilation. We may try to interpret loss within our own developed framework of beliefs, but may be forced to create a new understanding of reality in order to proceed.

■ Grief is idiosyncratic, both universal and unique. As such, effective therapeutic interventions will be client-led, with the bereaved as the active locus of control for proceeding.

■ Grieving is active, affirming or reconstructing a personal world of meaning that has been challenged or ruptured by loss. It is a period of decision making, practically and existentially, not a time of passive waiting through a series of emotional transitions or stages.

■ Emotions during grief are functional and useful guides. The bereaved must reconstruct a world that restores a semblance of meaning, direction, and interpretability to life. Emotional states hold something important for us to learn in this process, and should not be viewed as dysfunctional conditions to be extinguished or overcome.

■ The reconstruction of a grieving person's identity is a social process, at once individual and regulated by societal and family norms.

■ Grieving individuals adapt to loss by restoring coherence to the narratives of their lives, making sense of their own great continuing story, putting the pieces of the shattered puzzle back together like any trauma survivor, finding a way to fit what happened into a life that is not

only surviving but also ultimately, it is hoped, thriving.¹¹

Recent Research

It is interesting that in the present debate on the validity and applicability of various grief and treatment models, a major study recently conducted by Maciejewski et al at Yale (the Yale Bereavement Study¹²) in New Haven, Conn, asked, What does typical grief look like? The study concluded that the bereaved do tend to report experiences in line with the "Stage Theories" of Kübler-Ross, Bowlby and Parkes, and Worden when tracked during the first 24 months after a loss, with several notable distinctions. In particular, the study showed that not depression, but yearning was the most prominent negative emotion a mourner experienced after a death. Acceptance was the most common and steadily increasing indicator throughout the length of the study, rather than defining a final stage of arrival.

Further observations were that disbelief decreased from a maximum at 1 month postloss, yearning peaked at 4 months, anger was utmost at 5 months, and depression was highest at 6 months following the loss. Acceptance increased steadily throughout the 24 months post-loss observation period.¹²

A co-author of the Yale Bereavement Study, Holly Prigerson, PhD, has been central in developing proposed criteria for "prolonged or complicated grief disorder" as a new diagnostic category to be included for publication in the *Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-V)* now in development for publication in 2012. In the Yale Bereavement Study, negative cognitive-emotional indicators for grief began to decline after 6 months, supporting Prigerson's recommendation that persistently severe, distressing, or disabling signs of separation distress at more than 6 months postloss be diagnostic of the disorder. However, more than 50% of the sample population for the study was older than 65 years, mostly older widows "with a fair amount of preparation for their loved one's death." Those with knowledge of a patient's diagnosis of terminal illness for at least 6 months prior to the death were more accepting than those

who had less time to adjust to the new reality. Bereaved parents and others suffering from traumatic or violent losses were excluded from the study and likely would express a different set of norms.¹³

Diagnosing Complicated Grief

Prigerson et al^{14,15} propose a model for diagnosing prolonged or complicated grief in the presence of a diagnostic cluster of at least 6 months' duration, including symptoms of separation distress, traumatic loss, and shattered meaning.

Mardi Horowitz, MD, professor of psychiatry at the University of California in San Francisco, and her colleagues¹⁶ proposed a similar model, but one that requires 14 months postloss before a diagnosis can be made. Diagnostic criteria from each model include specified percentages of signs and symptoms causing clinically significant impairment in social, occupational, or other important areas of functioning.¹⁷

Both diagnostic models are available online at www.redmh.org/research/specialized/grief.html.

Important Issues for Caregivers

The individual, intrapersonal experience of grief is similar across cultures,¹⁸ though bereavement *practice* can vary profoundly. A grief reaction on the anniversary of a loss, for example, seems to be part of the circadian, somatic nature of sorrow rather than purely culturally conditioned. I observed this response in a young child who had no coaching to expect such a resurgence of grief at a particular time, and whose parents were surprised by the anniversary, as well. They had been out of the United States without the possibility of contact with their 6-year-old child for several weeks. During that time, an important linking object, a little bear he and his mother had chosen together before the trip, had been taken from him by someone in a frightening and traumatizing way.

When the boy's mother returned and the child told her some of what had happened, she sympathized with him and together, they chose a bear as a substitute for the lost bear. The incident was forgotten until exactly a year after the

loss of the first bear. The child came to his mother in tears of grief over the bear. He told her the traumatic details of the loss, which he had never mentioned before, but which had come into his consciousness for review quite unexpectedly a year later, with all its attendant feelings.

The ways in which a person responds to—or expresses—grief feelings are qualified by culture as well as experience. A good question to ask in caregiving is “What is required or expected by the grieving person’s culture in this situation?”

Grief practices across cultures serve an important purpose, and it is important to honor them. Monica McGoldrick, PhD, LCSW, director of The Multi-Cultural Family Institute of New Jersey, in Highland Park, has developed training on ethnic patterns for the medical school curriculum. McGoldrick, co-editor of the text, in *Ethnicity and Family Therapy*,¹⁹ has posed these questions for cross-cultural sensitivity:

- Are certain types of death particularly traumatic for this sociocultural group?
- What rituals are prescribed for managing the dying process and aftermath?
- What beliefs exist regarding what happens after death?
- What emotional expressions are appropriate in response to this loss? For example, Puerto-Rican traditions such as crying, screaming, and hysteria are common, expected, and even respectful ways of mourning at a funeral. In contrast, an American family of British descent believes it is important not to show grief in an outward display of emotions, but to keep a “stiff upper lip.” In this latter case, it is deemed “responsible” to keep personal problems to oneself, and not be “a bother” to anyone. Caregivers unaccustomed to either of these two extremes could misinterpret and label a culturally normal response as “pathologic” in attempting to fix the problem.¹⁰

It will be helpful if caregivers know when to be watchful for signs of prolonged or complicated grief. Perhaps the patient or survivor held unrealistic expectations about life and death; maybe a support system was or is lacking. If the illness or manner of death is stigmatized (eg, from AIDS), or if death marks the



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end of an ambivalent or abusive relationship, an individual may have trouble with grief.

Prolonged dying also places a great strain on caregivers, depleting their physical and emotional resources and predisposing them to illness on the rebound. Other questions about the circumstances of the death that should be considered in assessing grief include:

- Are substance abuse or other compulsive behaviors present, or a history of multiple or unexpressed losses? These may be risk factors for complicated grief.
- Was there no choice about seeing the body?
- Is litigation involved?
- Does the survivor experience consuming guilt or blame?
- Was the loss abrupt or traumatic or both?

Research into traumatic loss indicates that such grief can be prolonged, pervasive, and debilitating without indicating a psychiatric disorder.¹⁵ Grieving survivors of trauma victims should be reassured that the intensity of their feelings is entirely normal and acceptable. According to recent studies, most of those who grieve need only time and sympathetic company. However, long-lasting grief in cases of shocking loss can

resemble a traumatic stress response, and may respond to treatments recommended for posttraumatic stress disorder (PTSD) or depression.²⁰

Family caregivers and survivors will not be alone in experiencing the pain of loss. Grief will impact health professionals caring for those who suffer and die. Jeffrey Kauffman, LCSW,²¹ specializing in the treatment of grief and trauma, writes about the professional caregiver’s awareness of his or her own mortality:

One’s own denials and dissociations of death anxiety in relation to oneself, may, in reaction to the grief of others, block empathy or open it up. Our own grief is always there in some way in our every encounter with the grief of others. It may be both an impediment and a means of empathetic connection at the same time, but it is always there. For each of us, as we approach the work of supporting others in their grief and facilitating the mourning process, we approach a place which is spiritually and psychologically very powerful, both healing and dangerous. The caregiver should be prepared with self-awareness and an openness to the vulnerability of self and other and to the great spiritual and psychological wounds that occur in grief.²¹

Basic issues intrinsic to the helping professions—which grief will activate—must be addressed.

First, there is the reality of attachment and loss for anyone who is empathetic. A healthcare professional may say inwardly, “You’ve engaged me. I’ve invested myself in you. Now you’re leaving.”

Then, there can be the narcissistic injury of, “My job was to heal you, but I can’t, and that feels terrible.” Frustrated altruistic strivings may include, “I’m in this business to give life and to help others, so my energies must go to the living, not the dying.”

There may be personal issues that are brought to the surface, or a crisis of faith brought on by particular circumstances: “This one is too close to home!” or “Why this, God?” It may be a matter of grief overload, as observed in healthcare professionals working in hospice or emergency trauma situations: “Now this is just too much!”

Any of these natural responses would lead healthcare professionals to do exactly what the patient fears the most and needs the least, that is, to withdraw emotionally and physically, become curt or perfunctory, and abandon bedside manner. What can one do?

The following case scenario illustrates how grief counseling helped the parents with three other children cope during the terminal stage of one child's cancer, her loss, and the bereavement process that followed the child's death.

Case Presentation

A family of two parents and four children had been struggling valiantly for several years with treatment of one of their children for brain cancer. Kendra (not her real name) was an elementary school-aged child who, by reason of an unrelated condition, had been both heroically independent and needfully more dependent on her parents throughout her young life. This situation set the stage for bitter irony at her prognosis of terminal cancer and acute separation distress after her death.

Kendra's siblings each had their own unique and special relationship with her. The oncologists waited to determine the child's eligibility for hospice care until every possible hope had been exhausted, as the parents would have desired and expected. Kendra was considered to be just a few days away from death when she came on hospice service. The parents—not wanting to upset either Kendra or her siblings with anticipatory grief—were distressed about whether and how to tell their other children the truth about their sister's critical status. A hospice bereavement counselor was called in as part of the interdisciplinary team to assist them in coping and decision making.

Because of the parents' reluctance to speak of this coming crisis, the counselor suggested that they would build trust and reduce their other children's isolation and panic if they would speak to them in a loving, containing, age-appropriate, but genuine, manner before Kendra began actively dying. The parents were unwilling to make this choice and expressed the fear that they would not be able to handle the strong emotions that might ensue.

The counselor respected the parents' choice but proposed that they think about what it would be like if they were to speak

with their other children about the reality. The counselor invited Kendra's parents to begin to say some of the words they might say. They parents did this hypothetical role play with the counselor; eventually, they did use the thoughts they had rehearsed to shepherd their family through Kendra's death several days later. Different members of the hospice team kept vigil with the family throughout the dying process.

The counselor stayed connected to the family for 2 years after Kendra's death for bereavement counseling in the form of "grief walks" in the beautiful, natural landscape near where the patient was born. In assessing the parents' coping strategies, it was clear that physical activity—"being able to move when you just feel like running away"—would both facilitate discussion during the walk. It was also needed as a relaxant to set the stage for the difficult emotional work of grief that occurred during the last segment of each session.

Opening Discussion

It is important for healthcare professionals dealing with grief and loss to explore their own "grief landscape". They should ask themselves,

- What are my issues with loss at this point in my life?
- What is my history with grief?
- What losses have impacted me, which still exert pressure on my ability to cope?
- What does my belief system tell me about the meaning of suffering, of life, and of death?

All this exploration can take time, but it is worthwhile to assess periodically, to observe and acknowledge losses, pressures, and unreconciled grief in one's life. In fact, it can be encouraging to look back from a new perspective year by year and see how things change. Those who develop a measure of comfort with life and death issues—and learn how to live with their own grief and losses—will become more capable of administering effective, life-giving care, even to someone who is dying. Their person and presence will be able to instill confidence and hope that is genuine and based in reality.

What are some of the major concerns of consciously dying persons? Often, they have concern or even guilt regarding those whom they will leave

behind. Dying persons have fear of

- losing control
- loss of dignity
- loss of self-determination
- ceasing to be
- pain
- being alone
- the unknown

Responding to these concerns requires that physicians and caregivers maintain an attitude of empathy, attentiveness, and respect, as well as a willingness to take time, be present, and listen. Nonverbal communication is important. Healthcare professionals should sit down and invite sharing: "You may have some questions.... Tell me your thoughts on this matter.... I'd like to hear your concerns.... You must wonder if you're going to get well."

Ira Byock, MD, past president of the American Academy of Hospice and Palliative Medicine, has written a practical and compassionate guide to *Dying Well: Peace and Possibilities at the End of Life*.²² The appendix contains many examples of questions that family members or patients may want to ask and insightful responses through which the healthcare professional can open up a helpful conversation.

What Do We Need During Grief?

Without a doubt, patient, family, and healthcare professionals share some of the same needs when faced with the grief process. Healthcare professionals need time alone and time with others to feel and understand their own losses. They need rest, relaxation, nourishment, and diversion to be replenished from the exhaustion of grief. They need a sense of security, trust, and hope in the future, gained by experiences of being cared for. Healthcare professionals need that which will give impetus and direction to life when it seems to be without meaning. They need lightheartedness, simple pleasures, and humor, which provide balance and relief from stress. Metcalf and Flible²³ provide a helpful resource along these lines.

Finally, healthcare professionals can benefit from access to the transcendent or spiritual realm of life. As Byock observed²²:

It is a paradox of dying that a person can seem to grow strikingly in the realms of spirit and soul as the physical self dramatically shrinks.... The contemplative place of prayer or meditation can provide a place of safety and distance—not from, but *within*, the experience. This tender vulnerability [of spiritual composure and openness] seems a prerequisite for the deepest tasks of inner development.

In the words of the Ancients:
 “Hear my cry, O God; attend to my prayer.

From the ends of the earth I will cry to you,
 When my heart is overwhelmed;
 Lead me to the rock that is higher than I.”²⁴

So we fix our eyes not on what is seen, but on what is unseen. For what is seen is temporary, but what is unseen is eternal.²⁵

Comment

Bereavement is a multifaceted process, posing a challenge to the patient-family system in interlocking dimensions—personal, social, physical, practical, emotional, and spiritual—with imperious demands for change. The grief process carries the potential for either decline or growth in the health and well-being of any of those involved. Physicians who are both educated about the grief process and willing to assist dying patients and their families beyond just prescribing therapeutic regimens will certainly ensure a more healthful closure to a sad but normal process of life.

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Furthermore, patients and their families wanted help in formulating the questions they should ask physicians, lawyers, and other professionals. We also learned that, while some patients and families do not want to think about death and dying, it is important to help people plan for the what-if situations that they will inevitably confront. Social workers and other mental health professionals can initiate these conversations as a normative part of the life span.Â Toward the end of a terminal illness, it is important to revisit decisions and preferences that were made earlier in the process to determine whether they hold. Has the patient decided where he or she wants to be at the end? With whom? In the grieving process, patient, family, and health professionals have the same needs-rest, relaxation, nourishment, a sense of security, trust, hope in the future, and humor among them. Grief, defined as a shared, universal, and natural neuropsychobiologic expression in response to loss, is distinct from mourning, a practice that varies in expression across diverse cultures.Â The expression of feelings by the patients refers to each stage of grieving, according to the theory of mourning conveyed by Kubler Ross (1969), quoted by Potter & Perry (2006). This result is consistent with the theory expressed by Bruce (2002), in that the