



The grief process for patient, family, and physician

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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. To aid in an understanding of grief and its effects, the author looks at the models for grief proposed by Kubler-Ross, Bowlby, Parkes, Worden, and Wolfelt. Addressing patients' concerns requires physicians be empathic, attentive, and respectful and have willingness to take time, be present, and listen.

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To grieve, from the Latin *gravis*, is to carry the heavy burden of a loss. Grief is commonly defined as a state of deep mental anguish commensurate with many difficult emotions such as sorrow, heartache, anguish, pain, distress, misery, and woe; it can be effectively understood as a process encompassing a much broader range of experience. Initiated by loss, grief is a natural process of adjustment to a new state of affairs in a person's life. The grief process represents movement from life through death and back into life again. Grief will begin with any manner of loss, including decreased function or role, loss of assumed health, or diminished dream of the future.

For the cancer patient and all those related in the system of care, the grief process may begin at the time of diagnosis—or even before that point. Every change in status will alter the grief trajectory to some degree.

It is important to understand both

the process of grief and the practice of mourning. Human grief is a natural, inevitable neuropsychobiological response to any kind of significant loss. Mourning is the outward, shared expression of that experience. Grief is a universal phenomenon, whereas mourning assumes many different cultural expressions. To grieve and to mourn are natural and healthful processes, whereas to suppress or forgo grief and mourning is unnatural and harmful. Because normal practices of mourning vary across cultures and mourners bring their own respective life history and context to the grief experience, empathy, attentiveness, and respect are of primary importance in responding to grief and mourning in patient care.

What would be some of the common and normal grief reactions? Every one of us has experienced them to some degree in the face of loss. In the emotional realm, there may be depersonalization, disbelief, sadness, anger, guilt and self-reproach, panic, anxiety, loneliness, listlessness and apathy, shock, yearning, numbness and, depending on the circumstances, relief. Physical sensations might include muscular weakness, fatigue, tightness in the chest and throat,

dry mouth, nausea, and sensitivity to noise. The griever may become preoccupied, and 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. 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.¹

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 the 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 disruption and readjustment mean 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 may require change. A loss of roles, accustomed activities, capabilities, and personal dignity may occur. In a culture strongly emphasizing health and youth, disease and demise are very isolating.

Many people see suffering and loss as spiritually related. Some may have a feeling of being punished or forgotten by God, or of being purified and strengthened. Because a strong connection exists 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 a context or foundation for this current one. What is the family context, community context, or racial-ethnic context? What "undigested" grief is present that will become a part of the matrix for this new experience?

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Other factors contributing to a grief process include the suddenness versus the expectation of loss, the cause and course of an 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. Because the person being lost is neither clearly absent nor clearly present, it can be very difficult for survivors to know how to move through the grief.²

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 Kubler-Ross,³ Bowlby,⁴ Parkes,⁵ Worden,⁶ and Wolfelt.^{7,8}

Elisabeth Kubler-Ross, MD, psychiatrist and internationally known thanatologist, published her seminal study in 1969, titled *On Death and Dying*.³ 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 Kubler-Ross for assistance in a research project on “the crisis of death in human life.” Together they determined the best way to study death and dying was to ask terminally ill patients to be their teachers, through observation and interview.

The observations of Kubler-Ross now form the classic 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. These stages were at times overlapping or coexisting, but, in her model, 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 a dying patient, this withdrawal sig-

naled the end of the struggle to sustain bodily life and the investment of energy in letting go and moving on.

Kubler-Ross³ further observed, “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.” She defined this glimpse of hope as “the feeling that all of this must have some meaning, will pay off eventually if they can only endure it for a little while longer.” Interestingly, patients she interviewed showed the greatest confidence in those physicians who allowed them to express and maintain their hope, in whatever form.³ Even with acceptance of a terminal diagnosis, there can be the hope that one may continue to live to the end in a meaningful, zestful way, relating to life and being a unique personality through the moment of death.

British psychiatrists John Bowlby and Colin Murray Parkes collaborated on the grief process in the 1980s, bringing together insights from Bowlby’s Attachment Theory⁴ and Parkes’ studies of human information processing.⁵ Together they reformulated Kubler-Ross’s five stages into four phases of grief and observed that these phases 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 there exists a greater need to sustain caregiving rather than viewing grief as a series of progressive stages with a predictable and orderly end.

The initial phase of this model, that of *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 phase, there is a strong but adaptive need to withdraw, to be numb, and unresponsive.

Phase two is called *searching and yearning*. While in this phase, a person will attempt to undo or retract the distressful reality with thoughts like, “This

couldn’t have happened! Why this? Why us? Why now? If only...!” The affect is angry, agitated, and frantic.

The third phase of grief, *disorganization and despair*, represents full penetration of the distress and of facing the loss. In this phase, one might hear statements such as “My life is over. I just don’t care anymore. I can’t go on.” Depression, disorganization, absentmindedness, and apathy exist. These responses, normal in this phase of grief, should be supported and not confused with a pathologic process.

Finally, the fourth phase is that of *rebuilding and healing*, in which the griever will begin restructuring and reorganizing to proceed. One begins to take on the changes and move forward in life; the loss is no longer defined in terms of the self. Rather, there is a renewed sense of identity, which goes beyond—and is greater than—the loss. There will be more energy and sociability and an ability to view one’s grief in a larger perspective.

J. William Worden, PhD, psychotherapist and researcher in the field of terminal illness and suicide, is professor of psychology at Harvard Medical School and director of an extensive National Institutes of Health research project on life-threatening illness and life-threatening behavior. His text, *Grief Counseling and Grief Therapy*,⁶ 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 come back into equilibrium and complete bereavement. These tasks need not follow a specific order, but can be concurrent, cyclical, or overlapping, and will be worked on with effort by a griever until balance is regained. Worden’s four basic tasks of mourning are the following:

- to accept reality of the loss;
- to experience the pain of grief;
- to adjust to an environment in which the deceased is missing; and
- to withdraw emotional energy and invest it into another relationship.

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 griever becomes overwhelmed, and a pathologic process appears. Worden's 12 clues toward diagnosing pathologic grief⁶ (Figure 1) might indicate a need for treatment to resolve chronic, delayed, exaggerated, or masked grief reactions.

Alan D. Wolfelt, PhD, is the most recent major voice in the field of thanatology. He is the founder and director of the Center for Loss & Life Transition in Fort Collins, Colorado (Figure 2), and is known internationally as a grief educator and care provider. Whereas previous models have emanated from the modern perspective 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 there are no predictable or orderly stages. The mourner is the teacher, rather than the recipient of another's expertise; griever and supporter go on a journey of discovery together.

Wolfelt's approach is therefore much more experiential and narrative; he teaches that caregivers to the bereaved should "companion," rather than treat people in grief. In his words, "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."⁷

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

Checklist

- The griever cannot speak of the deceased without experiencing intense and fresh grief.
- Some relatively minor event triggers an intense grief reaction.
- Themes of loss arise in a clinical interview.
- An unwillingness to move material possessions of the deceased.
- Medical symptoms like those of the deceased appear.
- Radical changes in lifestyle occur after bereavement
- A long history of subclinical depression or false euphoria is present.
- A compulsion to imitate the dead person is present.
- Self-destructive impulses appear.
- An unaccountable sadness occurs at a certain time each year.
- A phobia about illness or death related to the deceased is present.
- Knowledge of circumstances surrounding the death

Figure 1. Worden's 12 clues toward diagnosing pathologic grief. (Source: Worden JW. *Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner*. New York, NY: Springer Publishing Co; 1982.)

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. You don't "get over it," but you learn to live with it and reconcile yourself to it. In Wolfelt's grief work, one moves toward the pain in order to *walk* through it (vs *work* through it).

Still, the connection between Wolfelt's philosophy and the earlier models is apparent. In place of the *four phases of grief* (cf Bowlby-Parkes), Wolfelt describes *seven dimensions of grief* (eg, thoughts, feelings, and behaviors), all or

any of which could come into focus at any time. These dimensions are:

- shock-denial-numbness-disbelief;
- disorganization-confusion-searching-yearning;
- anxiety-panic-fear;
- physiologic changes;
- explosive emotions;
- guilt and regret; and
- loss-emptiness-sadness-depression.

Wolfelt sees *six central needs of grief* (cf Worden's *four central tasks*), which 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 vs deatathesis 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.

New to the process are the following:

- 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, which will provide a strengthening brace while healing takes place in the months and years ahead. This support system comprises fellow human beings who will companion the griever and encourage self-compassion whenever a *normal resurgence of intense grief occurs*.

Wolfelt's system also includes five signs of complicated grief, which may indicate a need for professional assistance. These behavior patterns include *postponing grief* by indefinitely delaying its expression, *displacing grief* by directing intense feelings elsewhere, *replacing grief* by prematurely reinvesting feelings in another relationship, *minimizing grief* through rationalizations, or *somaticizing grief* by converting feelings to physical symptoms.⁸

Resources

- **Association for Death Education and Counseling**, an interdisciplinary organization formed to assist professionals and lay people in the field of dying, death, and bereavement.
<http://www.adec.org>
- **Center for Loss & Life Transition**, Alan D. Wolfelt's organization for grief counseling.
<http://www.centerforloss.com>
- **National Cancer Institute**, a resource for patients, families, caregivers, and health professionals.
<http://www.cancer.gov/cancer-information>

Figure 2. Useful Web sites

Important issues for caregivers

The individual, intrapersonal experience of grief is similar across cultures, but bereavement *practice* varies profoundly. A grief reaction on the anniversary of a loss event, for example, seems to be part of the circadian, somatic nature of grief rather than purely culturally conditioned. This author 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. In contrast, 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 griever's culture in this situation? Grief practices across cultures serve an important purpose, and it is important to honor them. Monica McGoldrick, LCSW, PhD, is Director of Family Training at Rutgers Medical School, University of Medicine and Dentistry of New Jersey, where she has developed training on ethnic patterns for the medical school curriculum. McGoldrick, coeditor of the text, *Ethnicity and Family Therapy*,⁹ 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, a contributing author observed that 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." It is deemed "responsible" to keep personal problems to oneself, and not be "a bother" to anyone. A caregiver unaccustomed to either of these two extremes could easily misinterpret and pathologize a culturally normal response in attempting to fix the problem.⁹

It will be helpful if the caregiver knows when to be watchful for signs of 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, or if death marks the end of an ambivalent or abusive relationship, there may be trouble with grief.

Prolonged dying also places a great strain on caregivers, depleting the system and predisposing survivors to illness on the rebound. Is substance abuse or other compulsive behaviors present? These factors represent a built-in foundation for complicated grief. A history of mul-

tiples or unexpressed losses can also expand a traumatic grief. Was there no choice about seeing the body? Is litigation involved? Does the survivor experience consuming guilt or blame?

Was the loss abrupt and/or traumatic? New research into traumatic loss indicates that such grief can be prolonged, pervasive, and debilitating without indicating a psychiatric disorder. Grieving survivors of trauma victims should be reassured that the intensity of their feelings is entirely normal and acceptable. According to a recent pilot study,¹⁰ most of those who grieve need only time and sympathetic company. However, long-lasting grief with traumatic loss can resemble a traumatic stress response and may respond to treatment modalities recommended for posttraumatic stress disorder or depression.

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. 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 empathic. 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 us 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?

Opening up the discussion

It is important for those of us in healthcare professions dealing with grief and

loss to explore our own “grief landscape.” Ask yourself, “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 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 very 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 the consciously dying person? Often, there is concern or even guilt regarding those who will be left behind. There is fear of:

- losing control,
- dignity,
- self-determination,
- ceasing to be,
- being in pain,
- being alone,
- the unknown.

Responding to these concerns requires having an attitude of empathy, attentiveness, and respect, and a willingness to take time, be present, and listen. Nonverbal communication is important. Sit down. 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*.¹¹ The appendix contains many examples of questions that family members or patients may want to ask and insightful responses through which the professional can open up a helpful conversation.

What do we need during grief?

Without a doubt, patient, family, and professionals share some of the same needs when faced with the grief process. As healthcare professionals, we need time alone and time with others to feel and understand our losses. We need rest, relaxation, nourishment, and diversion to be replenished from the exhaustion of grief. We need a sense of security, trust, and hope in the future, gained by experiences of being cared for. We need that which will give impetus and direction to life when it seems to be without meaning. We need lightheartedness, simple pleasures, and humor, which provide balance and relief from stress. (Metcalf and Felible provide a helpful resource.¹²)

Finally, we can benefit from access to the transcendent, or spiritual, realm of life. As Byock¹¹ observed:

It is a paradox of dying that a person can seem to grow strikingly in the realms of spirit and soul as [their] 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.

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