Grief After a Death From Cancer

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As we know, cancer is not a single disease. There are over 150 different types of cancer. Some are relatively treatable and boast high cure rates while others are more lethal. Some, such as lung cancer, are associated with habits or behaviors and may cause a sense of guilt, blame, and opprobrium. Other forms of cancer may be highly disfiguring, create considerable suffering, or cause personality changes. Such conditions can create ambivalence on the part of survivors that can complicate grief. Moreover, the many decisions associated with a cancer diagnosis—from diagnosis and treatment to end-of-life care and decisions—can generate other complicating factors for survivors’ grief. Different forms of cancer can create very distinct issues that haunt families after a cancer death.

This chapter begins by exploring in more depth these complicating factors, offering strategies for health and bereavement professionals as they deal with families. However, it also notes the unique role that health professionals may have in treating cancer. Since cancer is often a prolonged illness, professionals may develop relationships with patients and families that span years. These professionals may also experience grief when a patient dies. This issue also needs to be explored in this chapter.

COMPPLICATING FACTORS IN CANCER DEATHS

Prolonged Illness and Grief

Early research (Rando, 1983; Sanders, 1983) indicated that while sudden loss raises complications for grief, so does prolonged illness. There are a number of reasons for this. In prolonged illness, there is often the perception that the ill person suffered a great deal through the illness experience. In addition, there is likely to be considerable disfigurement. In many cancers, for example, patients may waste away to a seemingly skeletal version of a former self. Other cancers
may cause unsightly tumors or disfigure a patient's face or neck. Other times, there may be physical residues of the treatment: hair loss, amputations, bloating, or scarring. Such disfigurement can exacerbate perceptions that the patient is suffering. Moreover, disfiguring illnesses add to a sense of ambivalence (Doka, 1997). As the illness disfigures the patient, family and significant others may find themselves physically repulsed by the patient's appearance even as they continue to love and care for the person. These mixed feelings can generate a strong sense of guilt when the patient dies. Both guilt and ambivalence are associated with complicated grief (Rando, 1993; Doka, 1997).

In certain forms of cancer, such as brain tumor, there can be considerable personality changes and mental deterioration. This can result from both the disease process or as a side effect of treatment. In and of itself, these changes create an additional sense of loss—a form of psychosocial loss. That is, the persona of the patient is so changed that family and friends grieve the person who once was. This can even be the case when changes are positive. For example, in one case, a patient with a history of alcohol abuse ceased drinking as he underwent chemotherapy. After his death, his wife described the time of his illness as one of the best in their marriage. She felt cheated of all the time that was missed throughout their married life because of his alcoholism. In other cases, negative changes in personality may lead to increased ambivalence and complicate memories of the person who died as well as the sense of the relationship, thus complicating grief.

**Blame, Guilt, and Disenfranchised Grief**

Issues of guilt and blame also can complicate grief when someone dies of cancer. There can be multiple sources of guilt. Some forms of cancer are identified with lifestyle factors such as tobacco use. While studies have shown mixed results in the extent to which even smokers see their tobacco use as responsible for cancer (Bertero, Vanhanen, & Appelin, 2008; Mumma & McCorkle, 1983), other studies have indicated that persons with lung cancer recognize that the stigma of smoking is associated with their illness and believe the stigma has lessened support (Chapple, Ziebland, & McPherson, 2004; Faller, Schilling, & Lang, 1995). The perception that the individual shares responsibility for his or her illness may not only lessen support during the course of the illness, but also disenfranchise the grief of survivors (Doka, 2002).
Even where there is no perceived link to causation, there may be other sources of guilt. Since mortality rates vary among types of cancers and prognosis is often uncertain, there may be a perception that the patient did not fight hard enough to survive (Berckman & Austin, 1993). Given that cancer is an extended illness, that early detection enhances survival in many forms of cancer, and that there are often choices of treatment modalities, there are numerous opportunities for surviving family members to reassess choices and decisions made throughout the course of the illness. Blame and guilt may result, centered perhaps on the patient, health professionals who were perceived to have been slow to respond or treat, or surviving family members including oneself. In summary, issues of guilt and blame should always be evaluated in grief assessments.

**Ethical Decisions at the End of Life**

Ethical decisions made at the end of life also can complicate grief (Doka, 2005). The individual or family making the decision can be torn between a desire to end suffering and a continued quest to retain hope even in the midst of impending death. Individuals or family members may experience conflict between following their own beliefs and honoring the expressed wishes of the deceased.

Sometimes the conflict can be between family members. Since one person within the family system generally holds the health proxy, there may be discord as other family members question decisions that have been made. These end-of-life decisions can create family conflicts or revive family disputes. Such disagreements can limit subsequent support while generating concurrent crises such as family fights that complicate the grief process.

The manner of death, too, may complicate subsequent grief. The decision to terminate life support may not ensure an easy death. Family members may even interpret or misinterpret the final actions of the dying person as evidence of pain and distress. Even when the death does not occur with signs of evident distress, families may be uncomfortable with the circumstances surrounding the death. For example, it is generally believed that neither artificial feeding nor hydration is necessarily palliative. Yet, decision makers or other family members may still perceive that the patient died thirsty or hungry, complicating grief. On the other hand, decisions to continue treatment may lead families to believe that the patient needlessly suffered. Family decision makers then may wish they acted to ease such suffering.
Two final points should be made in this section. End-of-life decisions are generally made in a context of interaction and communication with medical staff. Mixed messages, poor communication, staff disapproval of decisions, and isolation can exacerbate the decision-making process, increasing both individual distress as well as familial conflict.

Second, these decisions need not necessarily complicate the grieving process. Active involvement in the decision-making process may give surviving family members a sense of control in an otherwise uncontrollable time and may result in a sense that their actions contributed to an eased death for their loved one.

**Loss, Grief, and the Caregiving Experience**

The caregiving experience should be explored as well. Grief is inherent in caregiving, as caregivers must relinquish time, roles, and independence as they assume the role of caregiver. At the time of death, the caregiving experience may both facilitate and complicate grief. Prolonged illness, especially when it involves caregiving responsibilities, allows surviving family members the opportunity and insight to see the physical deterioration of the patient. Thus, there is less sense of shock at the time of death.

Moreover, prolonged illness does give individuals opportunity to finish business—to say goodbye, talk over past issues, and possibly resolve conflict. And the very experience of caregiving can be a demonstration of love that may be perceived as atoning for prior conflicts and difficulties.

While there are aspects that facilitate grief, other factors complicate it. Prolonged illness and caregiving are both stressful. This affects grief in at least four ways. First, the cumulative effects of prolonged stress from the illness and caregiving are draining, sapping the ability to respond to yet another series of stressful events necessitated by the loss. In such cases, it is not unusual for caregivers to experience a range of reactions that might complicate grief such as guilt or even relief to be freed from the incessant demands of caregiving, arousing yet more guilt.

Second, these effects may be experienced throughout the social network, limiting opportunities for support. Third, an extensive period of caregiving can isolate caregivers from their traditional support networks. These networks might be dissipated by the time of the patient’s death, limiting social support. Fourth, the stressful context of caregiving can fray relationships, creating or exacerbating conflicts between caregivers or with the dying person that may...
need to be later addressed (see Doka, 2001). It is no surprise that caregiving for family members dying of cancer has been associated with high levels of distress (Tomarken et al., 2008).

**When a Child Dies**

Though the death rates for children and adolescents in developed societies tend to be low, cancer remains a major cause of nontraumatic death in childhood and adolescence. The death of a child is inherently complicated as it challenges parental suppositions that they will predecease their child, hence challenging their assumptive world (Rando, 1993). Moreover, the death of a child creates widespread grieving affecting surviving siblings and grandparents. Grandparents are often disenfranchised in their grief—expected to support the parents despite their own significant sense of loss (Nehari, Grebler, & Toren, 2007). When an adult child dies, surviving parents may be disenfranchised. In these cases, the parental assumption still remains that their child will remain alive through the parents' lives. When an adult child dies, the focus of support often is on the surviving spouse and children.

**INTERVENTIONS AFTER A CANCER DEATH**

*As the Patient Approaches Death: Needs and Interventions*

When families and intimate networks are approaching the imminent death of a cancer patient, they may need the following help as they deal with their ongoing needs.

**Dealing with affect.** Families may struggle with a series of ambivalent emotions as death approaches. They may feel relief and subsequent guilt as they anticipate the end of caregiving. They may struggle with all the emotions of grief. They will need opportunities for validation and information. In the beginning of the terminal phase, families may need to understand their options when care is palliative. These options may include varied bridge programs, hospice, or palliative care programs. As death approaches, families may need to be informed about what will occur as the patient actively dies. Such information may inform any ethical choices at the end of life.

**Balancing demands.** For many caregivers, responsibilities and demands may increase. Caregivers may need assistance at this time prioritizing and balancing...
the varied responsibilities they face as well as finding and accepting support from formal and informal networks.

*Interacting with the patient in meaningful ways.* Even as the patient’s life ebbs, family members can still communicate in meaningful ways. If the patient is conscious, there are varied opportunities for life review and offering legacies. For example, in living eulogies, family and friends are invited to share their memories with the patient prior to death. With ethical wills, patients address the values they would like to pass on to their intimate network. Dignity therapy trains volunteers to work with patients, constructing a bound life story of the patient that is shared prior to death and then presented to the family. Research has indicated that these meaning-centered approaches have value for patients and families (McClement et al., 2007). Even when the patient is comatose, family members can be encouraged to continue to touch and communicate with the patient as well as to engage in ritual and spiritual activities such as prayer or readings.

*Preparing for death.* Families may need to focus on what they will need to do as death approaches. Have they made plans for a funeral? Are legal documents such as advance directives in order? What are personal acts that they may need to do prior to a patient’s death? Is there a particular way that they need to say goodbye?

Professionals can assist family caregivers in a number of ways here. First, family members will need information on what to expect as death occurs. They may need to review advance directives. As stated earlier, it may be critical here to review decisions. For example, family members may need to be reminded that feeding tubes or hydration may cause additional discomfort at the end of life. Such information at this time may eliminate potential conflicts and mitigate later distress over actions. Second, family caregivers may need to review and rehearse final actions. As death approaches, for example, they should know who to call and what they need to do.

**When Death Occurs**

At the time of death, a number of interventions will assist caregivers:

*Allow time alone.* Do not rush removal of the body. Remember that the family may need time alone to say goodbye.
Empower ritual. The moment of death is a sacred time. Offer them options for a ritual. Perhaps they would wish to light a candle, say a prayer, or find another meaningful way to address the moment.

Allow grief. It is appropriate at this moment for families to express their grief. Do not and—as much as is in one's power—do not let others inhibit that expression.

Help with the details. Families may be confused and disoriented at this time. They may value assistance in calling the funeral home and informing others (Doka, 2001).

After the Death

Validate expressions of grief. Validation is an essential aspect of grief support. Validation means that individuals' experience of grief is listened to, understood, accepted, and explained as a valid response to the loss. No expressions of grief are inappropriate. Responses such as “You shouldn't feel guilty” or “How can you be upset after all your years together” are common but serve to deny and invalidate grief. Rather, patients and caregivers need to have these experiences of loss and expressions of grief acknowledged. This gives space for individuals to explore their many reactions to their experience. This is critical.

Help families deal with the affective issues aroused by the loss. As stated earlier, patients and their networks often lack opportunities to ventilate the emotions aroused by the situation. When the patient was alive, family and friends may feel disloyal, unfeeling, or inhibited in expressing emotion. Counselors should encourage emotional expression, identify and validate the emotional responses that clients experience, and explore strategies for coping with these emotions. It is critical that counselors recognize the broad range of ways in which clients may achieve emotional release. For some, ventilating by crying can be helpful; for others, emotional energy can be expressed in activity or cognition (Martin & Doka, 1999).

Help individuals recognize and respond to the changes in their own lives. An individual who experiences loss is likely to experience a series of secondary losses that spring from the initial loss. Sometimes this may even be a relationship with a professional caregiver. It is not unusual in a cancer death for families to bond with a range of health professionals including secretaries, technicians,

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2 Worden (2009), Humphrey (2009), and Rando (1993) offer excellent resources for grief counselors.
and aides. Families may need opportunities to recognize the contributions of such individuals to their loved one's care. Many times helping persons to acknowledge these changes can be beneficial. Simply asking, “In what ways has your own life changed since...?” allows individuals to enumerate these losses. Sometimes family members themselves will be surprised at the extent to which their lives have changed. Having identified the losses, individuals can then develop strategies for coping with them, perhaps regaining some of what was lost (possibly in modified form) and mourning the loss of what cannot be salvaged.

Explore methods of coping. Coping can be defined as the “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as passing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141). Coping strategies can be diverse: Some are helpful (such as reframing thoughts or sharing emotions with others). Because the conditions surrounding loss can create periods of sustained stress, counselors will find it useful to explore individuals’ coping strategies. In this exploration, coping strengths can be identified and encouraged. Unhelpful coping strategies can also be identified and clients can then assess alternative strategies. Among the issues that might arise in a discussion of coping strategies are concerns about support. One key coping skill is utilizing one’s support system effectively. Asking individuals to identify and assess their informal support systems can be useful in many ways. It can reinforce the idea that there are others to whom they may turn. It can lead to discussions about who has or has not been forthcoming, allowing the assessment of “surprises”—that is, individuals who did not come through as expected or those who provided unexpected support. This discussion can identify barriers to support, such as a reluctance to use or seek support.

Review decisions made in the course of the illness. From the decision to seek treatment, there are numerous decisions in cancer care. Should this mole or lump be examined? Should one try surgery or chemotherapy? Should one enter an experimental protocol? Should one continue treatment or accept that care is now palliative? What decisions should be made as death nears? These are examples of some of the questions encountered throughout the course of cancer therapy. After the death of a patient, family members may need to reexamine the choices made to be assured that they acted wisely with the information they knew at the time.
Reinforce a sense of connection to the person who died. Individuals retain a connection with the person even after that person’s death. After a prolonged illness, surviving family members and others may struggle with that sense of connection. They can be overwhelmed with images or behaviors experienced throughout the illness. Counselors can help review the person’s life and use expressive approaches such as photographs to help revive memories and images prior to the disease.

Explore spiritual issues raised by the patient’s condition. Sometimes, individuals may experience a shattering of assumptions—their beliefs about the nature of the world or the future—which can give rise to a profound spiritual struggle. Again, counselors can validate this struggle, provide space to explore the spiritual issues raised by the illness, and allow clients to assess the ways in which they can effectively utilize their beliefs, rituals, and faith communities.

Counselors may employ many resources as they assist individuals in dealing with losses. Support groups, for example, can offer respite, validation, suggestions for coping, and hope. In many of the same ways, bibliotherapy, or the use of books or self-help literature, can be helpful. Like groups, it can offer validation, help, and suggestions for coping. And it is available whenever an individual needs support and comfort.

Rituals, too, are helpful. Funerals and memorial services that are inclusive, personal, and participatory can allow ventilation of grief reactions, empower a sense of community and social support, stimulate recollections of the deceased, offer structure at a difficult time, provide spiritual succor, and bring mourners together. Therapeutic rituals can be developed throughout the grieving process to reaffirm a continuing bond, mark transitions within the grieving process, affirm the life of the deceased, and finish any unfinished business (Martin and Doka, 1999).

**Formal Caregivers and Grief**

While healthcare professionals in the past were expected to keep an emotional distance from their patients (Vachon, 1987; Lev, 1989; Figley, 1995), this was difficult to do in practice. Fulton (1987), for example, applied the lessons of the Stockholm syndrome to the health professional-patient relationship. The

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3 Material here is drawn from Doka (2005).
Stockholm syndrome, which emerged from a study of the relationships between hostages and captors, emphasized that often captors and hostages developed an intense and mutually productive bond. Fulton viewed the phenomenon as broader than that of hostage taking. To Fulton, the underlying process was more inclusive; persons tend to bond quickly in crises. Healthcare workers and other formal caregivers are often involved in intense crises situations that can result in forging a strong bond. Thus when a health professional develops a strong bond with a particular patient, the death of that patient then generates grief. Naturally this bond is individual. Not every caregiver becomes so bonded to each of his or her patients all the time. Yet, certain losses may provoke a strong grief reaction. Papadatou (2000) notes that even beyond the loss of an individual patient, staff may experience additional losses.

This is particularly true in cancer. Treatments often take place over years. Staff, including a range of technicians, may interact with patients and families over years—sharing both the triumphs and disappointments that arise through the course of the disease. When a patient dies, such staff may lose not only a relationship with a patient but with the family as well, exacerbating feelings of loss. The very nature of cancer treatment exacerbates a phenomenon of vicarious grief (Kastenbaum, 1988). Health professionals may have to publicly share the patient and family’s optimism while understanding the likely prognosis; in effect, grieving for the family.

Papadatou (2000) also described other factors that contribute to a health professional’s sense of loss. Staff may experience a loss of their own unmet goals or expectations regarding the patient. They may have wished to do something else such as additional treatment or perhaps an act of kindness prior to the death. For example, in one case a nurse’s sorrow was compounded because her young patient died before she had the opportunity to bake him a promised treat. There may also be a loss of self as the professional confronts his or her own mortality. Staff may experience a reminder of past or anticipated personal losses and their own assumptions or beliefs may be challenged as the patient dies.

There may be factors that complicate the response to death. As patients face the end of life, family members may make decisions that are contrary to the health professional’s ethical stance. In some cases, such professionals may have little if any role in such deliberations, intensifying a sense of powerlessness that can affect subsequent grief reactions (Doka, 2005).
This grief can be manifested in many ways including anger, anxiety, powerlessness, hopelessness, sadness, or guilt. Staff can feel they are on emotional roller coaster and become emotionally depleted or depressed. They can become preoccupied with the disease or trauma, perhaps constantly fearing that they or someone they love will have a similar experience or defensively become unfocused, rigid, or apathetic. They may question their beliefs or sense of purpose, or become skeptical. Health professionals may even experience physical manifestations of stress such as aches and pains, sleeping and eating difficulties, or other medical maladies (Figley, 1995).

This grief may affect their relations with others. Staff members may seem angry and impatient. They may withdraw from others, become distrustful, overprotective, or hypervigilant. Such grief even may affect the work environment, lowering morale and contributing to staff turnover (Figley, 1995; Papadatou, 2000).

While the experience of professional grief is similar to other types of losses, Papadatou (2000) reminds us of a major difference in process. Because of the ongoing nature of the work, health professionals have to simultaneously oscillate between containing their grief and experiencing that grief. If staff members fail to contain their grief, they can become overwhelmed by constant loss and be unable to function within their position. However, if professionals constantly contain their grief, eventually this will inhibit contact with their patients. They will gradually dehumanize the person whom they serve. Only by fluctuating between these two processes, Papadatou (2000) posits, can healthcare staff maintain both their effectiveness and humanity.

As noted throughout this chapter, formal caregivers will need to confront their own grief. Both Vachon (1987) and Papadatou (2000) found that both individual and organizational factors influenced adjustment to the effects of cumulative losses, mitigating compassion fatigue. Individuals benefited from effective lifestyle management. Their grief, too, was facilitated by their own ability to validate their own grief and to find their own spiritual center.

Organizational factors also were critical. Organizations assisted health professionals when they acknowledged and supported their grief in such ways as offering education about professional grief, support groups, effective and caring supervision, and rituals where professional caregivers could acknowledge loss.
CONCLUSION
Grief, then, is an inherent part of the cancer experience. It begins at the time of diagnosis, if not even earlier with the anxieties generated from the early yet undiagnosed symptoms. This grief continues even after the death, affecting not only family and friends, but also the health professionals who become part of that intimate network. This grief needs to be acknowledged and treated as surely as the disease.

REFERENCES


