2001

Grief, Loss and Caregiving

Kenneth J. Doka
The College of New Rochelle, kdoka@cnr.edu

Follow this and additional works at: http://digitalcommons.cnr.edu/facpubs

Part of the Gerontology Commons

Recommended Citation
Caregiving and Loss

Family Needs, Professional Responses

Foreword by Rosalynn Carter
Edited by Kenneth J. Doka and Joyce D. Davidson

HOSPICE FOUNDATION OF AMERICA
Grief, Loss, and Caregiving

Kenneth J. Doka

Introduction

- Joan has been caring for her 17-year-old son Adam, who was born with severe developmental disabilities. She is ashamed of the resentment she feels when she sees her friends with their children, knowing Adam will never experience normal milestones such as graduation.

- Manuel’s wife has had Alzheimer’s for nearly six years. Working, caring for her, even arranging care has been a burden for both him and his adult children. Manuel feels lonely, guilty, and depressed.

- Cynthia’s husband has died after a long disabling stroke. For years she patiently cared for him, giving up activities and friendship to nurse and nurture. Now that he has died she struggles to find a new sense of identity and purpose.

- Robert has cared for his lover Lou for the nine years that Lou has struggled with HIV infection. Uninfected, Robert has supported Lou through Lou’s cycle of relapses and remissions. Even though he loves Lou, Robert now just wishes he would die so he can get on with his own life.
There are two common denominators in these vignettes. All of the individuals have been intensely involved in a caregiving experience. And all of them are encountering loss and grief, which is not surprising. Grief is a constant companion in the caregiving journey.

This chapter explores the nature of grief and loss inherent in the caregiving experience and begins by reviewing the process of anticipatory grief and mourning that encompasses all the loss experienced when an individual is chronically ill or disabled. A strong emphasis is placed on strategies of intervention for patients, families and intimate networks, as well as for professional caregivers. This is critical, as grief is so stressful that a failure to provide effective care can increase the distress of the patient and lead to fatigue and burnout in caregivers.

This is especially true when an individual approaches death. Here, support will play a critical role, one that may dramatically affect the experience of subsequent grief. The chapter then considers the grief that follows a loss, addressing factors in the caregiving experience that both facilitate and complicate loss. Again, a strong emphasis is placed on intervention strategies that can assist caregivers as they cope with loss. For even though the caregiving journey has ended, the journey through grief continues.

**Loss, Illness, Disability, and Grief**

One of the common misunderstandings of grief is that it is only a reaction to a death. It is this misunderstanding that clouds the concept of ‘anticipatory grief.’ Originally, anticipatory grief referred to grief reactions that resulted from an expected or anticipated death (Lindemann, 1944). For example, if someone is diagnosed with a terminal disease, that person, as well as his family and friends, may already begin to grieve the expected and eventual death.

But grief is a far broader concept. Grief results from a reaction to a loss—any loss, not just one related to death. Rando (2000)
has defined anticipatory grief as a reaction not only to an expected loss, but to all the losses—past, present and future—that are encountered in an experience of illness or disability. Anticipatory mourning, then, becomes the process whereby one continually adapts to these losses.

Loss is inherent in the caregiving experience. These losses are many. Depending on the underlying cause, clients or patients may experience losses of abilities, activities, or independence. They may have to relinquish significant roles, such as work and family roles. As one man with ALS shared: “My wife tells me I will always be a husband and father even though I no longer work. Yet it’s really not true. I no longer take my wife out. I really do not function as a husband any longer. And I do not even have the strength to pick up my child.”

There may be other losses as well. Some may be intangible, such as the loss of hopes, dreams or plans or the loss of body image or security. These losses may shatter the client’s assumptive world, causing them to question their beliefs about the nature of the world, as well as challenging spiritual and philosophical beliefs. There may be tangible losses, too. As income declines and health-related expenses rise, lifestyles may change. And each condition carries unique losses. For example, early-stage Alzheimer’s patients may grieve their loss of memory, a critical link to past, present, and others.

This grief is shared by family and others in the intimate network with whom one shares intense interaction and emotional investment. Members of that network also experience losses that are grieved. Again, some of these losses are intangible—the loss of hopes, dreams, or plans. One father, many years after his daughter was born with developmental disabilities, described his sense of loss: “Most parents over time learn that their children will not fulfill the hopes they have for them. But most parents have twenty some odd years to figure that out. My wife and I learned it in minutes.” These intangible losses may create spiritual pain and confusion, challenging one’s assumptions about the world.
Conditions such as Alzheimer's may generate a sense of psychosocial loss (Doka & Aber, 1989; Doka, 2001). Psychosocial loss refers to situations where the persona is so changed, in this case by illness or disability, that intimate others experience the loss of that person as she once was. In extreme cases, such as advanced Alzheimer's, spouses may even face cryptowidowhood, or hidden widowhood. Here the loss of the marriage relationship is total, though the person remains alive (Doka & Aber, 1989).

Other losses are tangible. Caregivers within the intimate network give up time, independence, roles, and activities as they tend to the person. They may experience secondary losses such as friends or income. These losses and subsequent grief may not be acknowledged by others. In fact, they may face public admiration for their selflessness, perhaps making their own feelings of resentment even harder to bear.

These losses are experienced by professional or paid caregivers as well. Over time they may become emotionally invested in the patient as well as the intimate network. Their losses may be associated with the patient or family as they watch the continued deterioration of the patient or developing dysfunction in the family due to the increased stress. They may experience a loss of their beliefs and assumptions or hopes and goals (Papadatou, 2000).

Since loss is inherent in the caregiving experience, so is grief. This grief may manifest itself in a number of ways. Physically, individuals may experience a range of reactions, including fatigue, insomnia, aches and pains, more than likely exacerbated by the fact that grief is but one source of stress. Other reactions may be emotional. Persons may experience many emotions—sadness, anxiety, guilt, anger, jealousy, to name but a few. Many of these emotions, even paradoxical ones, may be experienced simultaneously. Grief may have cognitive effects. Individuals may constantly think about the condition of the person. They may become obsessive or forgetful. Their minds may race from one thought to the next. They may be troubled by dreams or other sleep disturbances.
Spiritually, individuals may find it difficult to find meaning in the experience. They may question their beliefs or become angry with God. Others may turn even more intently to their faith for support or solace.

All of these reactions are likely to be expressed in a range of behaviors, including manic activity or lethargic behavior. Some individuals may plunge into caregiving while others become more distant and remote. Some may lash out in anger, while others act out in other ways, including substance abuse. Some may channel grief in almost transcendent ways, perhaps becoming advocates or moving into other realms of caregiving.

In summary, issues of grief and loss are inherent in the caregiving process. This grief is experienced by everyone involved—patients, caregivers within the intimate network, and paid caregivers. All will need support as they mourn their many losses.

**Providing Support: Interventions and Self-Care**

Strategies for intervention and support will be different at distinct periods in the caregiving experience. And, of course, they will be different for professional caregivers and family caregivers. In early phases of the disease, or in other circumstances depending on awareness, grief may be shared by the patient or client. Thus, such individuals will need support for grief as well. Patients and caregivers, then, may need to do the following.

- **Validate Expressions of Grief**
  Validation is an essential aspect of grief support. Validation means that the individual’s experience of grief is listened to, understood, accepted, and explained as a valid response to the loss. Too often caregivers and patients are made to believe that natural expressions of grief are either inappropriate or ungrateful. “You shouldn’t feel guilty” or “How can you be upset after all your years? Count your blessings.” Such expressions, however common and well-intentioned, deny or invali-
date grief. Patients and caregivers need to have these experiences of loss and expressions of grief acknowledged, allowing space for individuals to explore their many reactions to the experience. This is critical. Professional caregivers may believe that expressions of grief are inappropriate since they do not share a kin or prior relational tie. Yet here, too, grief is an appropriate response that needs validation.

• **Inform Clients and Families**
Patients and caregivers both may need information about the underlying condition. For example, in certain diseases, fatigue or mood swings may be a common symptom or side effect of medication. As patients and their intimate networks know more about the underlying condition, their ability to cope and sense of control is likely to be greater. In educating patients and intimate networks, it is important to recognize the phenomenon of “middle knowledge” (Weisman, 1972). This means that dying persons and members of their network drift in and out of the awareness of dying or other serious conditions. This means that patients and families will sometimes accept, and sometimes fail to accept and acknowledge, the information they have been given. The implication of middle knowledge is that one should always follow the patient and family member’s lead. They will let us know what information they are ready to hear. It is critical to understand that patients and families may choose, at times, not to acknowledge information they once seemed to accept.

• **Help Patients and Families Deal with the Affective Issues Aroused by the Loss**
Patients and their networks often lack opportunities to ventilate the emotions aroused by the situation. Because the patient is alive, family and friends may feel disloyal, unfeeling, or inhibited in expressing emotion. The patient, too, may feel it is inappropriate to express his emotional reactions. All parties
may struggle with a wide range of emotions, among them anger, guilt, anxiety, and shame. Education about the condition may alleviate some of the affective issues, but clients may need additional opportunities to explore and ventilate their emotions. Counselors should encourage emotional expression, identify and validate the emotional responses that clients experience, and explore strategies for coping with these emotions. Questions such as, “Many times clients in your situation have expressed to me feelings of ______. Have you experienced this?” can provide the freedom to explore previously unacknowledged affect.

In addition to the illness, the caregiving experience may arouse feelings as well. Caregivers may feel resentful of the burdens placed on them, perhaps angry that others are not more helpful. These feelings are likely to be exacerbated when the relationship before illness was ambivalent. Caregivers may feel resentful of their new responsibilities, guilty about lapses of patience, or even regretful that they cannot do more. Patients may resent their increasing dependence, or be ambivalent about the help they are given. Exploring these reactions can allow them to acknowledge their own limits or to develop alternative strategies for future contingencies that can reinforce a sense of control. 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 emotions can be expressed in activity or cognition (Martin & Doka, 1999).

- **Help Clients 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. In psycho-social loss, these secondary losses can be profound. As mentioned earlier, clients may lose prior companionship, shared activities, and contact with others. They may have less
personal time and thus be forced to relinquish other significant roles or pleasurable activities. And the changes may occur so rapidly (or so gradually) that they may not realize how significantly their lives have been altered and how the changes have added to their stress.

Many times helping clients to acknowledge these changes can be beneficial. Simply asking, “In what ways has your own life changed since _______?” allows clients to enumerate these losses. Sometimes clients themselves will be surprised at the extent to which their lives have changed. Having identified the losses, they 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 may be 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 individual clients’ coping strategies. In this exploration, coping strengths can be identified and encouraged. Unhelpful coping strategies, such as substance abuse, 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 and respite. One key coping skill is utilizing one’s support system effectively. Asking clients 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 also identify barriers to support, such as a reluctance to use or seek support.

These considerations can in turn lead to a discussion of respite. For the aware patient, respite in the form of visitors or other activity can provide needed diversion. For family caregivers, respite is essential to effective adaptation. Counselors may find these caregivers reluctant to consider their respite needs for a number of reasons, such as the inability to find or trust alternative caregivers, concerns of the patient, feelings of guilt, or perhaps even the gratification experienced when one feels essential and needed. Nonetheless, family caregivers should be encouraged to explore both their respite needs and their respite strategies. The very question of how they meet their own needs for respite validates the legitimacy of deriving strategies to meet their own needs.

• Help Clients Plan Realistically for the Future

Aware patients, as well as their family members and friends, need to plan for the future. Clients may be resistant to planning for three reasons: First, in many situations, future possibilities may seem dismal. Second, many may have learned to adapt by simply taking each day as it comes. Third, given the reality of middle knowledge, clients, whether patients or families, may simply choose not to discuss an uncertain future. For all of these reasons, counselors should respect their decisions.

This concern has many dimensions. One issue involves the question of advance directives. It is important to allow discussions of advance directives should the subject arise, even to invite clients to address these issues. First, in addition to the process of anticipatory mourning, there is a concurrent process of anticipatory bereavement (Gerber, 1974). This means that patients may need to take objective actions prior to further decline. Second, addressing future possibilities allows patients to consider available options.
are not viable, the discussion of alternatives still reinforces a sense of control.

- **Explore Spiritual Issues Raised by the Patient's Condition**
  Much of the time, clients experience a shattering of assumptions—most of their beliefs about the nature of the world or the future—which can give rise to a profound spiritual struggle. This struggle can be complicated, particularly as the demands of caregiving can limit opportunities for spiritual support—for example, limiting time for participation in religious services or spiritual practices. 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 patients and caregivers in dealing with losses. Support groups can offer respite and validation, as well as ways for individuals to explore their response to the underlying condition. Support groups exist for cognitively functioning persons with a variety of conditions, as well as for caregivers. Some of these groups may be specific to a given condition such as ALS, Alzheimer’s or developmental disabilities. Others focus on the caregiving experience and are open to any caregiver. The list of resources in the appendix offers information about national organizations that can refer to local support groups.

  In many of the same ways, bibliotherapy, the use of books or self-help literature, can be helpful. Like groups, bibliotherapy offers validation, help, and suggestion for coping. And it has the advantage of being available whenever an individual needs support and comfort.

  Other techniques may also be helpful. Caregivers and patients may find complementary therapies such as meditation, imaging, or other approaches to be useful. These strategies can reduce stress and reinforce a sense of control.
Rituals, too, may be offered. Rituals are acts that evoke meaning. Through the experience of caregiving, rituals may offer individuals a sense of both meaning and control, allowing one to act out reactions. One man dying of cancer turned over his checkbook to his adult daughter, conveying his trust in her ability to now handle things. This ritual allowed him a dignified way to relinquish a significant role.

It is critical to remember that the needs addressed here are shared by all—patients, caregivers with the family or intimate network, and professional caregivers. It is especially critical to offer support for these professionals. Not only can they become close to their patients, but to the families as well. The very nature of their work means that they may experience cumulative losses leading to compassion fatigue and burnout. Their own sense of grief can easily be disenfranchised (Doka, 1989, 2001).

As the Patient Approaches Death: Needs and Interventions

In many cases the role of a caregiver can go on for many years, perhaps even across the life span. But in other cases the underlying condition of the patient moves from a chronic to a terminal phase. When families and intimate networks approach the imminent death of a 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 may be fearful and confused as to what they will do as caregiving responsibilities, once a large part of their lives, cease. As noted earlier, they will need opportunities for validation and information.
• **Balancing Demands**
  For many caregivers, responsibilities and demands may increase. Caregivers may need assistance at this time in prioritizing and balancing the varied responsibilities they face, as well as finding and accepting support from formal and informal networks.

• **Preparing for Death**
  Families may need to focus on what must be done as death approaches. Have they made plans for a funeral? Are legal documents such as advance directives in order? What personal acts might they need to do prior to a patient's death? Is there a particular way in which they need to say goodbye?

  Individuals 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 and other 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 decisions. Second, family caregivers may need to review and rehearse final actions. As death approaches, for example, they should know whom 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.

  — Allow the expression of grief. It is appropriate at this moment for families to express their grief. Do not inhibit that expression, and, as much as is in one's power, do not let others inhibit that expression.
—Empower ritual. The moment of death is a sacred time. Offer loved ones the option for a ritual. Perhaps they wish to light a candle, say a prayer, or find another meaningful way to address the moment.

—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.

And finally, at the moment of death, it is critical not to neglect professional caregivers. They, too, may need to mark the moment and grieve.

After the Death: Grief and Caregiving

It is often said that sudden loss is difficult for survivors, while prolonged loss is easier for survivors (though more difficult for the dying person). In fact, some of the early thought was that anticipatory grief often mitigated the grief survivors experienced at the time of death—that is, that much grief work had been completed. The reality is different. In any loss, survivors will experience the many manifestations of grief we have mentioned. When illness is prolonged, there are factors that will facilitate the grieving process, but there also are factors that complicate grief.

Prolonged illness, especially when it involves caregiving responsibilities, does allow survivors to become aware of the severity of the problem as it continues to unfold. As one caregiver shared: “Each time I came to take care of my father, I realized how much he had declined—even from the past week. Bathing him, I could see the progress of the deterioration. When he died I was ready. I felt he was, too.” Moreover, prolonged illness gives individuals the opportunity to finish business—to say goodbyes, 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.
Other aspects of prolonged illness may complicate the grieving process. Prolonged illness and caregiving are both stressful, affecting grief in at least three ways. First, the cumulative effects of prolonged stress from the illness and caregiving are draining, sapping one’s ability to respond to yet another series of stressful events. Second, these effects may be experienced throughout the network, limiting opportunities for support. Third, the stressful context of caregiving can fray relationships, creating or exacerbating conflicts between caregivers or with the dying person that may need to be addressed later.

Other factors may complicate grief as well. Survivors may be troubled by the extent that the deceased suffered. Such experiences may challenge spiritual assumptions and beliefs. Survivors may also be concerned about care decisions, such as the timeliness or appropriateness of particular medical decisions.

There are a number of interventive strategies that can assist. It is critical, of course, to validate loss. There is often an assumption by others that now that the illness has ended and caregiving has ceased, the ordeal is over. In fact, grief now continues, and survivors are likely to experience a roller coaster of reactions that will, in an individual way, ebb and flow over the next years.

In the grief process, the individual will deal with many emotions. He or she will struggle with spiritual issues and concerns such as the meaning of the experience, will readjust to a life without the person, will continue to adjust to the reality of the death, and will relocate the deceased. The latter refers to the ways in which one continues a relationship with the deceased, who, while not physically alive, still lives in memory (Worden, 1991).

In caregiving after prolonged loss, a number of issues may emerge that may complicate a survivor’s attempt to deal with the grieving process.
• Survivors may need to review the caregiving experiences, addressing the times they felt positive about, the times that concerned them, and the lessons they learned from the process. For some, journaling may be an effective way to gain perspective on the experience.

• Survivors may need to review the illness, focusing once again on treatment decisions. Opportunities to review those decisions with medical personnel may help reassure them that choices made, given an appreciation of context and information they knew at that time, were appropriate.

• Survivors will often struggle with memory. The later experiences of caregiving and illness can overwhelm other more pleasant memories. It may be helpful for survivors, when they are ready, to review photographs or videos of the deceased as a way to regain earlier images and recollect other experiences.

• In some situations, especially those where the caregiving role was all-absorbing, survivors may need to re-establish and develop identity. Redefining oneself as something other than a caregiver and finding new meaning in life may take time and considerable reflection.

Professional Caregivers and Grief

As noted throughout this chapter, as well as in other chapters in this book, professional caregivers will need to confront their own grief. Both Vachon (1987) and Papadatou (2000) found that both environmental and individual factors influence adjustment to the effects of cumulative losses, mitigating compassion fatigue. Individuals benefited from effective lifestyle management. Their grief, too, was facilitated by their ability to validate their own grief and to find their own spiritual center. But environmental factors
also were critical. Professional caregivers benefited when organizations acknowledged and supported their grief in such ways as offering grief education, support groups, effective and caring supervision, and rituals in which they could acknowledge their loss.

Conclusion

Grief is a constant companion to the caregiving experience, one that affects everyone involved. That grief cannot be minimized. Effective interventions, however, have a critical role in making the experience of grief understandable and shared. That illumination and support is the gift that can be offered to caregivers. Perhaps it will be enough.

Kenneth J. Doka, PhD, Mdiv, is Senior Consultant to Hospice Foundation of America and a professor of gerontology at the College of New Rochelle in New York. He is an ordained Lutheran minister and a former president of the Association for Death Education and Counseling (ADEC) and recipient of ADEC’s 1998 Death Educator Award. He is former Chairperson of the International Work Group on Death, Dying, and Bereavement. Dr. Doka has been a panelist on Hospice Foundation of America’s National Bereavement Teleconference since 1995. Dr. Doka serves as editor of Omega as well as Journeys, a newsletter for the bereaved published by Hospice Foundation of America. He is the author of numerous books as well as over 60 published articles and chapters.