CHAPTER 10

Grief and Dementia

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INTRODUCTION

Grief is the constant yet hidden companion of Alzheimer's disease and other related dementias. Grief can arise when an individual in the early stages of the disease fearfully encounters the symptoms and anticipates the losses that the disease entails. Grief will certainly be experienced by family members as they view the slow deterioration in the memory and even the being of the person they love. Grief will increase as family members see, from that decline, a stranger emerge: a stranger who needs unceasing care.

That grief will be experienced even after the death—complicated by all the feelings that arose in the course of caregiving, such as the caregiver's own losses and discomfort, guilt about institutionalization, and perhaps even troubling feelings of relief and emancipation at the death. Professional caregivers, who in moments of intimate care, saw in their patient a glimpse of a former self and developed a caring connection, may also share that grief.

This chapter explores the grief both in the disease as well as in the mourning that follows the death. At all levels of the experience, grief can be disenfranchised by the shame, secrecy, and stigma that are companions of Alzheimer's disease. The chapter also seeks to enfranchise this grief by discussing strategies that can be used to support and validate all the grief throughout the course of the disease.

GRIEF AND ALZHEIMER'S DISEASE

Therese A. Rando (1986, 2000) reminds us that the term, "anticipatory grief" or as she prefers, "anticipatory mourning," is useful yet paradoxically misunderstood. It is misunderstood when the term simply is seen as a reaction to an anticipated or future loss. Here “anticipatory grief” is conceived as limited—a person reacts to the foreknowledge of an impending loss.

Rando’s redefinition of anticipatory mourning is useful. To Rando (2000), “anticipatory mourning” is a reaction and response to all losses encountered in the past, present, or future of a life-threatening illness. These losses and the grief reactions they evoke are part of the daily experience of those who experience Alzheimer’s disease or other dementias. Patients, families, and even professional caregivers can experience these losses.

In Alzheimer’s disease and in many dementias these losses can be profound. First, there is the very loss of the past as memory deteriorates. As one ceases to remember, the links to the past are severed. One no longer recalls experiences or relationships from memory. This type of loss was poignantly expressed by one Alzheimer’s patient who, struggling to recount an incident from childhood, cried, “I used to remember!”

The deterioration of memory also affects the present. Memory links one to another, allowing one to recall the relationships and histories that bind a person to another. Those affected may no longer remember the individuals around them—unable to recall or to express the relationship. One woman with Alzheimer’s disease had a long, close relationship with her daughter-in-law. Yet, as the disease progressed, she could only express the relationship as “the woman who married my son”—a term that caused a great deal of grief to the younger woman as it seemingly invalidated their long, positive relationship.

As memory lapses, other losses follow. One may no longer be able to effectively function in other roles. Work and other cherished tasks may have to be relinquished. There may be a gradual loss of independence.

In the early stages of dementia both the patient and the family may experience these losses. As the disease progresses, the patient may no longer have the ability to cognitively experience loss and grief. Also as the disease progresses, the sense of specific loss and deterioration may be replaced by a generalized feeling of “wrong–being,” a vague sense that something is not right. Moreover, this generalized sense may be manifested in behaviors that indicate inner pain, such as expressing agitation. For though cognition declines, feelings and states of emotional stress remain (Rando, 1993).

Eventually it may be that the patient experiences “psychological death”: the loss of individual consciousness. The person ceases to be aware of self. “Not only does he not know who he is—he does not know that he is" (Kalish, 1966, p. 247). Naturally others can only infer this state.

There is one other issue as well. Even as individuals struggle with dementia, they may experience additional significant losses apart from the illness. A loved one, for example may become ill, be hospitalized or institutionalized, or die.

Unfortunately, there is little research that considers how an individual with dementia copes with loss. As noted earlier, Rando (1993) emphasizes that the loss of cognition should not be compared with the absence of emotion. Grief in dementia may be evident in changes of behaviors such as unusual or increased manifestations of agitation or restlessness.

However, persons with dementia may not be able to be aware of the loss. They may, as mentioned earlier, have a vague sense that something is not right, or that some significant individual, perhaps one they cannot even identify, is missing. Persons with dementia may confuse the present loss with earlier losses. For example, Herrmann and Grek (1988) documented two cases where bereaved spouses with dementia delusively believed that a parent rather than a spouse had died. They may retain a constant delusion that the person is still alive (Vennen, Shanks, Staff & Sala, 2000).

In other situations, persons with dementia may be unable to retain the information that an individual has died. They may ask repeatedly what has occurred to that person. They may even mourn the loss only to later reiterate the question. In such cases, caregivers may need to acknowledge their own frustration and be reassured that such behaviors are normal in the disease and are not indications of an inadequacy of explanations. It might be useful to return to a picture or memory each time the person with dementia questions the loss or expresses a sense of grief. Naturally, in individuals with Alzheimer's or other dementias, expressions of grief will be affected by a variety of factors, including the extent of disease and loss of awareness, the immediacy of the lost relationship, and the affected persons' abilities to communicate their loss. It is critical, however, to be sensitive to that loss. It has even been hypothesized that significant losses, as well as the inherent changes that occur as a secondary effect of loss may exacerbate the dementia (Rando, 1993; Kastenbaum, 1969).

The family, however, experiences a continuous and profound sense of loss and subsequent grief—a grief that becomes more intense as the patient's symptoms increase (Ponder & Pomeroy, 1996). The family may experience a deep sense of "psychological loss"; that is the persona of the person, or the psychological essence of an individual's personality is now perceived as lost even though the person is physically alive. The sense of individual identity is so changed now that family members experience the death of the person who once was. (Doka & Aber, 2002)

Spouses may become "crypto widows"—married in name but not in fact. They may grieve the losses associated with that role—losses of intimacy, companionship, and sexuality (Doka & Aber, 2002; Teri & Reifler, 1986).

The very experience of caregiving may complicate grief. Caregivers may experience secondary losses such as the loss of social and recreational roles, work roles, and relationships with others. These losses and the increased demands of caring for someone with a progressive illness as well as the experience of psychosocial loss may generate an unceasing state of grief sometimes identified as "chronic sorrow" (Mayer, 2001; Burke, Hainsworth, Eakes & Lindgren, 1992; Loos & Bowd, 1998) and a reactive depression (Walker & Pomeroy, 1996).

Progressive dementia also diffuses caregiver grief in another way. As individuals deteriorate, their ability to monitor and regulate their behaviors diminishes. They may exhibit a range of bizarre and unusual behaviors such as foul language or indecent and inappropriate actions. They may relive earlier traumas. For example, some holocaust survivors, as they experienced Alzheimer's disease, began to hoard food and experience troubling flashbacks or heightened anxiety (McCann, 2003). Others may express attitudes that were once self-censored, engaging for example in racial or personal diatribes. All of this behavior can humiliate, embarrass and isolate caregivers—increasing ambivalence and discomfort that subsequently can complicate grief. There also may be ethical decisions, such as withholding treatment, which may generate guilt, complicating grief. Moreover, the deleterious affects of caregiving may diminish coping abilities and the constant demands of care may limit social support (Bodnar & Kiecolt-Glaser, 1994).

Grief changes focus as the patient dies. For some the death may be a "liberating loss," (Jones & Martinson, 1992; Elison & McGonigle, 2003) characterized by feelings of relief and emancipation that caregiving responsibilities and the suffering of both the patient and family have ended.

Yet, others may actually grieve the loss of the caregiving role. They may now feel a lack of focus and meaninglessness in their present activities. For others, though, these feelings may be accompanied by guilt and sadness.

Survivors may reminisce about the caregiving experience, reflecting on times that they might have shown more patience or empathy. There might be considerable work, unfinished business, believing that there was more that could have been said or done. Such memories, while common and understandable, are related to greater depression, stress, and social isolation (Bodnar & Kiecolt-Glaser, 1994).

This grief may not only be manifested in affect but in cognition, behavior, and spirituality. It also may be experienced physically. Health consequences do not end with the transition of the caregiving role. In fact, increased medical symptoms in caregivers are associated with transitions from the caregiving role such as the nursing home placement or death of the person with Alzheimer's disease (Grant, Adler, Patterson, Dimsdale, Ziegler & Irwin, 2002).

Others may disenfranchise the grief that patients and survivors experience. Disenfranchised grief refers to losses that are not appreciated by others. In effect the individual has no perceived "right" to mourn. The loss is not openly acknowledged or socially sanctioned and publicly shared. Others simply do not understand why this loss is mourned and they may fail to validate and support grief (Doka, 1989, 2002).

Grief resulting from dementia can be disenfranchised for a number of reasons. Often the person with Alzheimer's disease or another form of dementia is devalued. They are seen as old, confused, and a burden. Death may be seen as a release—for both the caregiver and the person who died. Survivors may be expected to have already grieved in the course of the illness and to be relieved about the death. Even the customary statements of sympathy and support may be tinged with ambivalent sentiments like "this is a blessing," or "it must be a great relief." There may be little understanding of the impact of the loss and the depth of grief of survivors. And for persons with Alzheimer's disease or other dementias, grief may also be disenfranchised as they may be perceived as incapable of sustaining grief.

Naturally a wide range of factors that can include the nature of the relationship will affect the nature and extent of grief: the circumstances surrounding the loss, individuals' coping capacities, and grieving styles as well as other social and psychological variables (Worden, 2002; Rando, 1993; Martin & Doka, 1999). Ethnicity and culture certainly play a role. For example, Owen, Goode, and Haley (2001) found that African American caregivers compared with White caregivers were more likely to experience higher levels of grief.

Other research notes that manifestations of grief are different between those who cared for their partners with dementia at home compared to those who placed their spouse within a nursing home. Those who cared for the patient in the home reported exhaustion, stress, anxiety, and anger while spouses of individuals placed within nursing homes indicated higher levels of guilt and sadness (Rudd, Viney, & Presten, 1999; Collins, Liken, Kirz & Kokinakis, 1993).

While many factors may mediate the experience of grief, one fact remains. Grief is a companion to Alzheimer's disease at all phases of the disease and following death. The goal of support, then, is to acknowledge and validate the loss—to enfranchise grief.

ENFRANCHISING GRIEF

In validating grief, it is critical to revisit two points. First, grief is experienced by the person with Alzheimer's or other form of dementia, as well as by family members and professional caregivers. Second, grief is encountered throughout the illness as well as after the death. Assistance and support, then, should be offered to all that are involved throughout the illness and after the death.

For persons with dementia, two considerations are essential in offering support: validation and control. When an individual experiences dementia, there can be a tendency to invalidate that person's emotional expression. Often expressions of anxiety, anger, or other manifestations of grief are discounted and denied. Often this is done to protect the person—to offer glib reassurance that everything is fine even though the individual with dementia is aware and fearful of the manifestations of the disease.

This is unhelpful. Persons in the early stage of dementia have very clear awareness of symptoms of decline. Even later in the progression of the illness, individuals may have vague feelings of loss of capabilities. Empathetic listening, expressions of support, reassurances of remembrance by reaffirming relationships, and when appropriate, physical touch, are ways to validate and show support.

It also is important to respect the affected individual's sense of control. As persons feel abilities slip away, they may be determined to maintain as much control of their environment as possible. In the early phases of the disease, there may be expressions of anticipatory bereavement (Gerser, 1974) or actions where the persons clearly need to plan for impending losses. Individuals may need to finish business—contacting associates, giving instructions and then reviewing or creating advance directives. This too should be supported. However, not every person will choose to confront feelings, or plan for the future. That, too, is a way to cope.

There are a number of strategies that may assist family members as they cope with the loss both prior to and following the death (Doka & Aber, 2002).

PROVIDE EDUCATION ABOUT THE UNDERLYING CONDITION

It is important to assess each family member's perception of the affected individual's underlying condition. Often, the family's understanding of that condition can be faulty. In asking families to describe the underlying cause, counselors can determine whether the client's theories of causation sustain false hopes or unrealistic beliefs (e.g., that the person can control behavior or will get better).

Exploring family members' beliefs gives counselors the opportunity to provide education at each client's level. Counselors should be aware of and suggest resources to families. Associations, self-help groups, and nonprint and print media—particularly books by people who have experienced similar losses—can all be useful in the educational process. Such education not only provides realistic information about the nature and course of the condition, it also enhances a sense of coping and control by allowing family members a meaningful sense of activity and by providing them with opportunities to anticipate and plan for future contingencies.

ASSIST PERSONS IN DEALING WITH THE EMOTIONAL ISSUES RELATED TO LOSS

Often family members feel constrained in recognizing and expressing their emotions. Because the affected person is alive, perhaps living in the same environment, and in some cases defined as not responsible for his or her state, individuals may lack the opportunity for emotional expression, feel personally inhibited from expressing negative emotions, or even face social sanction from friends and relatives who consider such expression disloyal or unfeeling. Moreover family members, especially caregivers, may have considerate emotional issues related to the caregiving experience. They may feel angry and resentful towards the person with dementia or at others who they feel are unsympathetic or unsupportive. They may feel guilty about their ambivalence in caregiving or any feelings of relief and emancipation they might experience at the time of death. Family members may add unnecessary guilt by comparing their reactions to the person with dementia to others. With all of these emotions, counselors can assist by creating a nonjudgmental atmosphere where individuals can express and explore these complicated emotions. In addition to reassurance that such feelings are normal, counselors can offer strategies such as journal writing, ritual, or addressing an empty chair, that assist individuals in acknowledging their emotional needs.

ASSISTING FAMILY MEMBERS IN RECOGNIZING AND RESPONDING TO CHANGES IN THEIR OWN LIVES AND IN THE LIFE OF THE SIGNIFICANT OTHER

When people experience significant loss in their lives, they are likely to find that their lives subsequently change. Thus in dementia, people will often experience many modifications in the daily course of their lives. They may lack the prior companionship; cease to engage in previously enjoyable activities; take on new responsibilities; lose contact with friends or relatives; experience loss of dreams and expectations; and have unmet psychological, social, sexual, and financial needs. After the death, they may experience other changes such as the loss of a meaningful role. These changes can occur so quickly that persons may not realize just how profoundly their own lives have been altered or have the time to develop effective coping strategies. In response, counselors may wish to try several approaches.

First, they may want to review with the individual ways in which life has changed. Often the simple question, "In what ways has your life changed since ____?" can release a flood of responses. Counselors can assist individuals in determining these secondary losses that are most significant and what aspects of loss can be regained (perhaps in a modified way). They can explore responses and strategies for dealing with such losses.

Next, counselors may want to discuss the nature of the family members' support systems. Here family members can consider such issues as assessing the extent and nature of the support system (which may provide strategies for respite and resumption of missed activity), the use of that support system (which may allow further discussion of coping styles and problem-solving abilities), and "surprises" in the support system (e.g., people who individuals were surprised to find were there for them, as well as people who individuals felt were not supportive). This last issue is particularly significant because it may provide further opportunity for the counselor to discuss emotional responses such as anger and resentment and to help persons develop their problem-solving skills and coping strategies. Upon assessment, individuals may recognize that they did not adequately communicate their needs or feelings to others in their support system or that they used others in inappropriate ways. In one case, a woman was very angry that her daughter seemed unable to listen to her complaints about the demands placed on her by her spouse's dementia. Upon reflection, the woman realized that her daughter's strengths were always in active doing rather than passive listening. Once the woman realized that, she modified her expectations of her daughter and found that her daughter was extremely supportive as long as the mother confined her requests to asking for help in active tasks, such as providing rides for her father or doing chores.

Counselors can also assist families in finding additional sources of support, such as self-help groups, day care and respite programs, and, if necessary, institutional care. Often this approach has additional value because it allows clients to reduce stress and to take direct actions that may diminish guilt and reaffirm control. Support groups have been particularly successful for both caregivers as well as persons newly diagnosed with Alzheimer's disease (Wasow & Coons, 1987; Simank & Strickland, 1986; Yale, 1989). These groups can decrease isolation, facilitate grief, and exchange information and resources. But counselors must do more than simply have clients identify needs and sources of support. In some cases, counselors may need to explore resistance and ambivalence toward such support. As Quayhagen and Quayhagen (1988) note, some caregivers may experience considerable guilt over leaving the care of the person to others; and accepting help from formal agencies may no longer allow the defense of denial.

With families, a counselor can explore role problems, dilemmas, and ambiguities. One of the most significant problems of dementia, especially for spouses, is that it creates considerable role strain and generates additional burdens. For example, the spouse may remain legally married but effectively be widowed because the companionship and sexuality that were part of the prior relationship no longer exist. Often in these situations it is helpful for persons to explore the tensions, ambiguities, burdens, and difficulties that accompany the state of crypto widowhood. It is also helpful to explore all possible options because, even if an option is precluded for moral or practical reasons, the very consideration of that option reaffirms a sense of control and reduces the feeling that the future is totally constrained. In one case, a woman whose husband was institutionalized with Alzheimer's disease became involved in a relationship with another man, but she decided at this time she would neither divorce her demented spouse nor cohabit with her new love. Exploring those options, however, allowed her to affirm that she did have some control over events and that the decisions she made now were not necessarily final.

Counselors may wish to discuss the ways in which individuals generally cope with change and the ways in which they are coping with it now. They can help individuals assess which of their strategies are effective (reaffirming and reinforcing such skills) and which are not (providing opportunity to assess and develop better strategies). They may also want to explore current ways in which persons deal with stress and when necessary, teach clients effective stress-reduction techniques. They can explore clients' caregiving role. Clients are often very willing to take on caregiving responsibilities, but they may make decisions that do not adequately take into account their own or the other's role. For example, an individual's decision to quit work to take care of a spouse with Alzheimer's disease may remove him or her from a support system, may eliminate necessary respite, and may create financial problems. One might try to find other ways to resolve the issue. Thus counselors need to assist individuals periodically in assessing their caregiving plans and roles and in reviewing alternative plans. Finally, counselors can legitimize the needs of family members to help them recognize and balance their own needs with the demands of care.

HELPING FAMILIES PLAN REALISTICALLY FOR THE FUTURE

The nature of dementia often encourages an attitude of "one day at a time." In many ways such a perspective is functional. With irreversible syndromes, the future can be dismal. Nevertheless, it is important for individuals to plan for the future. Such planning allows clients a sense of control and permits them to rehearse problem-solving skills, anticipate future issues, and conduct necessary research within sufficient lead-time. In such sessions, it is important for counselors to reaffirm confidence in the individual's abilities, coping skills, and realistic hopes and to allow family members to explore the effects of change in their own sense of self, the sense of others, and their beliefs.

Dementias such as Alzheimer's disease can profoundly alter views of self or others as well as fundamental beliefs about faith and meaning. Individuals may be fearful of their own future—worrying about future dementia. They may question their feelings and beliefs about other family members—perhaps experiencing a profound sense of disappointment in the reactions or support of others.

They may even have troubling memories of the person with dementia—uncovering heretofore-unseen behaviors or attitudes. For example, in one case a woman was clearly discomforted by her mother's reactions to persons of a different race. Prior to dementia, her mother had been a strong supporter of the civil rights movement and had never expressed such attitudes. Such individuals will need space and opportunity to confront their beliefs and reconstruct meaning. Asking questions such as "How does this affect your beliefs about yourself and your family or your beliefs about the world?" can offer a beginning. Assignments in which clients seek out information or enter into discussion with others, including members of their own faith community, can facilitate this process. Tasks such as putting together videotapes or photo albums can reconnect individuals to earlier memories.

In addition to family members, it also is important to offer support to professional caregivers. Since many dementias progress over a long period of time, it is not unusual for nursing home aides, home companions and home-health aides to develop long-standing relationships with family members and the individual with dementia. When that person dies, the aide not only terminates a relationship with the individual but often with the family members as well. Here health aides may lose a position and income. They may need to develop another relationship almost immediately. In cases of advanced dementia, where decisions may have been made to terminate treatment, the aide's perspective may be unasked and unwelcome. Yet, professional caregivers mourn too. Their grief needs to be acknowledged and supported by the agencies that employ them. Empathetic debriefings following an assignment, notes from the family and agency, and policies encouraging participation in rituals offer tangible ways to support staff.

CONCLUSION

Grief is a constant companion to Alzheimer's disease and related dementia. It accompanies the patient and family. It journeys with professional caregivers. It is ever present—throughout the illness and after death.

It does not, however, have to be the only companion. As others—family and friends, counselors, and supportive others—travel together, the journey through grief continues. It is, though, now less lonely and not quite as frightening. ■

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