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# Loss and Grief Among Family Caregivers of Relatives With Dementia

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*This study describes family caregiver perceptions of the experience of loss and grief as it occurs prior to and following the death of a relative with dementia. A content analysis was conducted of responses to open-ended questions by a sample of 82 primary caregivers participating in a longitudinal study who had experienced the death of their relative with dementia. Six themes were identified: loss of person and relationship, loss of hope, predeath grief, expectancy of death, post-death relief, and caregiving reflections. Implications for clinical practice and research are presented.*

Our impetus for conducting this qualitative analysis came from a surprising finding that arose during quantitative analyses for a longitudinal study of family caregivers of relatives with de-

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mentia in the community. The most frequently reported finding in the bereavement literature is that individuals who have lost a relative through death experience increased psychological distress in the first 1 to 2 years following the death (Lattanzi-Licht, Kirshling, & Fleming, 1989; Lund, 1989; Osterweis, Solomon, & Green, 1984). Yet the results of our *quantitative* analyses of the psychological well-being of primary caregivers before and after bereavement suggested that caregivers experienced *improved* well-being during the year following the death of their relative with dementia.

The unrelenting strain and burden on families who care for a relative with dementia in the home have been repeatedly addressed in both professional and lay literature (Mace & Rabins, 1991; Office of Technology Assessment, 1987, 1990; Willoughby & Keating, 1991; Wilson, 1989). Based on these reports and our clinical experiences working with families, we speculated that the grief experience may have unique characteristics for these families because of the nature of the disease course of dementia and the caregiver's experiences while providing intensive home care.

Several authors have investigated aspects of the bereavement experiences of caregivers of relatives with dementia (Austrom & Gendrie, 1990; George & Gwyther, 1984; Malone, Haley, & Fleece, 1985), but conflicting findings exist in the literature regarding bereavement outcomes. For example, George and Gwyther (1984) report improved psychological well-being among bereaved caregivers of individuals with dementia, but Malone et al. (1985) report a decline in psychological well-being among former caregivers. Little systematic attention has been paid to identifying *family* perspectives about aspects of the dementia care situation that influence bereavement. This article describes family caregiver perceptions of the experience of loss

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and grief as it occurs before and after the death of a relative with dementia and begins to explore the relationship between pre-death experiences and postdeath reactions.

### **PERSPECTIVES FROM THE BEREAVEMENT AND CAREGIVING LITERATURE**

Family caregiving and bereavement, often treated as separate events, are, in fact, part of a single, chronic situation (Bass, Bowman, & Noelker, 1991). Some studies have tacitly recognized the relationship between caregiving and bereavement by an examination of the occurrence of anticipatory grief. Anticipatory grief is a psychological response that is initiated by a person's growing awareness of the impending loss of a loved one and the associated losses in the past, present, and future (Rando, 1986). Fulton and Gottesman (1980) speculate that the grief response that occurs in the months preceding the death helps the survivor to resolve aspects of the interpersonal relationship ("unfinished business"), to decrease attachment to the dying person, and to redirect energy to other relationships. Anticipatory grief has come to be regarded as a positive phenomenon because it may enable a person to work through emotional distress prior to the death, thus reducing the emotional impact following the death.

However, research evidence is contradictory regarding the extent to which anticipatory grief occurs and the influence it may exert on postbereavement outcomes. For example, Hill, Thompson, and Gallagher (1988) failed to find a relationship between anticipatory grief and subsequent bereavement outcomes. Other investigators have speculated that anticipatory grief is not simply grief in advance; it is different from postdeath grief in both duration and form and unrelated to postbereavement outcomes (Fulton & Gottesman, 1980).

With few exceptions, neither the bereavement nor the caregiving literature deals directly with how the *illness-specific* char-

acteristics of a relative's illness or other aspects of the caregiving experience preceding a relative's death might influence the bereavement process. In a study of family caregivers of frail elders, Bass et al. (1991) found that caregivers who reported higher caregiving strain and negative consequences of caregiving before the death of a relative also experienced greater strain following their relative's death. In an investigation of caregivers of individuals with dementia, George and Gwyther (1984) found that bereaved caregivers report higher levels of psychological well-being than do caregivers who continue to provide care in the home to a relative with dementia. Although the losses and grief experienced by family members as they care for a relative with dementia before death have been acknowledged (Austrom & Gendrie, 1990), families' perceptions of the relationship between predeath experiences and postdeath reactions have not been examined. The purpose of this analysis is to investigate and describe these experiences systematically.

## METHOD

### Design

As part of a 5-year longitudinal study of 350 individuals caring for a relative with Alzheimer's disease, 82 participants whose relative died during the course of the study were asked to and agreed to continue participation in the research. The mean number of months between the relative's death and the post-bereavement interview was 14 months ( $SD = 6.1$ ).

### Sample

Family caregivers were recruited for the longitudinal study through an extensive mailing distributed by local chapters of the Alzheimer's Disease and Related Disorders Association, the Michigan Association of Adult Day Care Centers, and health care agencies in southwestern Michigan. Caregiver/patient dy-

ads ( $N = 350$ ) in the sample for the larger longitudinal study met the following criteria: (a) The patient was at least 55 years of age and dependent in at least one activity of daily living (ADL), (b) the patient had received a diagnosis of Alzheimer's disease or other progressive dementia, (c) the caregiver was self-identified as the family member providing the most care to the patient with dementia, and (d) the patient was residing in the community at entry into the study. Procedures for obtaining informed consent and assuring confidentiality and anonymity of study participants were approved by the University Committee on the Rights of Human Subjects in Research. Telephone interviews and mailed self-administered questionnaires were used to collect information from participants at three data collection points over the 5-year study period.

Of the 82 caregivers who participated in the postbereavement interview, 70% ( $n = 57$ ) were spouses, 17% ( $n = 14$ ) were adult children or children-in-law, and 13% ( $n = 11$ ) were siblings or other categories of relatives. The mean age of the caregivers in the sample was 66 years ( $SD = 11$  years); 79% of the bereaved caregivers were female. The mean duration of caregiving prior to the relative's death was 5.9 years ( $SD = 4$  years). Forty percent of the relatives died at home, 33.3% died in a hospital, 18.3% died in a nursing home, and 13.4% died in other settings.

### Data Collection

Caregivers who agreed to continue in the research after the death of their relative participated in a telephone interview and completed a self-administered questionnaire. Questions yielding data for the quantitative component of the study focused on social, emotional, and financial changes that the caregivers had experienced since the death of their relative. Caregivers were also asked to respond to three open-ended questions regarding their bereavement experiences. Specifically, participants were asked to describe their experiences since the death of their relative, identify ways in which losing a relative to

dementia was different from losing a relative to another cause of death, and provide any additional information about the death of their relative from Alzheimer's disease.

### Data Analysis

Responses to the open-ended questions were transcribed verbatim, and the accuracy of the transcriptions was verified by a second person. Because the three questions yielded overlapping topics, no differentiation was made between responses to the three questions. Six members of the project staff reviewed the transcripts and formulated coding categories. Four coding categories were identified: predeath losses, responses to predeath experiences, characteristics of the "death event," and postdeath reflections.

Responses coded in the category *predeath losses* included statements of the losses that the caregiver experienced prior to the death of the relative. Responses coded in the category *responses to predeath experiences* included statements made by the participants about their emotional reaction to the losses experienced before the death of their relative. The category *characteristics of the death event* included descriptions of the circumstances of the actual death and statements reflecting emotional responses immediately following the relative's death. Responses coded in the category *postdeath reflections* included statements of emotional reactions after the immediate postdeath period.

Following the development of coding categories, two researchers independently coded the transcripts, and coding discrepancies were reconciled. Coded participant comments were entered on a computerized data base. Following procedures outlined by Miles and Huberman (1984) and Knafl and Webster (1988), themes were identified from the coding categories. The presence and frequency of identified themes was independently verified by three researchers. Illustrative comments for each theme were also extracted from the computerized data base.

## RESULTS

Six themes were identified and verified from the coded transcripts: loss of familiarity and intimacy, loss of hope for recovery, predeath grief, expectancy of death, relief following death, and caregiving perspectives.

### Loss of Familiarity and Intimacy

A prominent theme in caregiver reports of their predeath experiences was the awareness that the dementing illness had taken away the person they had known long before their relative's actual death. Over half (54%) identified specific changes in their relative that led to the sense of loss of familiarity in their relationship with their loved one. Statements such as "He wasn't the Dad I knew when he became violent. I had to keep reminding myself that the disease took away the Dad I once knew" reflected caregivers' sense that they had already lost the person they once knew. Another caregiver said, "The person I knew disappeared even though she was still physically alive."

The dementing illness and the accompanying changes in communication abilities contributed to caregivers' perceptions that they had lost a sense of intimacy in their relationship with their relative. Over one third (35%) pointed to a fundamental alteration in their relationship as a result of changes in communication patterns. References to the patient's inability to provide companionship or engage in reciprocal communication were common. One caregiver commented, "Dad seldom spoke. He didn't know any of us anymore. This is what hurt us the most because it made it seem like I was caring for a stranger." Participants identified these changes in dyadic communication as an important aspect that differentiated the experience of caring for a relative with dementia from caring for a person with another type of illness. One caregiver commented, "There was no way for verbal communication with my mother. Usually other illnesses allow for expression of pain, love, feelings, and thought." Caregivers appeared to feel that the person they were

caring for was like a stranger and that they had lost important aspects of their relationship with their loved one.

### **Loss of Hope**

Of the respondents, 46% reported their awareness during the predeath period of the inevitability of the decline of their relative as a result of the dementing illness. Even after any hope for recovery was lost, families remained intensively involved in providing care as their relative slowly deteriorated over a period of many years. One caregiver told us, "You are watching and watching, wondering what will happen next to take more of the person you love away."

The awareness that no hope of recovery existed was often accompanied by expressions of feelings of helplessness. In the words of one caregiver, "It leaves you with such a feeling of not being able to help them. You see your loved one getting worse and worse, and you can't help them get better at all." Often, expressions of feelings of helplessness were accompanied by specific references to the long duration of the illness. For example, one caregiver said, "We realized he could not have gone on the way he was. He slowly died for 13 years. It is very sad to care for someone you love and not be able to make them better."

### **Grief Before Death**

Nearly half (47%) of the respondents experienced grief repeatedly in response to the losses they encountered in the predeath period. As one caregiver put it, "I did all my grieving before my wife died. Every day I lost a little piece of her." Another caregiver stated, "I experienced grief in stages as the disease progressed and my wife lost parts of her mind," and "you can see the person deteriorate over a long period of time. . . . It is a very emotional thing. . . . It is a different type of disease because you feel the outcome is inevitable. . . . I felt I grieved many times before her death."



Caregivers' manner of portraying the quality of predeath grief was particularly vivid and included such descriptors as "raw," "overwhelming," and "wrenching." In many cases, the experience of predeath grief was colored by the physical and emotional exhaustion that the caregiver felt as a result of the burdens of caring for the relative: 32% mentioned the physical or emotional impact of the final stages of caregiving in describing their experiences of loss and grief. According to one spouse caregiver, "I was stretched physically, emotionally, and spiritually. Caregiving drained me, and I was exhausted." Another caregiver stated, "My wife died many times before her actual death. It took so much out of me. I went through each day wondering when it would all end."

### Expectancy of Death

Comments regarding the expectancy of death were made by 28% of the sample. Three fourths said they expected their relative to die when they did; one fourth stated that the death was unexpected. Feelings of shock and devastation in response to the death were associated with lack of expectancy of the timing of the death. One caregiver noted, "Not more than 6 weeks before his death the doctor had told me that my husband could live for over 10 years with Alzheimer's. I was prepared for this. When his death came so quickly, I was shocked." Another caregiver said, "Death was unexpected in that he was recovering with the treatment in the hospital. I knew there was no cure and death was the end result, but I expected it a year later. The way he died was a shock—I was devastated."

Positive comments ( $n = 18$ ) regarding the circumstances of the relative's death were associated with the expectation that the death was going to occur when it actually did. References to the peacefulness and calmness of the actual death were common and most often associated with the caregiver and other family members being present when the relative died. One caregiver stated, "It was a gentle end to a tremendously chaotic period of emotional and physical pain for all of us."

### Postdeath Relief

The emotional reaction that occurred most frequently in the immediate postdeath period was a feeling of relief, with 51% ( $n = 42$ ) of the sample reporting this reaction. One type of relief that was experienced was relief for the person who had died. For example, one caregiver reported, "I felt bad for the condition she was in. I was upset because she still knew that something was wrong. It was her fear that upset me. It [the death] was a relief." Another said, "It's a feeling of sorrow and still of loss and relief when you know that he is gone because he has suffered enough." A second type of relief was related to cessation of caregiving responsibilities. One caregiver added, "It was quite a relief not having that constant watch and not knowing what the next step will be to conquer. Not knowing what was in store made each new day hard to face. I'm glad it is over." Another caregiver stated, "The death itself was a mixed blessing. I was sorry to lose my wife, but at the same time I felt a great load was lifted."

Last, caregivers reported relief that their relative had died before their own emotional and physical resources were so depleted that nursing home placement was necessary. For example, one caregiver stated, "It was an easy and peaceful passing for him. I know if he had lived for an extended time I would not have cared for him at home. I am thankful I could."

Feeling relief often coexisted with feelings of loneliness and grief. One quarter (25%) of the participants mentioned feelings of loneliness during the postdeath period. However, respondents made a clear distinction between feeling loneliness for the relative as he or she was before death and feeling loneliness for the relative prior to the onset of the dementing illness. One caregiver stated, "I miss him like he was before Alzheimer's disease. I think about him almost every day, but the thoughts are always about when he was young and strong." Another caregiver stated, "You can't wish him back because he wasn't himself, and I could not share with him nor could we do anything together. I am lonely, but only for what might have been."

### Postdeath Reflections

As caregivers reflected about their caregiving experiences, many described lingering doubts about the decisions they had made about their relative's care. Regret was experienced by 23% of the respondents during the postdeath period and was most frequently associated with nursing home placement of the relative prior to death. Comments such as "I feel like he [husband with dementia] will never forgive me and that I'll never forgive myself for putting him in a nursing home" reflect the lingering doubts that caregivers expressed about the decision to institutionalize their relative. Other caregivers, while acknowledging how much they had done to care for their relative, continued to wonder if they could have or should have done more.

As caregivers reviewed their experiences, many identified the importance of their role and the meaning that they found in it. As one caregiver stated, "I'm glad I could care for my husband at home. I feel like I gave better care than he could have gotten anywhere else." One daughter stated, "The whole experience brought me closer to my mother before she died." Another caregiver added, "I learned a lot about myself and found it was a growing experience." According to one caregiver, "I'd do it all over again. It was a warm, loving, and growing experience."

Caregivers were more likely to comment on the meaning of caregiving when they were interviewed later in the bereavement period. Many caregivers appeared to need to synthesize and discuss the total experience of their relative's illness as they moved further in time from the death.

### PREDEATH EXPERIENCES AND POSTDEATH REACTIONS: IS THERE A RELATIONSHIP?

It is interesting to note that when former caregivers were asked about experiences *after* the death of their relative with dementia they frequently contributed information about their caregiving experiences *before* their relative's death. In doing so, caregivers

appeared to implicitly link specific aspects of their prebereavement experiences as a family caregiver to their reactions following the death of their relative.

To begin to investigate the relationship between predeath experiences and postdeath reactions, themes during the predeath and postdeath period were cross-classified. A clear relationship appears to exist between the acknowledgment of predeath losses and grief and the feelings of relief following a relative's death. When caregivers reported both their predeath experiences and postdeath reflections, those who reported a predeath grieving process were more likely to report feelings of relief following the relative's death. However, this relationship did not appear to hold true in situations in which caregivers also reported low levels of support from family and friends during the predeath and postdeath periods. Caregivers who experienced their predeath and postdeath grief in isolation from others did not report feelings of relief and were more likely to report persistent negative emotions during the postbereavement period.

Our beginning analyses of the relationship between predeath experiences and postdeath reactions support the presence of a relationship between aspects of these experiences among dementia caregivers. Illness-specific losses associated with dementia, the grief response that caregivers experience in reaction to these losses, and feelings of relief in the postbereavement period do appear to be linked. Because we did not include specific interview probes regarding social support during the caregiving process, we have limited information on how perceived social support influences this relationship. Although the conclusions we have drawn at this stage in our explorations are tentative, they provide important questions for future research about the grief process in dementia caregivers.

## DISCUSSION

The findings of this study illustrate the complexity and uniqueness of the loss and grief experiences as they occur among

family caregivers of relatives with dementia. The findings of this study support the presence of the phenomenon of predeath losses and responses among *some* dementia caregivers that has been noted by previous investigators (Austrom & Gendrie, 1990; George & Gwyther, 1984; Malone et al., 1985).

Although the predeath grief experienced by dementia caregivers bore some similarity to the concept of anticipatory grief as it has been described in the literature (Fulton & Gottesman, 1980; Hill et al., 1988; Rando, 1986), several differences are worthy of note. A beneficial aspect of anticipatory grief cited frequently in the literature is the opportunity for family members to resolve aspects of their relationship with the dying person (Rando, 1986). This opportunity to "finish unfinished business" was compromised among the caregivers in our sample because the dying person was unable to participate in this process as a result of the dementing illness. Fulton and Gottesman (1980) identify several psychological changes that may accompany anticipatory grief, including a decrease in the sense of attachment to the dying person and a redirection of energy to other relationships. Some participants in this study did report the perception that they were no longer providing care for their relative as they had known them prior to the dementing illness. However, most caregivers maintained a strong emotional attachment to the dying person. The intensity of the care provided to the relative often precluded redirection of energy to other relationships during the lengthy predeath period. The findings of our study suggest the need for further investigation of the extent to which anticipatory grief occurs and the dimensions of grief before death experienced among caregivers of relatives with dementia.

A significant number of caregivers discussed the sense of physical and emotional exhaustion that occurred during the final stages of caregiving for a dying relative. The burdens associated with providing care to a relative with dementia in the home have been frequently mentioned in the caregiving literature. Yet little consideration is given in existing research to the influence of the cumulative physical and emotional exhaustion

experienced by caregivers before the patient's death on their well-being in the immediate postbereavement period. Feelings of emotional and physical exhaustion are likely to place caregivers at great risk for physical and emotional dysfunction as they enter the difficult bereavement period, but this issue is in need of investigation.

Whereas most caregivers were aware that the functional decline and death of their relative with dementia was inevitable, this knowledge did not always translate into a sense that the death was expected *when* and *how* it actually occurred. Some caregivers reported intense feelings of shock related to the actual death. Other caregivers reported positive aspects of the death, most often describing emotional satisfaction about who was present and how the death occurred. As has been reported in the bereavement literature, specific memories of the actual death appeared to be vivid, detailed, and specific.

The emotion most frequently experienced in the postdeath period was a feeling of relief related to the cessation of the care burdens. Comments about relief were often intermingled with those of feeling loneliness and sadness following the death of a loved one. The intermingling of positive and negative feelings during bereavement has been noted by other investigators (Wortman & Silver, 1987), but our knowledge of the theme of relief as described in this article can be expanded by further investigation.

The loneliness for the lost loved one that participants reported feeling appeared to be most often related to feelings of loneliness for the person as he or she had been prior to the dementing illness. Participants appeared to have the need to consolidate their memories of the relationship with their loved one before this relationship was altered dramatically by the dementing illness. Many respondents spontaneously told us of their lingering doubts about the care they had provided or mentioned the positive aspects of the caregiving experience. These positive and negative statements rarely occurred simultaneously in a single caregiver. Caregiver reflections appeared to be either largely positive or largely negative as they consid-

ered their caregiving experiences. Despite the fact that the death of their relative had often occurred more than a year preceding the research interview, when caregivers offered negative responses, they described them with notable intensity.

The dying process is the final stage of caregiving for families who provide intensive care over a lengthy period of time for a relative with dementia. The results of this study support the importance of further investigation of how illness-specific experiences of caregivers prior to a relative's death influence their perception of death, their immediate reactions to death, and the perspective they develop over time about the caregiving experience.

### Practice and Research Implications

Based on the findings of our study, it is evident that family caregivers of a relative with dementia experience grief and loss issues that may differ from those of family caregivers of a relative with a different type of disease. Several implications for clinical practice can be derived from the findings of our study.

First, the multiple losses experienced by families prior to the death of a relative with dementia should be acknowledged by health care professionals working with these families. One of the most painful losses for such families is a direct result of the inability of their relative with dementia to engage in reciprocal communication. The opportunity afforded to many families of terminally ill individuals to review their relationship, resolve remaining conflicts, and say a final good-bye to a loved one is altered among families of relatives with dementia. In lieu of being able to discuss these issues with the dying relative, caregivers may benefit from encouragement to discuss "unfinished business" with a health care professional. The presence of grief responses before bereavement is also worthy of note. The combination of multiple losses and grief responses found in this sample suggest that bereavement counseling may be more appropriately initiated *before* the actual death.

Second, the fact that a number of the participants in our study did not expect the death of their relative to occur when it did has implications for clinical interventions with families during the final stage of caregiving. Health care professionals may assume that families know how the actual death will occur and recognize the signs of impending death. Because the duration of dementing diseases varies greatly, caregivers may expect their relative to live for many years. When working with caregivers before the death of their relative, it is important to teach families about the disease process, including the fact that death from an acute illness may occur at any time.

Third, even a year after their relative's death, caregivers continued to have a great need to discuss the experience of losing a relative to dementia and to gain a perspective on it. One caregiver's letter to our research staff illustrates the need for caregivers to share their experiences:

Thank you for allowing me to partake in this study. While my husband was alive, our friends avoided us. After he died, they still stayed away. The only time I was asked how I felt was when I was interviewed for your study. *Thank you* for asking—it helped me to sort things out.

As the caregivers in our sample reviewed their caregiving experience, feelings of relief were intermingled with feelings of loss and loneliness. Clinicians who focus only on the relief experienced by the primary caregiver may fail to support the grief process that also is occurring.

Even years after the death of a relative with dementia, former caregivers may still be attempting to develop a retrospective understanding of their caregiving experiences. Caregivers who continue to experience feelings of guilt and regret about their caregiving experiences may benefit from the opportunity to discuss these responses with the professionals who were involved in the care of their dying relative.

In this research, we identified six frequently occurring themes among families who have lost a relative as a result of a dementing illness. Although themes existed, there was no "typical"



grief experience among the individuals in our sample. Health care professionals must listen carefully to the unique aspects of the experience of each family caregiver in order to plan appropriate interventions.

In conclusion, there is a need for further research regarding how specific illnesses and social support affect prebereavement reactions and postbereavement outcomes. Our exploration of the common themes that emerged when dementia caregivers were asked to discuss their experiences may help health care professionals to better understand the responses of families during the final stages of caregiving.

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