

A Comprehensive, Stage-Sensitive Model of Grief in Dementia Caregiving

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Purpose: Grief is an overlooked but important element of the caregiver experience. This study defines a model of caregiver grief to aid in clinical intervention and to support further research. **Design and Methods:** This study addressed the grief responses of 87 spouse and adult-child caregivers of patients with progressive dementia representing mild, moderate, severe, and postdeath. Questionnaire data and qualitative findings from 16 semi-structured focus group interviews provide the basis for a descriptive model of anticipatory grief in dementia caregiving. **Results:** Significant differences emerged between spouse and adult-child caregiver groups as a whole and as a function of Clinical Dementia Rating impairment level. Caregiver grief was found to fluctuate between intellectual, affective, and existential poles depending upon current care demands and expectations. **Implications:** These findings suggest that anticipatory grief in dementia caregiving is "real" grief, equivalent in intensity and breadth to death-related grief.

Key Words: Alzheimer's disease, Anticipatory grief, Caregiver stress

Grief is a universal human experience—we all suffer losses and feel the anguish that follows. While it may be true that grief finds its full definition in response to death, significant grief reactions emerge in response to other losses as well. Bearing witness, for

example, to the gradual "death" of a loved one's memory and personal identity from Alzheimer's disease (AD) brings a unique form of grief associated with present and anticipated losses prior to bodily death. For all too many caregivers, the burden of this grief is carried alone without meaningful social recognition or support (Doka, 2000).

Although much is known about grief in response to death (Archer, 1999; Meuser & Marwit, 2000; Stroebe, Stroebe, & Hansson, 1993; Weiss, 2001), relatively little has been written about grief associated with progressive cognitive decline, as in AD. It has been suggested that anticipatory grief, if experienced openly and adaptively, can reduce the later burden of grief when a loved one dies. In other words, the "grief work" may be accomplished during the illness phase and be largely resolved when bodily death occurs. Research findings are at best mixed on this hypothesis (Rando, 2000). In the case of cancer, where cognitive functions usually remain intact, caregivers and patients have an opportunity to discuss the impending death and offer mutual support. It makes sense that such processing might foster adaptive resolution of grief. In the case of dementia, however, cognitive decline makes it difficult, if not impossible, for patients and caregivers to grieve together. The issue of anticipatory grief with dementia is largely unexplored.

The first significant reference to grief in the AD literature can be found in the caregiver handbook *The 36-Hour Day*: "Grief associated with a death may be an overwhelming experience in the beginning, and gradually lessen. Grief associated with a chronic illness seems to go on and on" (Mace & Rabins, 1981, p. 164.). In a November 1982 address to the Academy of Psychosomatic Medicine, Dr. Rabins added: "In the course of a dementing illness, the patient's family will experience a variety of emotions that vary over time. We conceptualize the process through which many families go as one of chronic grief" (Rabins, 1984, p. 374).

Since then, only a handful of studies have examined this topic to varying degrees. In an early interview-based study of caregivers, Wasow and Coons (1987) uncovered a wide range of grief and loss responses that defied simple categorization: "All that can be said for sure is that the coping mechanisms

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for survival seem as infinite as the number of respondents" (p. 29). Their one consistent finding was the traumatic nature of nursing home placement for caregivers in their sample (which fostered feelings of guilt, regret, frustration, etc.).

Hundreds of studies on caregiver burden, depression, stress, and coping have appeared in the literature since the early 1980s. Surprisingly few of these studies discuss grief to any significant extent. In 1991, Carol Farran and colleagues challenged researchers to look beyond a stress-coping paradigm and consider how personal suffering may influence caregiver outcomes (Farran, Keane-Hagerty, Sallo-way, Kupferer, & Wilken, 1991). They interviewed 94 caregivers about their losses, regrets, and attitudes. Frequency counts revealed that grief reactions were commonly reported: loss of relationship (reported by 52% of their sample), mourning losses (42%), changing communication with the care receiver (32%), loss of freedom (31%), loss of future plans (30%), and observing care receiver's loss of mental capabilities (29%). Similarly, Bowd and Loos (1996), in a study of 68 dementia caregivers, showed that "difficulty dealing with grief" ranked 10th of 30 care-related issues. Later, when Loos and Bowd (1997) asked caregivers to list the range of losses they faced, four grief-related themes emerged: loss of social and recreational interaction, loss of control over life events, loss of well-being, and loss of occupation. Pomeroy and colleagues noted that grief is a "universal response" to the devastating losses that emerge during dementia progression (Walker & Pomeroy, 1996, 1997; Walker, Pomeroy, McNeil, & Franklin, 1994). Data derived from administering the Beck Depression Inventory to both caregiver and depressed samples suggest that caregiver grief is qualitatively different from typical depression (Walker & Pomeroy, 1996).

A few studies have attempted to look at caregiver grief at different points in the progression of the disease. One study of 60 spousal caregivers (Rudd, Viney, & Preston, 1999) examined differential reactions for men and women. According to this study, caregivers who had already placed their loved one in a nursing home showed more sadness and guilt feelings than their home-care counterparts. The balance was the opposite for anger. Female spouse caregivers reported higher levels of anxiety, sadness, and anger than their male counterparts, suggesting a possible gender difference in caregiver grief responses. Bass, Bowman, and Noelker (1991) examined pre- and postdeath factors in grief among AD caregivers. They found that predeath appraisal of care quality (e.g., Mom is getting good/bad care overall) was inversely related to emotional distress after the death. In other words, a positive view of the care provided to a loved one with dementia may enhance grief-related adjustment later when this person dies. Mullan (1992) found additional evidence that predeath experience can have an impact on postdeath adjustment: "The sense of loss caregivers experienced while still providing care significantly af-

fected bereavement adaptation. Those who experienced more loss before the death were less distressed after the death: they were less depressed and had a greater sense of mastery" (p. 680). These findings suggest that benefits may accrue from anticipatory grieving.

Ponder and Pomeroy (1996) propose that there may even be a certain flow to grief over time during the caregiving experience. They administered the nondeath loss version of the Grief Experience Inventory (GEI) and their own Stage of Grief Inventory (SGI) to a mixed sample of 83 spouse and adult-child caregivers. They suggest that caregiver grief may flow over time in accordance with dementia progression: Denial → Over-involvement → Anger → Guilt → Acceptance. Viewing grief level (measured by the Despair Scale of the GEI) as a function of time since dementia diagnosis, they report a fluctuating course: high grief intensity through the first 2 years of caregiving, a drop in years 3–4, followed then by a rebound in year 5 and beyond. They interpreted this pattern and other findings to indicate a lack of acceptance and resolution of grief after many years of caregiving. Active grieving over time in the care experience may not ameliorate the burden of grief later on. This contradicts the beneficial anticipatory grief findings of Bass and colleagues (1991) and Mullan (1992).

Gilhooly and colleagues reported a linkage between anticipatory grief and social death (i.e., the point where the dementia patient no longer has a meaningful interpersonal identity). "The most interesting factor . . . comprised the caregiver's beliefs that it was as if in some ways their dementing relative was already dead, that their actual death would come as a blessing . . ." (Gilhooly, Sweeting, Whit-tick, & McKee, 1994, p. 36). For some caregivers, grieving losses during dementia progression may be more significant than postdeath grieving.

From these studies, a picture of grief in AD caregiving is beginning to emerge, although it is still quite fuzzy. No studies to date have examined the differential impact of grief on the two main types of caregivers (i.e., spouse vs child), and only one study (Ponder & Pomeroy, 1996) has looked at the fluctuations that occur over the course of dementia progression from diagnosis to death. Rigorous efforts to measure dementia-related grief and provide appropriate support to caregivers (and AD patients themselves) are sorely lacking.

The current study attempted to fill these gaps by systematically investigating the grief responses of spouse and adult-child caregivers of dementia patients (mostly AD) in mild, moderate, severe, and deceased stages. The primary research questions address (a) the key characteristics of caregiver grief (e.g., denial, sadness) at each stage of dementia progression from mild to postdeath; (b) the differences and similarities between spouse and adult-child caregivers; and (c) the buffering effects, if any, of anticipatory grief. It was hypothesized that spouse and adult-child caregivers would demonstrate distinctly

different patterns of grief over the course of dementia progression. Given that this was an exploratory study, the nature of these differences was not specified. The objective was to develop a stage-sensitive, caregiver-specific descriptive model of grief that could serve as a basis for developing a psychometric instrument to measure the full range of dementia caregiver grief responses.

Method

Participants

Participants were recruited through the St. Louis Chapter of the Alzheimer's Association, the Memory and Aging Project (MAP) at Washington University's School of Medicine (the clinical research arm of the Alzheimer's Disease Research Center [ADRC]), and by word of mouth. Of the 121 caregivers who initially expressed interest in the study, 87 completed the focus group phase (35 from MAP and 52 community volunteers). The remainder either dropped out (changing care schedules was a common reason) or asked to be included in the second phase of the study that could be completed at home. Forty-two spouse and 45 adult-child caregivers for dementia patients were assigned to one of 16 focus groups (8 for spouses, 8 for adult-children). Groups ranged in size from 2 to 9 participants, with 14 of the groups having 5 or more members. Demographic and care-related characteristics of spouse and adult-child caregivers are presented in Table 1.

Procedure

Participants were mailed a questionnaire packet consisting of a face sheet describing the study, an availability checklist for scheduling, and a Group Assignment Questionnaire (GAQ). The GAQ asked about demographic characteristics of the respondent and characteristics of the care situation (e.g., percentage of care provided). The GAQ also included the informant interview portion of the Clinical Dementia Rating interview (CDR; Berg, 1988; Hughes, Berg, Danziger, Cohen, & Martin, 1982; Morris, 1993), a semistructured interview that helps a clinician determine a dementia patient's cognitive-functional impairment status (0 = normal, 0.5 = very mild, 1 = mild, 2 = moderate, 3 = severe). The CDR measures six cognitive-functional domains (memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal affairs). Scoring rules allow the clinician to determine specific domain scores and an overall functional impairment rating (Morris, 1993). The assessing clinicians use their best judgment to arrive at CDR ratings. At the ADRC, where both patient and informant data are obtained, clinicians usually favor the family informant information unless clearly erroneous.

Caregiver type and the CDR overall ratings (derived via a standard algorithm of the 6 domain scores) were used to determine focus group assignment. There were eight adult-child groups, two for

each CDR level (1, 2, 3) and two for postdeath participants ($n = 45$). There were also eight spouse caregiver groups following the same pattern ($n = 42$). For subjects recruited through the ADRC ($n = 35$), patient/informant-based CDR scores from clinical assessments were available and utilized for these assignments. For subjects recruited from the community ($n = 52$), informant responses to the CDR interview (administered in questionnaire form) were utilized. Mean comparison of CDR ratings for each group (patient/informant and informant only) showed no statistical difference. This differential utilization of the CDR is consistent with ADRC clinician emphasis on informant data, as noted above.

The packet also included the Anticipatory Grief Scale (AGS; Theut, Jordan, Ross, & Deutsch, 1991) and the Many Faces of Grief Questionnaire (MFG; designed for this study). The AGS is composed of 27 grief-related items responded to on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Three items were excluded due to lack of face validity and unclear direction for scoring (e.g., "I feel close to my relative who has dementia"). The AGS was originally validated on a sample of 27 female spouse caregivers of dementia patients ($\alpha = 0.84$; present sample: $M = 61$, $SD = 13$, $\alpha = 0.84$). The MFG is a checklist of 51 symptoms and reactions commonly reported in the grief literature grouped by subheadings of Emotions (e.g., sadness, anger, longing for what was), Cognitions (e.g., disbelief, denial, negativity), Physical (e.g., lack of energy, weight gain/loss, sleeping too little/too much), Spirituality (e.g., questioning meaning of life, loss of faith, turning toward prayer/God), and Social (e.g., loneliness, feeling alienated, jealous of others without problems). Participants were asked to consider the presence or absence of each symptom in their current life (past 3 months only) and respond on a 7-point Likert scale ranging from 1 (not at all) to 7 (very much). Total points for all items served as the final MFG score for grief analysis (present sample: $M = 142$, $SD = 52$, $\alpha = 0.93$).

Focus Groups.—Focus groups were conducted on the premises of the ADRC at Washington University in St. Louis. There were two groups for each caregiver type (Spouse, Adult-Child) at each CDR stage (very mild–mild combined [CDR = 0.5–1], moderate [CDR = 2], and severe [CDR = 3]) and also postdeath (Deceased). All groups were 2 hours in length; they were videotaped with the exception of the Spouse CDR 3b group, which was lost as a result of camera failure. Fortunately this was our smallest group, having just two members.

Both investigators led each group and employed a semistructured interview that progressed through the following six areas: (1) Tell us something about yourself—your family, work, and interests; (2) What was your parent/spouse like before he or she became ill with dementia—work, interests, role in your life? (3) What were your reactions to the early recognition of dementia (to early cognitive changes, to the diag-

Table 1. Characteristics of Focus Group Sample (N = 87)

Group Statistic	<i>n</i> (%) or <i>M</i> (<i>SD</i>)
Adult-Child Caregivers—Demographics (<i>n</i> = 45)	
Age, <i>M</i> (<i>SD</i>)	51.6 (9.6)
Gender	
Men	3 (7)
Women	42 (93)
Marital Status	
Married	30 (67)
Single	8 (18)
Divorced	5 (11)
Missing data	2 (4)
Race	
Caucasian	40 (89)
African American	3 (7)
Asian	1 (2)
Education, <i>M</i> (<i>SD</i>)	16 years (3)
Religion	
Protestant	22 (49)
Catholic	12 (27)
Jewish	4 (9)
Other	5 (11)
Missing data	2 (4)
Adult-Child Caregivers—Features of Care	
Caring/cared for	
Mother	38 (86)
Father	4 (9)
Mother-in-law	1 (2)
Grandmother	2 (3) ^a
Status	
Current	35 (78)
Former	10 (22)
Percentage of Care (<i>SD</i>)	75% (27)
Dementia	
Alzheimer's disease	36 (84)
Vascular dementia	4 (9)
Other dementia	3 (7)
Missing data	2 (4)
Years Since Diagnosis, <i>M</i> (<i>SD</i>)	5.8 years (3.6)
Hospice used? (5 missing values)	
Yes	5
No	3
Spouse Caregivers—Demographics (<i>n</i> = 42)	
Age, <i>M</i> (<i>SD</i>)	71.8 (9)
Gender	
Men	17 (40)
Women	25 (60)
Marital Status	
Married	30 (71)
Widowed	11 (26)
Divorced	1 (3)
Race	
Caucasian	39 (93)
African American	3 (7)
Education, <i>M</i> (<i>SD</i>)	14 years (3.4)
Religion	
Protestant	17 (43)
Catholic	13 (33)
Jewish	5 (12)
Other	5 (12)
Missing data	2 (5)

(Table continues)

Table 1. Characteristics of Focus Group Sample (N = 87)
(Continued)

Group Statistic	<i>n</i> (%) or <i>M</i> (<i>SD</i>)
Spouse Caregivers—Features of Care	
Caring/cared for	
Husband	25 (60)
Wife	17 (40)
Status	
Current	32 (71)
Former	13 (29)
Percentage of Care (mean)	95% (<i>SD</i> = 11)
Dementia	
Alzheimer's disease	40 (95)
Vascular dementia	1 (2)
Other dementia	1 (2)
Years Since Diagnosis	6.3 years (<i>SD</i> = 3.7)
Hospice used?	
Yes	4
No	6

^aIn both instances, the participant reported being raised by the grandmother as the primary parent.

nosis)? (4) How has your life changed as a result of caregiving? What have been the major losses? (5) Would you characterize your experience as a grief experience? How have your grief reactions changed over time? and (6) What do you expect will be (or has been) the impact of early grieving on later adjustment to death?

A relatively fixed time frame was managed for each area of questioning. All groups ended with a debriefing and with a request for permission to possibly contact members in the future to collect longitudinal data. Participants were paid \$50 for their involvement in the focus group process.

Data Analysis.—Quantitative and qualitative analyses were employed. Quantitative analyses included descriptive statistics, mean difference comparisons (*t* tests, chi-square), and correlations. Qualitative analyses were conducted with the assistance of a panel of 11 health professionals (2 psychologists, 4 social workers, 2 nurses, 2 hospice/pastoral care workers, and 1 health administrator) and 3 undergraduate psychology students trained by the investigators. Members of this panel were divided into teams to review tapes and to provide descriptive narratives of each of the 15 available videotapes utilizing an outline similar to that in the Appendix, which presents a shortened version. Each rater viewed up to three videotaped sessions. At least three independent ratings were obtained for each Caregiver Type × Stage subset (Spouse—CDR 1, 2, 3, Deceased; Adult-Child—CDR 1, 2, 3, Deceased).

Major consistent themes and illustrative comments from these raters' narratives were compiled by the investigators and used to develop a summary narrative for each subset. The summary narratives for Spouse and Adult-Child CDR 1, 2, and 3 form the basis for a descriptive model of grief over the course

of AD; the summary narratives for Spouse and Adult-Child Deceased (D) provide the basis for assessing the impact of anticipatory grief (i.e., does prior grieving influence postdeath reactions?).

Results

Quantitative

The GAQ and other measures were administered primarily to aid in focus group assignment. Some of the quantitative findings from this effort are interesting and potentially meaningful, but small sample sizes may limit their validity and generalizability.

Means comparisons between adult-child and spouse caregivers (all levels of dementia combined) showed significant, but understandable, differences in age (spouse > adult-child), education (adult-child > spouse), and % of care provided (spouse > adult-child). Spouse and adult-child caregivers demonstrated similar levels of reported grief, CDR impairment, and disease-related scores.

Although spouse and adult-child caregivers achieved similar total scores on the MFG, mean comparisons on individual items revealed some statistically significant differences in grief emphasis. Child caregivers had significantly higher scores on jealousy of others, negativity, loss of interest in usual activities, and questioning the meaning of life. In contrast, spouse caregivers showed greater loneliness and loss of sexual intimacy. These differences largely make sense in light of potential life stage and social network differences between the spouse and adult-child groups.

Correlation data are presented for the combined sample and for each caregiver subgroup (see Tables 2A, B, and C). Of interest are significant negative correlations in all three tables between MFG scores and years since dementia diagnosis ($-0.45, p < .01$) and sum of CDR box scores ($-0.40, p < .01$), suggesting that overall grief level declines over dementia progression. In contrast, the AGS, for the combined sample, correlates inversely with years since diagnosis but not with CDR box scores, and does not correlate at all with either specific caregiver type.

Qualitative Findings—Grief Narratives of Active Caregivers

Analysis of focus group discussions proceeded from raw data (the videotaped sessions) to individual summary narratives by multiple independent raters to combined summary narratives focusing on prominent (repetitive) themes for each caregiver type at each CDR stage of dementia progression. What follows are abbreviated combined summary narratives for active caregivers, starting with adult-child CDR stages 1, 2, and 3, and followed by spouse CDR levels 1, 2, and 3. See the heading for each narrative below for the number of subjects interviewed for that stage. Table 3 captures and visually compares the essential elements of these six narratives which encompass the caregiver experience from mild to severe stages.

Adult-Child Caregiver (CDR 1, Mild, n = 10).—The grief experience of this caregiver group can be characterized as an approach–avoidance conflict. On one hand, these adult-children acknowledge their relatively new status as caregivers, and do so primarily by seeking information and making concrete care-related decisions. On the other hand, they noticeably avoid discussing the current and future emotional devastation facing both themselves and their parent. They tend to remain intellectualized, task-oriented, focused exclusively on their parent’s competencies and strengths, and appear to avoid talking about emotions. In addition, they tend to underestimate the burden that lies ahead. They share, somewhat abstractly, their wish for their parent to die soon, but they avoid talking about the inevitable trials and tribulations between now and that time. The “underestimation” or “minimization” of change is manifest in seemingly casual or “lighthearted” discussion of the transformations taking place. Yet, when directly confronted, they can acknowledge elements of grief such as fear, helplessness, hopelessness, anger, and jealousy of other more fortunate adult children of healthy parents or of parents with less disabling diseases; also they will describe initial feelings of burden such as loss of personal freedom and having to put future plans on hold. Grief is not expressed when talking about the parent who “is,” but emerges when asked to describe the parent who “was.” It is then that the contrast of trying to retain an image of the good and competent parent along with the sadness of the disappearing parent becomes prominent, and again exemplifies the approach–avoidance so characteristic of this phase.

The overall sense is that this group is beginning to experience grief but is struggling hard to contain it. They attribute the disease to “aging,” “life phase,” or being part of some other condition, such as depression. For the most part, this group stays present-oriented and positively focused. One gets the impression that they are scared, on the verge of emotional devastation, but still well defended. Their approach–avoidance conflict is manifest in the struggle between acknowledging the devastating emotional reality of their situation and denying the same.

Also discussed was the ripple effect throughout the adult-child’s own family. For a few, the parent’s early decline has brought relationships closer, but for most, it has produced conflict and feelings of abandonment (especially by siblings), resulting in what one member referred to as “double grieving.” These feelings were related mostly with sadness and disappointment, not anger. It appears that emphasizing issues in the extended family facilitates denial by providing a focus for intense feelings that might otherwise be expressed toward the parent.

Adult-Child (CDR 2, Moderate, n = 12).—For Adult-Child CDR 2 caregivers, the defensive denial of stage 1 gives way to a powerful recognition of personal loss and the inevitability of parental decline. The true impact of AD can no longer be avoided as care de-

Table 2A. Intercorrelations Among Key Variables for All Subjects Combined (N = 54–98)^a

	Age	Education	% of Care	Years Since Diagnosis	Years Since Death ^b	Sum of CDR Box Scores	Anticipatory Grief	Many Faces of Grief Total
Age		-.285**	.377**	.128	.015	-.026	.145	.076
Education			-.113	-.046	.035	.088	-.041	-.151
% of Care				-.096	-.345	-.087	.197	.170
Years Since Diagnosis					.372	.569**	-.276*	-.449**
Years Since Death						-.341	—	-.478
Sum of CDR Box Scores							.039	-.395**
Anticipatory Grief								.799**
Many Faces of Grief Total								

Note: CDR = Clinical Dementia Rating.

^aSpouse and adult-child caregivers, all CDR levels plus the deceased groups, including available data from dropouts. Some participants did not fill out all items on the group assignment questionnaire.

^bSample sizes for caregivers who had lost their loved one to death range here from 13–22.

* $p < .05$; ** $p < .01$.

Table 2B. Intercorrelations Among Key Variables for Adult-Child Caregivers Only (N = 24–47)^a

	Age	Education	% of Care	Years Since Diagnosis	Sum of CDR Box Scores	Anticipatory Grief	Many Faces of Grief Total
Age		-.132	.125	.216	.114	.021	.052
Education			-.002	-.068	.168	-.075	-.084
% of Care				.21	.87	.221	.167
Years Since Diagnosis					.567**	-.293	-.416*
Sum of CDR Box Scores						-.192	-.395**
Anticipatory Grief							.861**
Many Faces of Grief Total							

Note: CDR = Clinical Dementia Rating.

^aTable includes correlational data for all adult-child caregivers (CDR 1–3 and deceased), including dropouts.

* $p < .05$; ** $p < .01$.

Table 2C. Intercorrelations Among Key Variables for Spouse Caregivers Only (N = 16–48)^a

	Age	Education	% of Care	Years Since Diagnosis	Sum of CDR Box Scores	Anticipatory Grief	Many Faces of Grief Total
Age		-.111	.069	.119	.070	-.217	-.091
Education			-.046	-.008	-.020	.292	-.177
% of Care				-.400**	-.310*	.071	.164
Years Since Diagnosis					.573**	-.283	-.467*
Sum of CDR Box Scores						.299	-.340
Anticipatory Grief							.775**
Many Faces of Grief Total							

Note: CDR = Clinical Dementia Rating.

^aTable includes correlational data for all spouse caregivers (CDR 1–3 and deceased), including dropouts.

* $p < .05$; ** $p < .01$.

mands mount. Feelings are quite raw at this stage, with frustration and anger leading the way and guilt not far behind. Grief is focused largely on what the caregiver has lost. Said one distraught woman: “I was forced in one day to quit my job and go get her. I’m grieving more for myself and the loss of my life. I’m 43 years old and I can’t leave my house.”

Caregivers at this stage take on a certain “siege” mentality and escapist thoughts begin to emerge (“if only I could get away”). Tremendous energy is focused on just making it through the day with little cognitive reserves available for instrumental coping.

This stage may represent a peak in anger and frustration for adult-child caregivers. Anger is directed at the disease process, at personal losses, and, for some, at their demented parent. Although established parent-child patterns may continue at this stage, any pretense of normality disintegrates into talk of failure and frustration. A palpable fatalism and pining sadness appears to set in.

By Stage 2, longstanding parent-child roles become reversed, and adult-children are making important life decisions for their demented parents. Nursing home placement emerges spontaneously as a

Table 3. Grief Characteristics by Caregiver Type and Clinical Dementia Rating Stage

<p>Adult-Child Caregivers (CDR = 1, Mild)</p> <ul style="list-style-type: none"> Denial and avoidance Refusal to acknowledge future implication Focus exclusively on present Very task-oriented and intellectualized Emphasis on maintaining current competencies Avoidance of loss-related discussion unless pushed Losses are self-focused (e.g., loss of personal freedom) Minimization/Avoidance of feelings Struggle to contain all grief Predominant Feelings <ul style="list-style-type: none"> Surface—None Underlying—Fear, helplessness, anger, jealousy Holding onto the present Little manifest grief No talk of nursing home placement <p>Adult-Child Caregivers (CDR = 2, Moderate)</p> <ul style="list-style-type: none"> Rapid transition to reality of care Burden greater than expected Emotions are raw <ul style="list-style-type: none"> Predominant—Frustration, anger (at peak) Secondary—Guilt, wishing parent would die, fatalism, pining, sadness for what was Grief focused on self Efforts to maintain normalcy have vanished Loss focused on other (parent) Beginning to talk of nursing home placement—reluctance and dread Anticipatory grief—expectation of continued grief with some relief after death of parent New emotion: Fear of genetic transmission <p>Adult-Child Caregivers (CDR = 3, Severe)</p> <ul style="list-style-type: none"> Burden lifted primarily by nursing home placement Nursing home stops being a major theme New theme of interpersonal regret Losses: Lost relationship, lost opportunities Emotional shift from earlier stages—raw to reflective <ul style="list-style-type: none"> Predominant—Sadness, longing, loneliness, resignation, finalized loss Secondary—Anger, frustration Focus on other and conjoint (lost parent, opportunities) Nursing home placement produces: <ul style="list-style-type: none"> Initial feelings of turmoil and guilt Secondary feelings of relief Broadened philosophical perspective Grief expressed as being at an apex—additive across time to this stage Anticipatory grief—expectation that death will bring relief 	<p>Spouse Caregivers (CDR = 1, Mild)</p> <ul style="list-style-type: none"> Lack of denial and avoidance Reality oriented with regard to future Focus on present but projects into the future Acceptance of current competencies and changes Recognition and acknowledgment of losses Losses conjoint-focused (e.g., loss of companionship) Openly sad Openly experiencing grief Predominant feelings: <ul style="list-style-type: none"> Sadness Little resentment, jealousy, or fear Allowance for slippage in future Anticipation of escalation in grief Talk of avoidance of nursing home placement <p>Spouse Caregivers (CDR = 2, Moderate)</p> <ul style="list-style-type: none"> Smooth transition to reality of care Increasing burden accepted with dignity and responsibility Emotions are deeply felt but not raw <ul style="list-style-type: none"> Predominant—Sadness Secondary—Compassion, empathy, mild frustration Grief focus on the other Maintaining the relationship becomes important Normalcy vanished early on Loss focused on self—aloneness Thought of nursing home placement brings increased sense of loss, grief and guilt Anticipatory grief—belief that grief is at an apex and death will bring relief <p>Spouse Caregivers (CDR = 3, Severe)</p> <ul style="list-style-type: none"> Burden of care eased by nursing home placement New burden of caring for self Losses: Identity as member of a couple, distance from family and friends Increase in emotional intensity and rawness <ul style="list-style-type: none"> Predominant—Uncertainty about future, confusion, frustration, aloneness Secondary—Anger about situation and noncaring others Focus of self—Building a new, single identity Nursing home placement produces: <ul style="list-style-type: none"> Initial feelings of relief Secondary feelings on concern for self Grief expressed as both bitterness and sadness Anticipatory grief—less sure that death will bring relief
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focus of discussion. A few caregivers reluctantly acknowledged looking forward to placement as a release from excessive burdens of care; still others expressed a wish that their parent would die before or soon after placement so as not to suffer a slow, agonizing death. As might be expected, these reactions are accompanied by intense feelings of guilt.

Thinking about the future did not come easily for this group of caregivers. Many were still grappling with the harsh reality that they can't win in the face of this disease. Worry concerning potential genetic transmission to themselves and their children was a major underlying theme for many in our Adult-Child CDR 2 groups.

When asked to consider how they might react when their parent dies, most anticipated that they would feel relieved (i.e., that suffering would cease for both themselves and their parent). Yet, they anticipated that this would be replaced by the pain of "feeling like an orphan." Separation from the preceding generation is a fact of life for all of us, yet for dementia caregivers this experience appears especially acute due to the intense care-providing requirements preceding death.

Adult-Child (CDR 3, Severe, n = 13).—At Stage 3, adult-child caregiver discussions are marked by a

very different quality of grief than either of the first two stages. It may be best characterized as a true “grief of the soul.” With these individuals, the anger of stage 2 is replaced by a deep sadness for that which can never be again. The predominant theme is the final and absolute loss of the parent as a parent. Unlike earlier stages, where loss is accompanied by frustration and jealousy for others, now it is accompanied by sadness and resignation. One gets the sense that this is not loss in the making, but loss that has been finalized. Associated with this are expressions of helplessness surrounding the fact that there is nothing that anyone can do anymore.

Members talk about grief escalating across stages and being at its highest point early in Stage 3. They describe “markers,” “defining moments,” and “turning points” in their grief (including nursing home placement) as being “additive” in the sense that each experienced loss compounds all previous losses. Yet, while grief escalates linearly into Stage 3, they also speak of a diminution of grief with prolonged time in Stage 3, as if there is eventually an accommodation made to that which cannot be changed.

What is noteworthy at this stage is that grief is now associated with lost opportunities and with regrets over not having maximized experiences while the parent was psychosocially “alive.” They talk about their appreciation for their parent as coming too late; that they wish they had been more connected, more tolerant, and such, before their parent developed AD; that they had given their parent more attention and credibility; and that they knew then what they know now. The focus is more on these interpersonal regrets than on those intrapersonal burdens that dominated Stage 2.

An important distinction made by Adult-Child CDR 3 members is that of intense emotion versus insidious grief. This group appears to have arrived at an acceptance, but only because they have been worn down to this by experiencing continual deterioration. They talk about their relationship with their parent as “the long good-bye.” The sharply focused emotions of earlier stages are replaced by more global tiredness, longing, and pining, and a weighty emptiness.

Some positive aspects are empathy for their parent and a renewed philosophical perspective on life, relationships, and the caregiving experience. There is much concern expressed for what their parent must be experiencing, especially in those rare moments when the parent is lucid. These periods of lucidity are simultaneously “treasured” and discouraging—the former because they represent human connection, the latter both because they fail over time and because the content is often the parent’s wish to die. Some members spoke of being pleased with seeing their parent now releasing previously inhibited behaviors, such as providing hugs, desiring to walk hand in hand, and expressing thanks for little things that are done. While they spoke of the caregiving experience as being difficult, they also said it enhanced their understanding of aging, magnifying the value of human relationships, and contributing to their own

self-worth. If there is any silver lining in dementia caregiving for adult-children, this seems to be it.

Spouse (CDR 1, Mild, n = 10).—Spouse CDR 1 caregivers present a number of striking contrasts with Adult-Child CDR 1 caregivers. First, they are lower in denial and higher in their reality orientation with regard to their own feelings and with regard to what to anticipate over time. Their comments reveal a strong sense of togetherness with their involved spouse (“we’re in this together”) and a quiet determination to get on with the work of caregiving. Second, they are not as concerned with promoting their spouse’s current competencies. Rather than pushing their spouses to accomplish all that their diminishing skills can muster, these caregivers accept present circumstances and adjust their care responses accordingly. They recognize losses of function and may report feeling sad about such changes, but there is not a strong, felt desire to hold onto the past or to provide excuses for what is happening. Third, the focus of loss is less on self and more on the couple-oriented aspects of their experience (e.g., loss of companionship with spouse, loss of shared social activities, cannot go dancing together any longer).

Their sense of togetherness is changing (but still present), and this brings a quieter, sadder form of grief than that reported by adult-child caregivers. This acceptance of change may be a function of the spousal role and its location in the life cycle. There is a sense that spouses understand that aging brings decline and death closer and that eventually one has to prepare for self-sufficiency. Preparation for the inevitable differentiates these caregivers from adult-child caregivers. The one exception to this attitude of acceptance is a desire for the spouse with dementia to die first. The thought of leaving that person alone is more than many of these caregivers are willing to accept. There is also a resistance, particularly among the men in these groups, to placing their spouse in a nursing home. At this early stage, this action is viewed as a sign of defeat and one to be avoided at all costs.

Spouse (CDR 2, Moderate, n = 10).—Unlike the Adult-Child CDR 2 group, whose emotions are dominated by anger, the Spouse CDR 2 group’s emotions are dominated by compassion, frustration, and a loving redefinition of the relationship wherein the involved spouse is viewed and cared for as a “beloved child.” Caregiving, while burdensome, is provided as an accepted responsibility. Determination to provide the best care possible and not crumble under the burdens of care is as prominent as the underlying emotions. These members contrast their steady, plodding responsibility to their spouse with the heightened emotions they experienced at the time of learning the diagnosis. They describe the latter as a time of greater emotional upheaval. These folks are no longer reeling from that shock. They seem genuinely empathic and understanding, yet intensely saddened by the change in their spouse’s life, their own life,

and their conjoint life. They no longer look backward, but they also refuse to look forward. Instead, they seem intensely focused on the current tasks of providing the best care possible and maintaining some relationship, albeit a changed one. This unwillingness to be neither retrospective nor prospective appears to have a self-protective quality to it. Focusing exclusively in the present retains their connection with their involved spouse and supports their own sense of integrity, duty, and self-worth. Where there is anger at all, it is directed at the lack of involvement by adult children as collaborative caregivers.

The heavy burdens of caregiving in terms of time, demands for focused attention, and energy depletion are addressed, as are losses in the areas of intimacy, companionship, friendship networks, and personal autonomy. They express appreciation for whatever little respite they can gain. The overall impression, however, is that they take on the caregiving role with a remarkable degree of dignity and understanding.

For a few Spouse CDR 2 caregivers, nursing home placement has already occurred. These few report intensification of feelings of loss, grief, and guilt, suggesting that the prototypical Spouse CDR 2 caregiver may be experiencing a valley in the grief process sandwiched between peaks at diagnosis and nursing home placement. It is also worth noting that despite their reluctance to project into the future, Spouse CDR 2 caregivers do so when directly asked about anticipatory grief. They convey their belief that most of their grieving has (and is) taken place and that this will reduce their grief in the end.

Spouse (CDR 3, Severe, n = 9).—What stands out most for spouse caregivers in this advanced stage is a sense of being stuck and unsure how to proceed with life. Although nursing home placement relieved the physical burdens of care, the emotional struggles and sense of responsibility remain and these may be even more prominent now than before. Visits to the nursing home bring comfort at times (e.g., from an “unexpected hug”), but there’s a larger sense that the marital relationship (the intimacy, affection, sharing, and mutuality) has ended and a new relationship has taken its place. The togetherness of the past has given way to an uneasy individuality.

Living as a single person is a frightening concept. A number of caregivers questioned how it is possible to be an individual when your marriage partner is still living and obligations of care continue. Some expressed significant frustration and anger at being in a “life–death limbo.” Guilt and regret surface in response to such reactions.

In addition to experiencing the full loss of their marriage, many of these caregivers acknowledge feeling disconnected from both family and friends. The aloneness of this stage appears to magnify such interpersonal loss. Some group members reported working to strengthen and rebuild support networks. For others this is not so easy, particularly when feelings of bitterness get in the way.

Unlike our adult-child caregivers at this stage, these spouse caregivers do not seem particularly interested in trying to “figure out” or otherwise find meaning in what has happened. They are simply tired and desirous of relief, but they don’t necessarily view spousal death as the ultimate solution to their problems. There is a growing expectation that new manifestations of grief are coming along. How to live as an individual remains an open and confusing question.

Qualitative Findings—Anticipatory Grief Narratives for Previously Active Caregivers

Members of focus groups whose loved one had since died from AD addressed questions related to their grief experiences during mild, moderate, severe, and postdeath stages. Their retrospective perspectives differ in meaningful ways from the experiences reported by those actively caregiving and so are of questionable value. However, their current perspectives on the effects of anticipatory grieving on post-death grief are of considerable value and are reported here, in brief.

Adult-Child (Deceased, n = 10).—Members of Adult-Child D focus groups differed somewhat on the impact of having grieved throughout the dementia process. All reported being “worn down” by the caregiving process (“the funeral that never ends”); all reported an initial sense of relief immediately following their parent’s death; and all reported that the caregiving experience enhanced their ability to be compassionate and understanding (i.e., that the impact on character and philosophical outlook first noted in Stage 3 continued). However, there were some differences regarding the longer-term impact of anticipatory grief. For a few, postdeath grief seems to have been eased (“There was relief because she was in peace, but also because the responsibility was over”). However, for most it appears that the initial reduction in postdeath grief was followed by resurgence in grief (“I felt a sense of relief. I cried, because I was feeling so good that she was in peace. A big load was lifted off when she died. When time went on, though, the sadness came in. I have no parents left.” Another member: “I didn’t think it would be bad when mom died because I grieved while she was alive, but it was.” Yet a third example: “I just keep thinking, why did this happen? I am as sad now as when she died”).

Spouse (Deceased, n = 13).—It appears that, in general, the same is true for Spouse D focus group members. They describe significant and erosive grief during the caregiving process (“I have been grieving losses over the whole period of illness; there was a loss of person before a loss of body”), but they describe a grief that continues (“I have dealt with many losses. It is 3 months after his death and there is a void in my life now”). Obviously, the difficulties for

the bereaved spouse are more complex than those for the bereaved child, whose family of choice and whose social contacts are more intact; but for both types of caregivers, it appears that any initial grief reduction is followed by grief intensification (or at least continuation) for some period of time.

Discussion

The present study is, to our knowledge, the first to look at the grief process for AD caregivers from the combined perspectives of caregiver type and caregiver stage. The value of doing so is supported by the findings that indicate that the grief process is different for adult-child caregivers than for spouse caregivers and that the patterns for each are definable at each stage of dementia progression. This research represents the first phase of a two-phase study. The second phase will test a psychometric instrument designed to assess stage-specific and caregiver-specific grief with the eventual aim of developing appropriate intervention strategies.

The conclusions here, derived primarily from focus group discussions, suggest that from the earliest stage of care providing (CDR 1), there are fundamental differences in the grief responses of adult-child and spouse caregivers. Most noteworthy at this early stage is the differential degree of denial invoked. Adult-child caregivers appear to do everything possible to disavow all that is happening. In the language of awareness context theory (Glaser & Strauss, 1965; Hutchinson, Leger-Krall, & Wilson, 1997), they and their parent engage in a mutual pretense. These caregivers attribute early dementia to other conditions, such as normal aging or depression; they focus on their parent's capacities rather than on early signs of dementia; they minimize their feelings; and they avoid discussing the future. In contrast, spouse caregivers are more open, accepting, and realistic about their mate's present condition and about impending burdens (including the eventual task of facing nursing home placement). They are clearly sad. They operate more in an open awareness context.

In addition to these basic differences, it should also be noted that the two groups at the CDR 1 level differ in the focus of their loss issues. Adult-child caregivers, in keeping with their denial of their parent's dementia, are self-focused. Their loss issues relate to themselves, primarily loss of personal freedom and loss of support by siblings. Spouse caregivers, on the other hand, express loss issues that are largely other-focused (e.g., the beginnings of decline in their partner) and loss issues that are conjoint (e.g., loss of companionship).

Differences continue both within and across groups as the involved parent/spouse progresses from mild (CDR 1) to moderate (CDR 2) dementia. Most noteworthy with adult-child caregivers is that they are no longer able to maintain their denial and are now almost crippled with intense raw emotions. While sadness emerges, the predominant emotions tend to be

anger, frustration, jealousy of others who are not experiencing AD caregiving, and guilt over newly emerging wishes that the parent would die. Emotions are experienced as erupting, following the previously defended, artificially contained posture witnessed at the CDR 1 stage. When looking at the full progression of grief across the three stages, it appears that grief, as defined by emotional turmoil consequent to loss, is highest for this group at the CDR 2 stage. In contrast, spouse caregivers' emotions increase slowly and linearly from stages CDR 1 to 2. The sadness expressed at the CDR 1 stage continues to mount but is accompanied by an increase in empathy and compassion. Although the difficulties of caregiving are acknowledged, the responsibilities of caregiving are accepted with affection and dignity. There is little of the anger associated with unwanted burden and imposition experienced by the adult-child caregivers. The differences in the responses of each caregiver type are explainable by the nature of the relationship. Children do not anticipate the burdens of caregiving, nor do they accept these as part of life's natural developmental progression. On the other hand, spouses prepare for this all of their married life.

The most noteworthy marker of severe (CDR 3) levels of dementia for both groups of caregivers is nursing home placement. For the prototypic adult-child caregiver in this study, there is a sense of emotional relief that comes with nursing home placement. Their burden is lifted, and the intensity of feelings of the previous CDR 2 stage gives way to a mellowing of feelings. The space that was filled with anger, frustration, and jealousy is now filled with reflective and philosophical commentary. Where the previous focus of loss was on the self, the new focus of loss is on the other (e.g., how sad for the parent) and on the conjoint relationship (e.g., regrets over not knowing the parent better). These caregivers feel that the caregiving experience has made them more compassionate individuals. In contrast, spouse caregivers' grief appears now at its highest. For the first time, sadness is accompanied by, or sometimes superceded by, anger and frustration. Nursing home placement brings relief, but it also brings the unwanted realities of self-care and of being uncoupled. The focus of loss shifts from other and conjoint to self.

Most interesting in these scenarios are the differences in the quality of emotion experienced by each caregiver type at each stage, the intensity of emotion at each stage, and the differences in the focus of loss at each stage. To summarize, for adult-child caregivers, expressed grief is almost curvilinear; minimal at CDR 1, most intense at CDR 2, and moderated at CDR 3. For spouse caregivers, expressed grief increases linearly from CDRs 1–3. For adult-child caregivers, anger and frustration are predominant when grief is highest (CDR 2) and eventually shifts to sadness (CDR 3). For spouse caregivers, sadness is the predominant emotion during CDR levels 1–2 and shifts in the direction of anger and frustration at CDR 3. For adult-child caregivers, the focus of loss shifts from self at CDR levels 1–2 to other/conjoint at CDR

3. For spouse caregivers, their focus of loss shifts from other/conjoint at CDR 1–2 to self at CDR 3.

D groups were incorporated into the design to provide information to two questions. The first question was whether anticipatory grieving has an ameliorating effect on postdeath grief. Looking at the responses of both Adult-Child and Spouse D members, the answer appears to be “yes” initially and “no” in the long run. Members of both groups expressed relief for grief-related emotions immediately following their loved one’s death, but also reported high levels of grief over time. The second question is methodological and addresses whether one can rely on the accuracy of retrospective accounts of D participants and not have to collect independent cross-sectional samples of CDR 1, 2, and 3 groups. The answer to this appears to be “no” because a number of incompatibilities are displayed between current and retrospective accounts. For one, both caregiver types at CDR 2 and CDR 3 levels anticipated a permanent benefit from anticipatory grieving; however, as mentioned, D groups show that long-term benefits to early grieving do not accrue. For another, Adult-Child D members minimized experiencing anger in their retrospective accounts, yet adult-child CDR 2 members were enraged. In other words, postdeath idealization did not correspond with the intense anger expressed by adult-child CDR 2 participants. The methodological necessity of obtaining information cross-sectionally at each stage is further supported by inaccurate prospective expectancies. For example, spouse CDR 2 members reported their belief that their grief was the highest it will be in the caregiving experience; but, as it turns out, Spouse CDR 3 participants indicate that theirs is even higher. So, while focus group research in this area is highly time-intensive, it is impossible to cut corners and it appears necessary to assess grief as it unfolds.

The conclusions drawn above are primarily derived from a video-based analysis of focus group discussions similar to those delineated by Krueger (1994) and Vaughn, Schumm, and Sinagub (1996) in which raters build narratives based on internally consistent themes. In the present research, multiple independent raters were used to assure consistency of themes across groups. Only those themes that arose repeatedly from independent ratings were considered. The incorporation of quantifiable dimensions (the AGS and the MFG measure) was a secondary consideration. Combining quantitative measures with qualitative procedures produces a “methodological pluralism” which “respects both numbers and narratives and the distinctive forms of understanding that each can promote” (Neimeyer & Hogan, 2001, p. 113). Neimeyer and Hogan go on to say, “. . . even at this germinal stage in the application of qualitative paradigms to the study of loss, it is clear that they begin to paint a picture of bereavement that is far more complex and less tidy than that suggested by the artificially simplified and controlled canvasses of quantitative questionnaires” (p. 113). In the current research, this was true. While the quantitative and

qualitative findings were often compatible and mutually supportive, at other times they added complexity that required interpretive creativity. For example, correlational data indicated that the overall grief levels of adult-child and spouse caregivers are roughly equivalent, yet the qualitative analyses showed differences in the construction of grief processes across caregiver type and caregiver stages. Also, for example, while the correlational findings suggest that grief decreases as dementia progresses, thereby supporting the anticipatory grief hypothesis, the qualitative findings suggest more complex patterns across time and, in fact, support the anticipatory grief hypothesis in the short run only.

Some of the incompatibility between the quantitative and qualitative findings may have resulted from the poor response to the quantitative measures. First, and most important, not all participants filled out these measures. Some did not fill out the AGS and some left large portions of the MFG blank. Both the AGS and the MFG came at the end of a lengthy booklet, and some participants expressed fatigue. Furthermore, a number of participants who did complete these measures stated that they did so a month or more prior to their focus group participation and that they would now respond differently. This was especially true for the MFG scale.

One thing that is interesting is that while the MFG scale was newly devised and could only claim face validity, it correlated highly with the AGS, which is more established and which claims to be the only grief scale specifically developed for dementia caregivers. Therefore, the MFG, which demonstrated decent internal consistency ($\alpha = 0.93$), can now also claim some concurrent validity. Furthermore, the MFG scale showed the capacity to differentiate caregiver types on dimensions that are corroborated by the qualitative findings (e.g., adult-children scoring higher on jealousy for others, negativity, and questioning the meaning of life; and spouses scoring higher on loneliness and loss of sexual interest). Additional reliability and validity studies of the MFG scale may establish its utility for future research.

The present study supports the benefits of studying caregiver grief in a stage sensitive, caregiver-specific model. The divergent grief trajectories across stages for adult-child and spouse caregivers suggest that clinical interventions can be tailored with these dimensions in mind. For example, educative techniques designed to gently confront caregivers with accurate information may be most helpful for adult-child caregivers in the early stages, when they are in their greatest denial. Spouse caregivers at this same stage appear more realistic and knowledgeable about their situations and may benefit most from support groups. Likewise, these data suggest that anger management techniques might be uniquely appropriate for adult-child caregivers in the moderate stages, when their anger appears at its highest, but less appropriate for spouse caregivers, who appear to more typically experience extreme sadness rather than extreme anger at this same stage. Interventions at the

severe stage should emphasize a shift to individuality concerns for spouse caregivers (e.g., how to live alone), whereas the emphasis for child caregivers becomes one of philosophical integration.

Although there are limitations to using a focus group format for collecting behavioral data (e.g., abdicating methodological precision and control, less quantification of variables), there are recognizable advantages, such as obtaining a richness of information that can only be derived from real life narratives. Recent reviews have acknowledged these advantages for grief-related research (e.g., Neimeyer & Hogan, 2001) and have discussed ways to maximize precision (e.g., using semistructured to structured interviewing formats; prompting all participants to report their full range of experiences; recording only themes that appear consistently across raters). These criteria were followed in the present research. Another advantage of this qualitatively based design for the present investigations is that all prominent quotes derived from the focus group discussions of Phase I are available as items for the Phase II questionnaire. Approximately 190 of these quotes, or paraphrased versions, are currently being administered to a sample of 200 active caregivers. Their responses will be factor analyzed to develop a stage-sensitive, caregiver-specific instrument for use in various supportive settings (e.g., Alzheimer's Association support groups). The resulting grief inventory will also be compared to participants' responses to other instruments in the Phase II questionnaire; namely, the Beck Depression Inventory, the Geriatric Depression Scale-Short Form, the Assumptive World Scale, Caregiver Strain Index, and the Well-Being Scale. We anticipate that our investigations will characterize caregiver grief as a distinct form of distress in the larger depression-burden-stress constellation and will form the foundation for grief-specific interventions.

References

- Archer, J. (1999). *The nature of grief: The evolution and psychology of reactions to loss*. New York: Routledge.
- Bass, D. M., Bowman, K., & Noelker, L. S. (1991). The influence of caregiving and bereavement support on adjusting to an older relative's death. *The Gerontologist*, 31, 32-42.
- Berg, L. (1988). Clinical dementia rating. *Psychopharmacology Bulletin*, 24, 637-639.
- Bowd, A. D., & Loos, C. H. (1996). Needs, morale and coping strategies of caregivers for persons with Alzheimer's disease in isolated communities in Canada. *American Journal of Alzheimer's Disease*, 1, 32-39.
- Doka, K. J. (2000). Mourning psychosocial loss: Anticipatory mourning in Alzheimer's, ALS, and irreversible coma. In T. A. Rando (Ed.), *Clinical dimensions of anticipatory mourning: Theory, and practice in working with the dying, their loved ones, and their caregivers* (pp. 477-492). Champaign, IL: Research Press.
- Farran, C. J., Keane-Hagerty, E., Salloway, S., Kupferer, S., & Wilken, C. S. (1991). Finding meaning: An alternative paradigm for Alzheimer's disease family caregivers. *The Gerontologist*, 31, 483-489.
- Gilhooly, M. L. M., Sweeting, H. N., Whittick, J. E., & McKee, K. (1994). Family care of the dementing elderly. *International Review of Psychiatry*, 6, 29-40.
- Glaser, B., & Strauss, A. (1965). *Awareness of dying*. New York: Aldine Press.
- Hughes C. P., Berg L., Danziger W. L., Cohen, L. A., & Martin, R. L. (1982). A new clinical scale for the staging of dementia. *British Journal of Psychiatry*, 140, 566-572.
- Hutchinson, S. A., Leger-Krall, S., & Wilson, S. (1997). Early probable Alzheimer's disease and awareness context theory. *Social Science & Medicine*, 45, 1399-1409.
- Krueger, R. A. (1994). *Focus groups: A practical guide for applied research* (2nd ed.). Thousand Oaks, CA: Sage.
- Loos, C., & Bowd, A. (1997). Caregivers of persons with Alzheimer's disease: Some neglected implications of the experience of personal loss and grief. *Death Studies*, 21, 501-514.
- Mace, N. L., & Rabins, P. V. (1981). *The 36-hour day*. Baltimore, MD: The Johns Hopkins University Press.
- Meuser, T. M., & Marwit, S. J. (2000). An integrative model of personality, coping & appraisal for the prediction of grief involvement in adults. *Omega: Journal of Death & Dying*, 40, 375-393.
- Morris, J. C. (1993). The Clinical Dementia Rating (CDR) Scale: Current version and scoring rules. *Neurology*, 43, 2412-2414.
- Mullan, J. (1992). The bereaved caregiver: A prospective study of changes in well-being. *The Gerontologist*, 32, 673-683.
- Neimeyer, R., & Hogan, N. (2001). Quantitative or qualitative? Measurement issues in the study of bereavement. In M. S. Stroebe, R. O. Hansson, W. Stroebe, & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 89-118). Washington, DC: American Psychological Association.
- Ponder, R. J., & Pomeroy, E. C. (1996). The grief of caregivers: How pervasive is it? *Journal of Gerontological Social Work*, 27, 3-21.
- Rabins, P. V. (1984). Management of dementia in the family context. *Psychosomatics*, 25, 369-371, 374-375.
- Rando, T. A. (1986). *Loss and anticipatory grief*. Lexington, MA: Lexington Books.
- Rando, T. A. (2000). *Clinical dimensions of anticipatory mourning: Theory, and practice in working with the dying, their loved ones, and their caregivers*. Champaign, IL: Research Press.
- Rudd, M. G., Viney, L. L., & Preston, C. A. (1999). The grief experienced by spousal caregivers of dementia patients: The role of place of care of patient and gender of caregiver. *International Journal of Aging & Human Development*, 48, 217-240.
- Stroebe, M. S., Stroebe, W., & Hansson, R. O. (1993). *Handbook of bereavement: Theory, research and intervention*. New York: Cambridge University Press.
- Theut, S. K., Jordan, L., Ross, L. A., & Deutsch, M. D. (1991). Caregiver's anticipatory grief in dementia: A pilot study. *International Journal of Aging and Human Development*, 33, 113-118.
- Vaughn, S., Schumm, J. S., & Sinagub, J. (1996). *Focus group interviews in education and psychology*. Thousand Oaks, CA: Sage.
- Walker, R. J., & Pomeroy, E. C. (1996). Depression or grief? The experiences of caregivers of persons with dementia. *Health & Social Work*, 21, 247-254.
- Walker, R. J., & Pomeroy, E. C. (1997). The impact of anticipatory grief on caregivers of persons with Alzheimer's disease. *Home Health Care Services Quarterly*, 16, 55-77.
- Walker, R. J., Pomeroy, E. C., McNeil, J. S., & Franklin, C. (1994). Anticipatory grief and Alzheimer's disease: Strategies for intervention. *Journal of Gerontological Social Work*, 22, 21-39.
- Wasow, M., & Coons, D. H. (1987). Widows and widowers of Alzheimer's victims: Their survival after spouse's death. *Journal of Independent Social Work*, 2, 21-33.
- Weiss, R. (2001). Grief, bonds, and relationships. In M. S. Stroebe, R. O. Hansson, W. Stroebe, & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 47-62). Washington, DC: American Psychological Association.

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Appendix

Instructions for Videotape Raters (abbreviated version)

Watching the Videotape With Grief Researcher's Eye and Ear

What does this mean? Basically, you need to focus on the reported or manifest reactions of the caregivers as they discuss the losses that they've experienced. Many of our caregivers spoke in some depth about changes in their loved one's functioning as if they were attending a regular caregiver support group. Each person had to tell his or her Alzheimer's story be-

fore being able to discuss personal grief reactions. Your challenge is to filter out the stories and get to the heart of each person's felt grief reactions.

What is grief in this context? We used a definition from Dr. Therese Rando as a guide:

"a phenomenon encompassing the processes of mourning, coping, interaction, planning, and psychosocial reorganization that are stimulated and begun . . . in response to the awareness of . . . impending loss" (Rando, 1986, p 24).

Grief reactions occur when personally meaningful losses are **recognized** as having occurred or as impending. Recognition of loss initiates the grief process. Caregivers experience numerous "mini-deaths" over the typical 10-year course of Alzheimer's disease, yet many of these losses probably go unrecognized. These may include loss of companionship, shared goals, mutual support, longstanding roles, etc. Some of our caregivers appeared to recognize specific losses for the first time in response to our questioning. Sadness probably stands out as a core grief reaction for most people. Many other reactions are possible as evidenced by the list in The Many Faces of Grief questionnaire. Your job is to listen for these various grief reactions and make some judgments about what's important or meaningful for the people in the group and the stage of caregiving they represent (early, moderate, severe, postdeath).

Recording Important Impressions and Quotations

This part of the rating process involves more of your personal perceptions and experience. The enclosed Narrative Rating Form (which is also on the computer disk) lists each of the main questions for the study with space for you to record pertinent information. Your role here is to listen for key quotations, responses and concepts, and then record these as they apply to each question. Use bullet points to help separate your comments.

Please associate quotations to specific participants by assigning each person with a number and *putting it in parentheses after the quote*. Count off from left to right, such that the person immediately to Dr. Marwit's left is #1 and so on. Finish

each section with a few summary comments. The form has just one page per question—feel free to add extra pages if needed. For example:

"I had no idea what I was dealing with at the time . . . just that something was wrong . . . I was devastated when we finally learned Mary had dementia . . ." (2)

3 of the 5 group members report feeling overwhelmed by the news. Each learned at the point of diagnosis in the doctor's office. The other two had strong hunches of a problem and reported feeling somewhat relieved.

Although we attempted to follow a certain order in our questioning, you'll find that some participants provide answers to more than one question at the same time. As best you can, try to record your thoughts in the space for the appropriate question. You do not have to get everything written down, just key points as they relate to grief. We're not interested in stories about how particular patient's decline or past life stories. The only exception to this is where a story captures something important about the grief process for the caregiver. For example:

Bill (#2) reported having golfed with his Dad every week for most of his adult life. Now that his Dad has dementia and is in a nursing home, this shared activity is lost. "My Dad and I never really talked. We felt close to each other in our shared physical activities . . . I'm so distant from him now . . . I feel this deep sadness come over me every Saturday morning when we would have gone golfing . . . I miss sharing my thoughts with him."

In addition to recording responses and thoughts related to each question, keep an ear open for the **focus of loss** in the group. Are members discussing what they have lost personally (e.g., "I don't have any time for my kids. Caring for Dad is all-consuming and I so need a break") or are they more focused on what their loved one with dementia has lost (e.g., "I feel so sad that my husband can't garden anymore. He loved his garden so much and now he just seems like a shell of his former self. Every day I wish he could feel more like he used to"). Rate this focus for the group on the 1–7 scale listed on the form: 1 = complete focus on personal losses; 7 = complete focus on loved one's losses. Include explanatory comments for your rating as needed. The focus of loss rating is on the fifth page of the Narrative Rating Form.