Grief and Personal Growth Experience of Spouses and Adult-Child Caregivers of Individuals With Alzheimer’s Disease and Related Dementias

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Purpose: The purpose of this study was to describe the grief and personal growth experience of spouses and adult children of individuals with Alzheimer’s disease and related dementias and the factors contributing to these experiences. Design and Methods: We used a modification of the Marwit–Meuser–Sanders Caregiver Grief model to examine the factors that contribute to grief and personal growth. We used chi-square tests, t tests, multivariate analyses of variance, correlations, and hierarchical regression analyses in a cross-sectional analysis of 201 spouses and adult children caregivers at various stages of the disease trajectory. Results: Grief increased as the severity of the disease increased. When the spouse with Alzheimer’s disease lived out of the home, spouse caregivers experienced more sadness and longing, worry and isolation, and personal sacrifice burden than did adult children caregivers. Different factors influence grief and personal growth for caregivers of individuals with Alzheimer’s disease. The majority of caregivers experienced personal growth, with more growth experienced by adult children. Implications: Health care providers should consider using the Marwit and Meuser Caregiver Grief Inventory to screen for high levels of grief in caregivers of individuals with Alzheimer’s disease. Supportive services targeted for those with high levels of grief are suggested.

Despite the abundance of literature about the physical and mental health of caregivers of individuals with Alzheimer’s disease and related dementias (hereafter Alzheimer’s disease), two important concepts that have not been sufficiently addressed are grief and personal growth. The focus on grief in caregivers has challenged the stress–burden paradigm by conceptualizing grief as a critical component of the Alzheimer’s caregiver experience that may adversely impact his or her physical and mental health (Meuser, Marwit, & Sanders, 2004). This new paradigm may aid in understanding how caregivers grow and find meaning over the course of the illness and death trajectory (Butcher, Holkup, & Buckwalter, 2001). On the basis of focus groups and interviews with caregivers at different phases of the Alzheimer’s disease trajectory, Meuser, Marwit, and Sanders developed a conceptual model illustrating the relationship between grief and the overall health and well-being of caregivers. In response to the recognition of a personally significant loss, emotional health and well-being are affected. Simultaneously, multiple factors including the individual’s situation and cultural practices influence social support and coping and contribute to emotional health. Coping strategies and support are unique to the individual and impact the stress–burden constellation, grief, and personal growth. It is also hypothesized that causal influences oscillate back and forth between grief, personal growth, and the depression–stress–burden constellation. Using a modification of the Caregiver Grief model, in this study we expand the literature on grief and personal growth by describing the experiences of spouses and adult children of individuals with Alzheimer’s disease along the disease trajectory and identify the factors contributing to these constructs.

Key Words: Adult children, Caregiver, Coping, Grief, Personal growth, Spouse
We used the Caregiver Grief model (Mesuer, Marwit, & Sanders, 2004) in this study to examine the factors that impact emotional health and well-being in caregivers of individuals with Alzheimer’s disease. We used the short form of the Marwit and Meuser Caregiver Inventory (2005) to determine (a) the intensity of grief experienced by spouses and adult children of individuals with Alzheimer’s disease; (b) the difference in the intensity of grief experienced by spouses and adult children in relation to place of residence of the person with Alzheimer’s disease; (c) the intensity of grief relative to the stage of disease; (d) the association between the level of grief and individual factors, including age, severity of disease, social support, coping strategies, depressive symptoms, life satisfaction, and personal growth; (e) factors that contribute to higher levels of grief; and (f) factors that contribute to higher levels of personal growth.

Grief in Caregivers of Individuals With Dementia

Grief has been defined as the reaction to the perception of loss with normative symptoms including yearning, sadness, anger, guilt, regret, anxiety, loneliness, fatigue, shock, numbness, positive feelings, and a variety of physical symptoms that are unique to the individual (Rando, 2000; Shuchter & Zisook, 1993; Worden, 1991). Attachment theory provides a lens for understanding the grief processes of caregivers (Bowlby, 1969). Bowlby postulated that grief occurs when the safety and security that a person feels within a relationship become threatened. Children as well as adults yearn for bonded relationships with others. Despite the stress and strain that occurs between a caregiver and a care recipient, a bond exists that creates an intense form of attachment. As the caregiver senses the attachment with the care recipient changing or becoming strained as a result of the disease progression, grief is the natural by-product. Thus, as the disease and cognitive impairment worsen, the grief of caregivers increases (Meuser & Marwit, 2001; Ponder & Pomeroy, 1996; Sanders & Adams, 2005).

Only recently has the issue of grief related to Alzheimer’s disease and its progression appeared in the professional literature (Loos & Bowd, 1997; Meuser & Marwit, 2001; Rudd, Viney, & Preston, 1999). Early studies on grief and caregivers of individuals with Alzheimer’s disease examined the specific changes that occur within the caregiving experience that create loss. Results of these studies indicate that grief originates from losses in the quality of the relationship, roles, control, well-being, intimacy, health status, social interaction, communication, and opportunities to resolve issues from the past (Loos & Bowd; Sanders & Corley, 2003). These losses occur over the course of the disease and create a situation of so-called dual dying, in that the person with dementia seems to have died before the actual death occurs. Thus, caregivers grieve as each of these losses occurs, and then they experience an additional period of grief when the actual death of the person happens.

Differentiating Grief From Other Caregiver Outcomes

Although there is overlap between symptoms of depression and grief, researchers have demonstrated that the two constructs are different. The strongest evidence of the distinction between grief and depression can be found in the bereavement literature. Results of a treatment study focusing on bereavement-related depression using interpersonal therapy and antidepressant medications found that, although depression decreased, there was minimal impact on decreasing grief symptoms (Reynolds et al., 1999). Prigerson and colleagues (1995) assessed a set of common grief symptoms in elderly persons within the first 6 months of bereavement. On the basis of a principal components analysis of these data, the researchers identified two distinct consequences of bereavement: a depression factor and a grief-specific factor.

In the predeath grief literature specific to dementia care, Sanders and Adams (2005) found that almost 50% of the variance in depression scores was accounted for by grief. Similar findings were reported earlier by Walker and Pomeroy (1996). They concluded that “the depression reported by caregivers may in part reflect grief that is comparable to that of people who have suffered a non-death loss” (p. 252). These findings suggest that “to focus only on depression is to miss the larger context of loss and grief that defines caregivers’ daily experiences” (Meuser et al., 2004, p. 175).

Personal Growth

Although much of the research on caregivers of individuals with dementia has focused on negative outcomes from the caregiving experience, positive outcomes from the experience have also been documented (Kramer, 1997; Sanders, 2005; Tarlow et al., 2006). Some researchers suggest that between 55% and 90% of all caregivers experience positive outcomes in the form of personal growth (Butcher et al., 2001; Farran, Keane-Hagerty, Solloway, Kupferer, & Wilken, 1991). The concept of personal growth originated in the trauma and the postdeath grief literature with the overwhelming sentiment that “growth can emerge following difficult life events” (Hogan & Schmidt, 2002, p. 617). Hogan and Schmidt describe personal growth in the grief trajectory as a process of becoming more caring and connected to others, evaluating what is really meaningful in life, and reassigning priorities. Focusing on the personal
Differentiating Grief in Spouses and Adult Children

Whereas researchers have examined the differences in the caregiving experience between spouses and adult children and other caregiving outcomes, to date only one study has examined differences in grief between adult children and spouses (Meuser & Marwit, 2001). Through the use of focus groups, Meuser and Marwit found that there are profound differences in the manner in which spouses and adult children experience grief throughout the disease trajectory. During the initial stages of the disease, spouses experienced sadness but they also realized that their grief would escalate as the disease worsened. In the middle stages, spouses’ grief became externalized with feelings of sadness related to the impact of the disease on the care recipient. By the end stages of the disease, the grief of spouses became internalized with the focus on how they had been affected over the years by Alzheimer’s disease and how their lives would be different in the future as widows or widowers. During the early stages of the disease, adult children experienced denial and avoidance, which turned to anger. During the middle stages the dominant feelings were frustration, burden, and sadness. In the final stages of the disease, adult children experienced sadness, longing, loneliness, and resignation. For both spouses and adult children, grief escalated as the disease worsened (Ponder & Pomeroy, 1996; Sanders & Adams, 2005).

Focus of the Study

We used a modification of the Caregiver Grief model (Meuser et al., 2004) in this study to examine the factors that impact grief and personal growth in caregivers of individuals with Alzheimer’s disease. As we stated earlier, we used the short form of the Marwit and Meuser Caregiver Inventory (2005) to determine (a) the intensity of grief experienced by spouses and adult children of individuals with Alzheimer’s disease; (b) the difference in the intensity of grief experienced by spouses and adult children in relation to place of residence of the person with Alzheimer’s disease; (c) the intensity of grief relative to the stage of disease; and (d) factors that contribute to higher levels of grief and personal growth.

Methods

Participants

Participants in this cross-sectional descriptive study (N = 201) included 90 spouses and 111 adult children of individuals with a diagnosis of Alzheimer’s disease who self-identified as caregivers. We recruited participants from support groups sponsored by the Alzheimer’s Association, memory loss clinics, community caregiver support networks, extended care facilities, and by word of mouth.

Procedures

We obtained Institutional Review Board approval from the University and from the participating institutions. Potential participants received a pamphlet describing the study with a stamped, self-addressed postcard attached. Interested volunteers returned the postcard. Upon receipt of the postcard, we had interviewers contact potential participants by telephone; interviewers described the study in further detail and answered questions. The eligibility criteria for inclusion in this study were as follows: (a) spouse or adult child of a person with a diagnosis of Alzheimer’s disease, or (b) primary or secondary caregiver who provides a broad range of assistance. We used the definition of a caregiver given by the Family Caregiver Alliance (2006); that is, a caregiver is a person who has a significant personal relationship with a person with Alzheimer’s disease and who provides primary or secondary caregiving, who lives with or separately from the person receiving care, and who provides a broad range of assistance.

Of the 210 respondents who returned the postcards and were contacted, 201 (97.5%) completed the study. Reasons given for nonparticipation included “too busy” (n = 4; 44%), “change in health status of person with memory loss” (n = 2; 22%), and “not interested in participating” (n = 3; 34%). These nine nonparticipating caregivers did not differ from the study group in terms of demographic variables, including gender or relationship to the person with Alzheimer’s disease.

All participants completed a set of questionnaires that took approximately 40 minutes. They also participated in an interview that lasted between 30 minutes and 1.5 hours.

Measures

Demographic and Care-Related Information.— We collected data on each participant’s age, gender, education, religious affiliation, employment status, occupation, and total number of hours of care provided each day, additional life stressors besides the older adult’s Alzheimer’s disease, and health changes since the diagnosis. We assessed the use of supportive services by asking if the participant had participated in professional counseling or attended a support group since the diagnosis. Information about the person with the diagnosis of Alzheimer’s disease included gender, year diagnosed with Alzheimer’s disease, and place of residence. We
considered a person with Alzheimer's disease to be living out of the home if the person lived in a nursing home, lived in an assisted living residence, or lived alone with assistance from someone other than the family member.

**Grief.**—We used the short form of the Marwit and Meuser Caregiver Grief Inventory (MM-CGI-SF; Marwit & Meuser, 2005) to measure the grief reaction. The MM-CGI-SF is an empirically derived instrument based on spouse and adult child caregiver statements obtained under controlled conditions. The instrument is psychometrically supported by factor analytic techniques and demonstrates high internal consistency reliability. We measured the validity of the grief construct against measures including grief, depression, caregiver strain, well-being, and perceived family support. This 18-item instrument provides a total grief score and subscale scores measuring Personal Sacrifice Burden, Heartfelt Sadness and Longing, and Worry and Felt Isolation. Items are rated on a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree). Subscale items include the following: “I feel very sad about what this disease has done,” “The people closest to me do not understand what I’m going through,” and “I’m stuck in this caregiving world and there’s nothing I can do about it.” Higher scores indicate more grief. On the basis of the responses from focus groups and surveys from 292 family caregivers, Marwit and Meuser indicate that participants scoring over 1 SD above the mean may be at risk for grief complications. Cronbach’s alpha for the total score was $\alpha = 0.915$; those for Personal Sacrifice Burden, Heartfelt Sadness and Longing, and Worry and Felt Isolation were 0.834, 0.843, and 0.779, respectively.

**Personal Growth.**—The Hogan Grief Reaction Checklist (Hogan, Greenfield, & Schmidt, 2001) is a 61-item, self-report, Likert-style questionnaire empirically derived from bereaved individuals. It yields five analytically derived scales of grief: Despair, Panic Behavior, Blame–Anger, Detachment, and Disorganization; a sixth scale measures personal growth. We used only the Personal Growth subscale in this study. Responses range from 1 = does not describe me at all to 5 = describes me very well. Higher scores on the Personal Growth subscale indicate that the person is more forgiving, compassionate, tolerant, hopeful, and caring (e.g., “Since my spouse or parent became ill, I am more compassionate toward others” and “I care more deeply for others”). Cronbach’s alpha coefficient for the personal growth subscale was $\alpha = 0.881$.

**Social Support.**—The Inventory of Social Support (Hogan & Schmidt, 2002) is a five-item, Likert-type self-report questionnaire empirically developed from bereaved participants. Higher scores indicate more support. One question is, “There is at least one person I can talk to about my grief.” Questions are scored on a 5-point response scale ranging from 1 (describes me very well) to 5 (does not describe me at all). Cronbach’s alpha coefficient for this scale was $\alpha = 0.881$.

**Severity of Alzheimer’s disease.**—The Functional Assessment Staging of Dementia (FAST; Sclan & Reisberg, 1992) is a widely used tool administered to describe the functional ability of individuals with Alzheimer’s disease. The FAST is a 16-item scale that divides function into stages (e.g., compatible with incipient, mild, moderate, moderately severe, and severe Alzheimer’s disease). Studies have demonstrated that functional decrements in Alzheimer’s disease as assessed by the FAST proceed in a hierarchical, ordinal pattern, and that this pattern is helpful in the differential assessment of disease progression (Sclan & Reisberg). Caregivers were asked to respond to specific questions describing the ability of their spouse or parent to perform certain tasks. These activities (i.e., having difficulty putting on clothing; being unable to bathe properly) identify a level of functionality that is sensitive to the progressive decline of the person with Alzheimer’s disease. The severity of disease is based on the individual’s behavioral characteristics.

**Emotional Health/Well Being.**—The Positive States of Mind scale (PSOM; Horowitz, Adler, & Kegeles, 1988) assesses the extent to which the respondent was able to achieve each of six positive states in the previous 7 days: focused attention, productivity, responsible caretaking, restful repose, sensuous nonsexual pleasure, and sharing. An example of a state is “feeling able to attend to a task you want or need to do without many distractions from within yourself.” We summed responses to the items for a total score. Response categories range from 0 = unable to achieve the state to 3 = easily achieve the state. The PSOM has been shown to be positively associated with optimistic affective states and negatively associated with pessimistic affective states. Cronbach’s alpha was $\alpha = 0.885$.

**Coping.**—We assessed coping by using the Brief Cope Inventory (BC; Carver, 1997; Carver, Scheier, & Weintraub, 1989). The BC contains 28 questions; there are 14 coping reactions with 2 questions for each. We asked participants to identify ways they were “coping with the stress in your life since your spouse or parent developed a memory loss problem.” Items include the following: “I’ve been taking action to try to make the situation better,” “I’ve been getting help and advice from other people,” and “I’ve been praying and meditating.” We summed the responses for each of the subscales. We found that 10 subscales (Substance Use, Emotional Support, Reframing, Instrumental Support, Venting, Planning, planning,...

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Humor, Acceptance, Religion, and Self-Blame) had acceptable reliabilities and thus used them in our analysis (Nunnally & Bernstein, 1994). Cronbach’s alpha ranged from $a = 0.682$ to $a = 0.870$.

Depression.—We assessed depressive symptoms with the 20-item Center for Epidemiologic Studies–Depression scale (CES-D; Radloff, 1977). The CES-D measures a range of cognitive, affective, motivational, and somatic symptoms. Scores are computed by summing ratings for how frequently each symptom occurred during the previous week. A person with a score of 16 or higher on the CES-D is generally considered at risk for clinical depression (Radloff). Cronbach’s alpha was $a = 0.889$.

Marital Adjustment.—We measured marital adjustment in spouses of individuals with Alzheimer’s disease by using the Revised Dyadic Adjustment Scale (RDAS; Crane, Busby, & Larson, 1991). The RDAS is a self-report instrument with 14 questions that are measured on a 5-point fixed format ranging from 5 = always agree to 0 = always disagree. Scores range from 0 to 69; higher scores indicate a more adjusted relationship. The researchers revised the instrument by using a sample of 242 couples, 98 seeking marital therapy and a control group of 144 nondistressed couples. For the control group, $M = 52$ (SD = 7); for the distressed group, $M = 42$ (SD = 8; see Busby, Christensen, Crane, & Larson, 1995). Cronbach’s alpha for the total RDAS was $a = 0.872$.

Data Analysis

Analyses included descriptive statistics of mean, standard deviation, frequencies, and percentages. We made comparisons between groups by using independent chi-square tests, group $t$ tests, analyses of variance, and multivariate analyses of variance. We assessed relationships between variables by using correlations and hierarchical regression analyses.

Results

The ages of the participants ranged from 20 to 93 years. The majority of the 201 participants were Caucasian, Protestant, female, and had a college degree. As we expected, the spouses were significantly older than the adult children and had a lower level of education. There were more male caregivers among the spouses than there were among the adult children. The majority of spouses and adult children indicated that they received a great deal of support from their religious beliefs (see Table 1).

Moderately severe Alzheimer’s disease was the most prevalent disease severity category among the individuals with dementia, accounting for 46.3% of the participants; 26.4% of the participants had severe and 27.3% had mild to moderate Alzheimer’s disease. There were no significant differences in the severity of disease of the person with Alzheimer’s disease in regard to relationship of the participant: $\chi^2 (2, N = 201) = 1.11, p = .575$.

Support group attendance was reported by significantly more spouses than adult children. The majority of those in attendance indicated they found the group experience helpful. Some participants (17.8%) indicated that they discontinued group attendance because the facilitator failed to redirect emotional venting by participants. Significantly more spouses than adult children indicated health changes since the person with Alzheimer’s disease was diagnosed.

Marital Adjustment

Scores for marital adjustment of spouses of individuals with Alzheimer’s disease ($n = 87$) ranged
from 26 to 69, with a mean score of 52.49 (SD = 7.89) for the group indicating an average rating of a non-distressed marital relationship. There were no significant correlations between the RDAS and grief scores on Worry and Felt Isolation (r = –.137, p = .21), Heartfelt Sadness and Longing (r = .024, p = .83), Personal Sacrifice Burden (r = –.074, p = .50), and Total Grief Score (r = –.062, p = .57). There were no significant differences in the rating of the marital relationship dependent on whether the person with Alzheimer’s disease lived in the home (n = 56, M = 52.02, SD = 7.56) or out of the home (n = 31, M = 53.34, SD = 7.95); t(85) = –.74, p = .459.

Coping Strategies

We used a two-way multivariate analysis of variance (MANOVA) to compare the individual coping strategies utilized by caregivers of individuals with Alzheimer’s disease by relationship and place of residence. There was a significant difference based on relationship, F(10, 187) = 3.27, p = .001, and place of residence, F(10, 187) = 2.18, p = .021. Our univariate post hoc analysis revealed that spouses differed from adult children in regard to their use of substances, venting, reframing, and humor; F(1, 196) = 4.12, 9.80, 5.05, and 19.16 (p < .05), respectively. Each of these coping strategies was used significantly more by the adult child than by the spouse of the person with Alzheimer’s disease (see Table 2). In regard to the place of residence, planning was the only coping strategy that differed. Caregivers of individuals living at home scored higher (M = 2.98, SD = 0.82, n = 96) than did the caregivers of individuals with Alzheimer’s disease living out of the home (M = 2.68, SD = 0.94, n = 105). Both spouses and the adult children used planning to a greater extent if the person with Alzheimer’s disease lived in the home than if the caregivers of the person lived out of the home; F(1, 196) = 5.88, p = .016.

Intensity of Grief Experienced in Relation to Place of Residence

We used a two-way MANOVA to examine the impact of place of residence and caregiver relationship on level of grief. There was a significant interaction effect between place of residence and relationship to the person with Alzheimer’s disease for each of the subscales of Personal Sacrifice Burden, Worry and Isolation, and Heartfelt Sadness and Longing, with respective values of F(1, 197) = 7.00, p = .009; F(1, 197) = 7.12, p = .008; and F(1, 197) = 6.51, p = .011. Therefore, we stratified the data according to the place of residence of the person with Alzheimer’s disease, and we conducted separate analyses examining the level of grief for spouses and for adult children in relation to their place of residence. For the caregivers of individuals with Alzheimer’s disease living at home, there were no significant differences between the spouse and the adult child in regard to any of the grief subscales. However, when the person with Alzheimer’s disease lived out of the home, then spouses scored significantly higher on all of the grief subscales. They experienced significantly more personal sacrifice burden, worry and felt isolation, and heartfelt sadness and longing than the adult children caregivers (See Table 3).

Intensity of Grief Relative to the Stage of Disease

We performed a two-way MANOVA to examine the association between the relationship of the participant to the person with Alzheimer’s disease, severity of the disease, and the level of grief. There was no significant difference in the level of grief based on the relationship to the person with Alzheimer’s disease. As we expected, there was a significant difference in the level of grief in regard to the severity of disease; F (6, 386) = 3.825, p = .001. Our univariate post hoc
analysis revealed a significantly higher level of heart-felt sadness and longing in the moderate and severe Alzheimer’s disease group as compared with the mild group, regardless of the relation to the person with Alzheimer’s disease; \( F(2, 195) = 7.662, p = .001 \). There was no significant difference in regard to worry and isolation or personal sacrifice burden as the severity of the disease increased.

**Association Between the Level of Grief and Individual Factors, Emotional Well-Being, Coping, and Depression–Stress–Burden Symptoms (Caregiver Grief Model)**

Using the modified Marwit–Meuser–Sanders Caregiver Grief model, we performed hierarchical regression analyses that were based on the place of residence of the person with Alzheimer’s disease with the level of grief as the dependent variable. Because of the interaction of the place of residence and the relation to the person with Alzheimer’s disease, we performed two separate regression analyses. One analysis was for individuals living at home, \( F(12, 79) = 9.76, p < .0005 \), and another was for those living out of the home, \( F(12, 90) = 10.36, p < .0005 \). Each regression included individual and situational factors of severity of illness, hours of care, social support, and relationship to the person with Alzheimer’s disease, followed by the measure of emotional health (PSOM). Next, we entered the coping strategies that were significantly correlated to the MM-CGI-SF total score (emotional support, venting, planning, acceptance, religion and self-blame), followed by measures of the depression–stress–burden constellation (CES-D). The resultant models are found in Table 4.

For spouses and adult children who are caregivers for individuals with Alzheimer’s disease living at home, 59.7% of the variance in their level of grief was explained by the model. The relationship to the individual with Alzheimer’s disease (spouse or adult child) was not statistically significant in the final equation for this group. As positive states of mind increased, the level of grief decreased. As venting and depression increased, the level of grief increased.

For caregivers of individuals with Alzheimer’s disease living out of the home, 58.0% of the variance in grief was explained by the model. Adult children experienced significantly less grief than the spouses did. For this group, as planning, self-blame, and depression increased, grief increased.

**Personal Growth**

We performed a two-way analysis of variance to examine the association between the relationship of the participant to the person with Alzheimer’s disease, place of residence, and the level of personal growth. There was no significant difference in the magnitude of personal growth based on the place of residence, \( F(1, 197) = .026, p = .873 \), but there was a significant difference in personal growth based on the relationship of the caregiver to the person with Alzheimer’s disease, \( F(1, 197) = 4.05, p = .046 \). Adult children scored significantly higher on personal growth (\( M = 3.29, SD = 0.739 \)) than did the spouses of the individuals with Alzheimer’s disease (\( M = 3.07, SD = 0.717 \)).

**Factors Contributing to Personal Growth (Caregiver Grief Model)**

Using the modified Marwit–Meuser–Sanders Caregiver Grief model, we performed a hierarchical regression analysis with the caregiver’s level of personal growth as the dependent variable; \( F(13, 186) = 12.09, p < .0005 \). In the first step of the regression, we entered the individual and situational factors of severity of illness, hours of care, social support and relationship to the person with Alzheimer’s disease, followed by the measure of emotional health (PSOM). We then entered the coping strategies that
were significantly correlated to personal growth (emotional support, instrumental support, acceptance, reframing, religion, and self-blame), followed by the measure of the depression–stress–burden constellation (CES-D). The resultant model is found in Table 5.

Forty-six percent of the variance in personal growth was explained by the model. The level of social support, coping by reframing, and coping by religion significantly contributed to the caregivers’ personal growth, whereas the level of depression contributed to a decrease in personal growth.

### Discussion

In this study, we describe the grief and personal growth experiences of spouses and adult children of individuals with Alzheimer’s disease who provide primary or secondary care. The modified Caregiver Grief model (Meuser et al., 2004) provided a framework for analyzing the relationship of individual and situational factors, emotional health or well-being, coping strategies, social support and depressive symptoms on grief, and personal growth. Our findings indicate that different factors influence grief and personal growth for caregivers of individuals with Alzheimer’s disease. This suggests that the processes that are associated with these constructs are different.

This study identifies differences in how adult children and spouses of people with Alzheimer’s disease grieve the losses associated with this progressive disease. Although grief is universal and occurs after any significant bond is broken, findings from Meuser and Marwit’s caregiver study suggest that grief in the dementia caregiving situation is qualitatively and quantitatively different than other types of grief. They report a relationship between higher levels of grief and increased depressive symptoms, burden, and stress. Results from this study are consistent with Meuser and Marwit’s indication of an association between higher levels of grief with depressive symptoms and decreased well-being. At 8 years on average, the caregiving experience in dementia lasts longer than it does for most chronic illnesses. Backed by what caregivers reported, without proper attention or support caregivers are at risk for other problems over time (Meuser et al., 2004). Use of the MM-CGI-SF enabled us to identify participants whose scores were elevated, which indicated a high level of grief (Marwit & Meuser, 2005). Practitioners should consider using this instrument as a screening tool to identify caregivers who may benefit from additional support.

The high prevalence of depression in dementia caregivers has been well documented (Buckwalter et al., 1999). Zisook and Shuchter (2001) distinguish between depressive symptoms of grief that do not require intervention and a major depressive episode that requires professional intervention, including “the best combinations of education, psychotherapy, and pharmacotherapy” (p. 794). Practitioners need

### Table 4. Regression Analysis of Factors Contributing to Grief by Place of Residence

<table>
<thead>
<tr>
<th>Factor</th>
<th>Lives in the Home</th>
<th></th>
<th>Lives out of the Home</th>
<th></th>
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<tbody>
<tr>
<td>Individual, situational, and cultural</td>
<td>.168**</td>
<td></td>
<td>.221**</td>
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<tr>
<td>Relationship (spouse–adult child)</td>
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<td></td>
<td>-.195*</td>
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<td>Severity of disease</td>
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<td>Hours of care</td>
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<td>Emotional health, well-being</td>
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<td>.082**</td>
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<td>Positive states of mind</td>
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<td>Coping</td>
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<td>Coping by acceptance</td>
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<td>Coping by self-blame</td>
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<td>.287**</td>
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<td>Depression (CES-D)</td>
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<td>.382**</td>
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</table>

\[ R^2 = .597 \quad F(12,79) = 9.76 \quad p < .0005 \]

\[ R^2 = .580 \quad F(12,90) = 10.36 \quad p < .0005 \]

Notes: Total number of spouses and adult children, N = 201; lives in the home, n = 96; lives out of the home, n = 105. CES-D = Centers for Epidemiological Studies–Depression scale. *p < .05; **p < .01.
to be attentive to the fact that depression and grief are overlapping but different constructs. Reynolds and colleagues (1999) found that treating bereavement-related depression by the use of interpersonal therapy and antidepressant medications decreased depression but had a minimal impact on decreasing grief symptoms. Although treating depression can greatly diminish suffering and promote well-being, it is necessary for the clinician to provide support for grief-related issues.

According to Carver and colleagues (1989), focusing on the distressing situation may distract a person from engaging in active coping efforts. A health care provider may assist a caregiver redirect emotion-focused coping by reframing a stressful situation into more positive terms, moving toward acceptance. Thus the caregiver may resume more active, problem-focused coping actions. Findings from several bereavement-intervention studies are informative on this point. Although suppression of grief-related distress may be maladaptive (Stroebe, Schut, & Stroebe, 2005), increasing evidence suggests that rumination over grief-related distress is also maladaptive. Bonanno (2001) found that disclosure of negative emotions in bereaved individuals increased distress and somatic complaints whereas regulated or minimized disclosure of emotions and expression of positive emotions was related to recovery. Stroebe, Stroebe, Schut, Zech, and van den Bout (2002) found no evidence that disclosure of emotions facilitated adjustment. On the basis of the results from this study and the accumulating body of knowledge on emotional disclosure, health care providers need to consider providing a balance between emotional disclosures about circumstances that cannot be changed and a positive reframing of one’s life experiences that ultimately may result in personal growth.

Moskowitz, Folkman, and Acree (2003) have suggested that “positive emotions in the context of stress sustains coping efforts, facilitates cognitive processes, counteracts the negative physiological consequences of stress, elicits social support, and restores depleted social and psychological resources” (p. 493). We considered the measure of emotional health or well-being (positive states of mind) in this study because it is amenable to change. An example of how a health care professional could elicit positive emotions is by having a caregiver describe something that happened in the past week that made the person feel good, that was meaningful, and helped get him or her through the day (Moskowitz et al.).

Planning involves thinking about the problem, considering what steps to take, and coming up with action strategies (Carver et al., 1989). The process of thinking about the next steps in the Alzheimer’s disease caregiving situation can be particularly distressing because those decisions (e.g., placement in an extended care facility, future hospice care) result in further loss experiences leading to increased grief. However, during the interviews, the majority of the participants indicated that information about the progression of the disease and care options was helpful in the process of making realistic plans for the future.

We expected religious coping to contribute to decreased levels of grief either by providing a belief system that allows an individual to deal differently with grief-related losses or by providing a social network. Findings regarding religious coping with loss are mixed, with some studies finding a beneficial effect (Nolen-Hoeksema, 2001; Wyatt, Friedman, Given, & Given, 1999) and others reporting a negative effect (Rosik, 1989). Stroebe and Schut (2001) caution that although someone finds a coping mechanism helpful, it does not necessarily indicate that this mechanism actually does facilitate adjustment. Even though religious coping did not contribute to a decrease in the level of grief, it did contribute to increased personal growth. Future studies should examine additional objective indicators of religiosity such as degree of faith and frequency of religious behaviors.

In the bereavement literature, some researchers have suggested that social support may not uniquely help spouses who are grieving the losses related to the particular person who was their support (Stroebe, Zech, Stroebe, & Abakoumkin, 2005).

### Table 5. Regression Analysis of Factors Contributing to Personal Growth

<table>
<thead>
<tr>
<th>Factors</th>
<th>β</th>
<th>ΔR²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual, situational, and cultural factors</td>
<td>.220**</td>
<td></td>
</tr>
<tr>
<td>Relationship</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Spouse–adult child)</td>
<td>.104</td>
<td></td>
</tr>
<tr>
<td>Severity of disease</td>
<td>.078</td>
<td></td>
</tr>
<tr>
<td>Hours of care</td>
<td>.116</td>
<td></td>
</tr>
<tr>
<td>Social Support</td>
<td>.147*</td>
<td></td>
</tr>
<tr>
<td>Place of residence</td>
<td></td>
<td>.054</td>
</tr>
<tr>
<td>(home—not home)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional health, well-being</td>
<td>.036**</td>
<td></td>
</tr>
<tr>
<td>Positive states of mind</td>
<td>.094</td>
<td></td>
</tr>
<tr>
<td>Coping</td>
<td></td>
<td>.178**</td>
</tr>
<tr>
<td>Emotional support</td>
<td>.007</td>
<td></td>
</tr>
<tr>
<td>Instrumental support</td>
<td>.053</td>
<td></td>
</tr>
<tr>
<td>Coping by acceptance</td>
<td>.022</td>
<td></td>
</tr>
<tr>
<td>Coping by reframing</td>
<td>.367**</td>
<td></td>
</tr>
<tr>
<td>Coping with religion</td>
<td>.154*</td>
<td></td>
</tr>
<tr>
<td>Coping by self-blame</td>
<td>−.008</td>
<td></td>
</tr>
<tr>
<td>Symptoms of depression–stress–burden</td>
<td>.024*</td>
<td></td>
</tr>
<tr>
<td>Depression (CES-D)</td>
<td>−.243**</td>
<td></td>
</tr>
</tbody>
</table>

\[ R^2 = .458 \]
\[ F(13, 186) = 12.09 \]
\[ p < .0005 \]

Notes: Total number of spouses and adult children, \( N = 201 \). CES-D = Centers for Epidemiological Studies–Depression scale.

* \( p < .05 \), ** \( p < .01 \)
These authors found little evidence that social support buffers against the negative impact of loss. This finding would imply that grief is a process and that individuals cope with their grief at their own pace; the level of social support may neither accelerate nor improve the process. Although social support did not contribute to a decrease in the level of grief, it did contribute to personal growth. There is a large body of empirical evidence about the importance of social support and supportive counseling in decreasing depressive symptoms in caregivers (Mittelman, Roth, Coon, & Haley, 2004). The impact of place of residence of individuals with Alzheimer’s disease on the level of grief experienced was different for spouses and adult children. These findings are consistent with those of Rudd and colleagues (1999), who found that spouse nursing home caregivers expressed significantly higher levels of sadness and guilt than did home caregivers. The decreased burden of the adult child after parent’s institutionalization is consistent with findings of Meuser and Marwit (2001). The grief response in relation to place of residence should be kept in mind when families are making the decision to institutionalize a person with Alzheimer’s disease. Depending on the particular circumstances, family dynamics and differences in perceptions should be assessed and supportive interventions provided for family members when indicated. For many spouses, further losses are experienced after a spouse has been placed in a nursing home, including loss of the partner’s physical presence in their home and loss of control of the caregiving situation. Supportive interventions addressing the increased sadness and longing as well as the worry and felt isolation, especially for the spouses, are indicated. The spouse can be invited to continue participation in the caregiving role and to observe the person with Alzheimer’s disease receiving competent care. The effort to understand the complexity of the caregiving experience requires an understanding of the factors that may be associated with positive outcomes as well as negative outcomes. Like the findings by Sanders (2005) and Tarlow and associates (2006), the majority of caregivers in this study experienced personal growth (i.e., becoming more forgiving, compassionate, tolerant, helpful, and caring) as a result of the caregiving experience. Future prospective studies should examine the impact of the caregiver’s personal growth prior to the loved one’s death on adaptation after the death. Tarlow and colleagues suggest that “positive aspects of caregiving act as mediators to ameliorate the stresses of caregiving to help maintain the quality of life for individuals” (p. 434).

Conclusion

The present study has notable strengths. To our knowledge, this is the first study that quantitatively investigates the grief and personal growth reactions of both spouses and adult children by use of the MM-CGI-SF (Marwit & Meuser, 2003). Knowing the similarities and differences will be helpful to health care providers in their efforts to recognize factors that are associated with high levels of grief and personal growth. Repeated use of an assessment tool such as the MM-CGI-SF from diagnosis to the end of life may assist practitioners in identifying those who may be at risk for complications during the caregiving experience and after the death of the loved one. High levels of grief were associated with negative mental health outcomes whereas positive psychological states of mind contributed to decreased levels of grief. Therefore, we suggest that

Limitations

There are some acknowledged limitations that must be considered when one is interpreting the results of this study. Implied causal inferences have to be interpreted with caution in cross-sectional studies. Results are correlational and cause and effect is not being implied. Self-report measures rely on the participant’s voluntary disclosure; therefore, the results are dependent on the participant’s ability to recall and document information accurately. This self-selected sample was composed of primarily Caucasian, well-educated, female caregivers. Inferences to other groups should be done with caution. Although the diagnosis of Alzheimer’s disease was previously made by a physician, the level of present functioning was determined by use of the FAST instrument (Sclan, & Reisberg, 1992). The caregiver responded to a series of questions related to the ability of the person with Alzheimer’s disease to perform tasks listed in an ordinal manner. The severity of illness is determined by the highest level of functioning performed by the person with Alzheimer’s disease. Others have identified that this method may result in a decreased level of assessment as a result of the emotionality of the family member. However, we felt that the method of administration was sufficient for us to assess functional capacity “because an individual’s grief reaction is, by definition, tied to his or her perception of loss” (Marwit & Meuser, 2002, p. 753). Findings in this study regarding personal growth were based on an instrument developed to assess postdeath growth. An instrument specifically developed for Alzheimer’s caregivers, Positive Aspects of Caregiving (Tarlow et al., 2006), from the Resources for Enhancing Alzheimer’s Caregiver Health (known as REACH) studies, would be appropriate to use in future studies. Additional information about the marital relationship over and above the marital adjustment rating scale such as the number of marriages, divorces, and length of marriage may have impacted the level of grief in the spouse caregivers.
future prospective intervention studies should be conducted that explore the impact of enhancing positive psychological states prior to the loved one’s death on the grief the caregiver experienced after the death.

Nursing home personnel need to address the possible increased grief response in spouses after their loved one’s nursing home placement. Directors of nursing and social services need to be responsive to the individual grief needs of the caregivers. An awareness of the possibility of strained family dynamics at the time of nursing home placement can lead to the development of interventions targeted to the special needs of spouses and adult children. Providing the opportunity for continued participation in the caregiving process without compelling family members to do so is recommended.

Although social sharing and emotional disclosure are often regarded as helpful, venting of emotions did not contribute to lower levels of grief in this study. Health care providers should consider balancing emotional disclosure about circumstances that cannot be changed with positive reframing, which is associated with personal growth. Although social support did not contribute to decreased grief, it was a significant factor in increasing personal growth.

References


