Grief Among Dementia Caregivers: A Comparison Of Two Assessment Systems

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GRIEF AMONG DEMENTIA CAREGIVERS: A COMPARISON OF TWO ASSESSMENT SYSTEMS

by

Elizabeth Anne Mulligan

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Abstract

Research suggests that family caregivers of people with dementia may experience grief prior to the death of their care recipients, in part because of the series of losses they experience and the chronic nature of caregiving. Methods for assessing predeath grief, however, are just beginning to be developed, and basic questions about measurement remain. The purpose of the current study was to identify areas of overlap and disjunction in two self-report measures of predeath grief, one adapted from the postdeath literature (the Prolonged Grief Disorder Inventory) and one designed specifically for use with dementia caregivers (the Marwit-Meuser Caregiver Grief Inventory-Short Form). Results from 202 spousal and adult child caregivers of people with dementia suggest that grief is an important component of the caregiving experience, and that it is related to, but distinct from, depression. Based on their psychometric properties and on confirmatory factor analyses, both measures appear to be appropriate for use with dementia caregivers. There were several areas of overlap between the measures in terms of their relationships with characteristics of caregivers and of the caregiving situation (e.g., spousal versus adult child relationship with the care recipient), although these associations varied somewhat across subscales. One area of discrepancy between the measures was the number of caregivers identified as potentially in need of intervention; the Prolonged Grief Disorder Inventory was a more conservative tool. This dissertation represents an important first step in understanding the grief experienced by dementia caregivers. Future research is needed to determine if predeath grief as measured by each instrument is predictive of long-term distress and dysfunction in the context of longitudinal studies.
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Grief is a combination of affective (e.g., anger), cognitive (e.g., preoccupation with thoughts about the loss), and behavioral (e.g., avoidance) reactions to a loss (Stroebe, Hansson, Stroebe, & Schut, 2001b). Traditional theories of the natural history of grief propose that people go through stages – shock and disbelief, followed by separation distress, despair and anger, and finally acceptance (Bowlby, 1980; Kubler-Ross, 1970; Parkes & Weiss, 1983) – but empirical evidence suggests that normal grief is characterized by overlapping reactions and tasks (Davis, Nolen-Hoeksema, & Larson, 1998; Prigerson & Jacobs, 2001; Stroebe & Schut, 2001). Theories about the resolution of grief typically describe tasks such as accepting the loss, finding some meaning from the loss, and adjusting to a new life (Neimeyer, Prigerson, & Davies, 2002; Worden, 1991).

For most people grief does not result in any serious negative consequences (Bass, Bowman, & Noelker, 1991; Mullan, 1992; Stroebe, Hansson, Stroebe, & Schut, 2001a). Over time, people who grieve are able to form new relationships, participate actively in work and leisure, and feel hopeful about the future. For a significant minority of people (10-20%), however, symptoms are more severe and take a longer time to resolve (Barry, Kasl, & Prigerson, 2002; Latham & Prigerson, 2004; Prigerson, Bierhals, Kasl, & Reynolds, 1996). Not only does their sense of shock and longing remain constant, but they are also unable to adjust to life without the deceased (Prigerson et al., 1999). They may be preoccupied with intrusive thoughts and have difficulty forming new connections with people or participating in meaningful activities (Prigerson, Vanderwerker, &
Maciejewski, 2008). These people experience what has come to be called prolonged grief disorder.

In the sections that follow, I review research on the development of diagnostic criteria for prolonged grief disorder. I then argue for the usefulness of applying this diagnostic entity to dementia caregivers, a group of people who experience grief prior to physical death. I discuss predeath applications of the prolonged grief disorder model and compare them with a second model of dementia caregiver grief developed by Marwit and Meuser (2002). Finally, I describe potential risk and protective factors for predeath grief among dementia caregivers.

**Development of Prolonged Grief Disorder as a Unique Syndrome**

Empirical evidence suggests that prolonged grief disorder may deserve a place in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association, 2000). In particular, researchers contend that prolonged grief disorder is distinct from other clinical syndromes like major depression based on its unique symptoms, risk factors, associations with negative outcomes, and responses to interventions (Lichtenthal, Cruess, & Prigerson, 2004; Prigerson et al., 2008; Zhang, El-Jawahri, & Prigerson, 2006). Table 1 includes a full list of the proposed diagnostic criteria. These criteria were developed based on a series of studies that used principal components analysis (Prigerson, Frank, Kasl, & Reynolds, 1995), exploratory factor analyses (Prigerson et al., 1996, 1999, 2008; Prigerson & Jacobs, 2001; Prigerson, Maciejewski et al., 1995), expert consensus (Prigerson et al., 1999), confirmatory factor analysis (Boelen & van den Bout, 2005), and item response theory (Prigerson & Jacobs;
Two groups of researchers proposing different diagnostic systems compromised for the latest version of the diagnostic criteria (Horowitz, Siegel, Holen, & Bonanno, 1997; Prigerson et al., 1999).

In order to receive a diagnosis of Prolonged Grief Disorder using the most recent criteria (Prigerson et al., 2008), respondents must report that they experience at least one symptom of separation distress (e.g., longing for the deceased) daily; endorse 5 of the 9 cognitive, emotional, and behavioral symptoms at least daily or “quite a bit”; and report impairment in functioning. These symptoms must be present for at least 6 months, a criterion that was proposed because (a) diagnosis at that point is most predictive of negative longitudinal outcomes, and (b) grief is less likely to resolve on its own after that period of time (Prigerson, Bierhals, Kasl, & Reynolds, 1997). The sensitivity, specificity, and positive and negative predictive values of these criteria are all above .94 when compared to a criterion standard developed by maximizing agreement between diagnoses made using a minimum-threshold grief attribute assessment in item response theory and diagnoses of prolonged grief disorder made by trained clinical raters (κ≥ .90) (Prigerson et al., 2008).

Longitudinal studies have shown that certain individual difference variables place people at increased risk for developing prolonged grief disorder. In particular, perceived lack of social support, female gender, African American race, lack of preparation for the death, insecure attachment style, childhood abuse and neglect, and marital closeness are all associated with the development of prolonged grief (Barry et al., 2002; Chen et al., 1999; Goldsmith, Morrison, Vanderwerker, & Prigerson, 2008; Silverman, Johnson, &
Prigerson, 2001; Vanderwerker & Prigerson, 2004). In contrast, with the exception of female gender and childhood abuse and neglect, these risk factors are not associated with the development of bereavement-related major depressive disorder or posttraumatic stress disorder (Zhang et al., 2006). These risk factors suggest a unique etiology for prolonged grief disorder.

Additionally, based on longitudinal studies in which prolonged grief symptoms served as an independent variable, prolonged grief disorder is associated with distinct physical and mental health outcomes. For example, high symptom levels of prolonged grief at 6 months postdeath were associated with more physical health events, hospitalizations, cases of cancer and high blood pressure, and depressive symptoms at 12 to 15 months postdeath (Chen et al., 1999; Prigerson et al., 1996, 1997). Even after controlling for depression at 3 to 6 months postdeath, more grief symptoms at 3 to 6 months postdeath were associated with lower self-esteem, more depressive symptoms, and poorer sleep quality at 18 months postdeath (Prigerson, Frank et al., 1995).

Several researchers have conducted reviews and meta-analyses of treatment studies for grief and concluded that, in general, treatments for grief are not very effective (Jacobs & Prigerson, 2000; Jordan & Neimeyer, 2003; Kato & Mann, 1999; Schut, Stroebe, van den Bout, & Terheggen, 2001). Because the majority of these treatment studies were open to all mourners, one possible explanation for these findings is that the heterogeneity of the samples may have diluted treatment effects. These researchers have suggested that interventions should focus on high-risk mourners, and subsequent postdeath interventions have targeted this group of bereaved individuals. Additionally,
because prolonged grief disorder was not responsive to traditional treatments for depression, such as interpersonal therapy and tricyclic antidepressants (Pasternak, Reynolds, Schlernitzauer, & Hoch, 1991; Reynolds et al., 1999), novel treatments have been developed.

In the first randomized controlled trial for the treatment of prolonged grief disorder, Shear, Frank, Houck, and Reynolds (2005) compared a 16-session therapy designed specifically to address prolonged grief disorder with standard interpersonal therapy. All participants met criteria for prolonged grief disorder. In comparison to the interpersonal therapy group, participants in the prolonged grief disorder therapy group improved significantly more on measures of grief, depression, and functional adjustment, and they responded to the intervention more quickly. Other teams of researchers have had similar results with cognitive-behavioral interventions designed specifically for people with prolonged grief disorder (Boelen, de Keijser, van den Hout, & van den Bout, 2007; Wagner, Knaevelsrud, & Maercker, 2006).

To summarize, in comparison to other disorders, prolonged grief disorder has unique symptoms, risk factors and etiology, and responses to interventions (Reynolds et al., 1999; Shear et al., 2005; Zhang et al., 2006). Most studies have focused on prolonged grief after death, but researchers have argued that the diagnostic criteria for prolonged grief disorder can be applied to losses other than and prior to death (Prigerson et al., 1999, 2008). One group for whom the diagnosis may be relevant is people caring for individuals with dementia. Dementia caregivers may experience symptoms of predeath prolonged grief, such as yearning for their family member to be healthy again and feeling
shocked about the person’s illness. The sections that follow describe why dementia caregivers may be susceptible to predeath prolonged grief, and they detail two methods for assessing grief among caregivers.

**Predeath Grief Among Dementia Caregivers**

**Why might dementia caregivers be susceptible to predeath prolonged grief?**

As of 2007 nearly 10 million Americans provided unpaid care to a person with dementia, and the majority of these caregivers were family members (Alzheimer's Association, 2008). Family caregivers of people with dementia may be susceptible to predeath grief because of several characteristics of this particular disease. First, providing care for a person with dementia is especially demanding because, in comparison with other chronic illnesses, people provide more hours of care and provide care for a longer period of time (Alzheimer's Association and National Alliance for Caregiving, 2004). Due to the slow progression of the disease, caregivers experience a series of losses over a period of years, including their relationship with the care recipient, the ability to control and plan for the future, prior roles, jobs, and social relationships (Adams & Sanders, 2004; Loos & Bowd, 1997; Meuser & Marwit, 2001; Sanders & Corley, 2003). These losses accumulate as the disease progresses (Ponder & Pomeroy, 1996), and caregivers may not have the time to process or accept these losses as they are still actively engaged in providing care. Additionally, caregivers’ personal and social resources may diminish over time, leaving them with fewer resources when coping with death (Bodnar & Kiecolt-Glaser, 1994).

Second, care recipients become increasingly cognitively impaired and confused as the disease progresses. They are physically alive but not psychologically present, a
phenomenon that Pauline Boss (1999) refers to as ambiguous loss for caregivers. The body is there, while the person gradually recedes. Caregivers may feel unsure about how to cope with this loss of personhood. Because the care recipient is still alive, friends, family members, and caregivers themselves often do not realize that they are grieving and may not view grief as an acceptable experience (Adams & Sanders, 2004; Meuser, Marwit, & Sanders, 2004; Waldrop, 2007). Even if caregivers are able to recognize their feelings, expressing grief while the patient is still alive may be stigmatized (Jones & Martinson, 1992; Sanders & Corley, 2003), and healthcare professionals may mislabel grief as depression or burden (Ponder & Pomeroy, 1996). Therefore, caregivers may experience a form of disenfranchised grief by which they are neither able to express nor receive support for their grief (Doka, 2004).

Third, the long-term, unpredictable course of dementia and care recipients’ problem behaviors (e.g., wandering, mood swings) foster feelings of ambivalence among caregivers (Farran, Keane-Hagerty, Salloway, & Kupferer, 1991; Sanders, Ott, Kelber, & Noonan, 2008). Caregivers may experience a mixture of feelings including anger as they continue to make more personal sacrifices, bitterness that they are responsible for providing care, longing for the prior relationship with the care recipient, and guilt about their wish for fewer caregiving responsibilities (Dupuis, 2002; Rudd, Viney, & Preston, 1999; Sanders et al.; Walker & Pomeroy, 1996). These mixed feelings can remain even after institutionalization of the care recipient, when caregivers feel guilty about their decision and question the utility of their visits (Dupuis; Loos & Bowd, 1997; Rudd et al.).
In spite of this potential susceptibility to predeath grief, interventions for dementia caregivers have focused on depression, strain, and burden rather than grief (Schulz et al., 2002). These interventions have been modestly successful, but their clinical significance has been questioned (Gitlin et al., 2003; Pinquart & Sorensen, 2006; Schulz et al.). For example, in a meta-analysis of caregiver interventions, Sorensen, Pinquart and Duberstein (2002) found statistically significant improvements of only 0.14 to 0.41 standard deviation units for outcomes such as depression, burden, well-being, and disease knowledge. Researchers have contended that some negative aspects of caregiving have been overlooked by current interventions (Frank, 2008; Sanders et al., 2008). Predeath grief may be one such phenomenon. It is worth noting that researchers are not proposing that interventions for grief replace existing interventions for depression and burden, but rather that they be added to multi-component interventions that can be tailored based on each caregiver’s needs (Sanders & Adams, 2005).

Additionally, interventions for predeath grief may be important given the suggestion that high levels of grief may be a causal factor for predeath burden and depression (Meuser et al., 2004). Predeath grief may therefore contribute secondary disability that could be avoided. There is also limited evidence that predeath support is associated with better postdeath adjustment. In particular, Schulz, Boerner, Shear, Zhang, and Gitlin (2006) found that dementia caregivers who were enrolled in psychosocial or skills-training interventions prior to the death of their care recipient were significantly less likely to meet criteria for postdeath prolonged grief disorder in comparison with control group participants. As in the postdeath literature, determining
which caregivers are experiencing distressing grief responses is important because they can then be targeted for interventions. It may be possible to identify these caregivers using the diagnostic criteria for prolonged grief disorder (Prigerson et al., 2008) or through another measure developed specifically for use with dementia caregivers (Marwit & Meuser, 2002).

**Applying Prigerson’s model to predeath caregivers.** One way to identify which dementia caregivers might benefit from interventions for grief is to apply Prigerson and colleagues’ (2008) diagnostic criteria for prolonged grief disorder. These researchers developed a measure for predeath grief, the Prolonged Grief Disorder Inventory (PG-12), which was adapted from the postdeath Inventory of Complicated Grief-Revised (Prigerson & Jacobs, 2001). They reworded items from the postdeath inventory by replacing any mention of “death” with “illness.” For example, “I cannot accept the death” became “Have you had trouble accepting the patient’s illness?”

Researchers have used various versions of the PG-12 in samples of different types of predeath caregivers. Across studies, predeath prolonged grief disorder symptoms were weakly to modestly correlated with depressive symptoms (e.g., $r = .16$ in Tomarken et al., 2008; $r = .32$ in van Doorn, Kasl, Beery, Jacobs, & Prigerson, 1998). In a study of 315 dementia caregivers whose family members were in a nursing home, Kiely, Prigerson and Mitchell (2008) distinguished predeath grief symptoms, as measured by a 10-item version of the PG-12, from depressive symptoms using an exploratory factor analysis with varimax rotation. They restricted their analysis to two factors that accounted for 44% of the common variance. Only one item, “Your emotional distress about the care recipient’s
illness has significantly impaired your social, occupational, or other areas of functioning” loaded similarly on both the grief and depression factors. All remaining items had high factor loadings on either the grief or depression factor (ranging from .46 to .70) and low loadings on the other factor (ranging from -.12 to .28).

Additionally, several studies distinguished symptoms of predeath prolonged grief from symptoms of depression based on their unique associations with characteristics of caregivers and of the caregiving situation. Van Doorn and colleagues (1998) found that an insecure attachment style and a security-enhancing marriage were independently associated with symptoms of prolonged grief in a mixed caregiver sample, but these two variables were not predictive of symptoms of depression. In Beery and colleagues’ (1997) mixed caregiver sample, changes in role function (e.g., changes in time spent on recreational activities) were only predictive of depression, and duration of caregiving was only predictive of grief. Of note, both groups of researchers used a 19-item version of the PG-12.

In addition to differentiating grief from depressive symptoms, one group of researchers has investigated the prevalence of prolonged grief disorder among caregivers based on an earlier version of the diagnostic criteria and a 19-item version of the PG-12. Prigerson and colleagues (2003) found that 8% of a sample of caregivers of people with cancer met diagnostic criteria for predeath prolonged grief disorder. This rate is slightly lower than the rate of prolonged grief disorder found in postdeath studies (rates of 10 to 20%; Barry et al., 2002; Goldsmith et al., 2008; Latham & Prigerson, 2004).

All of these studies provide support for applying Prigerson and colleagues’ model
of postdeath prolonged grief disorder to predeath samples. The PG-12, however, has ranged in length from 4 to 19 items during its evolution, and no studies have used the latest 12-item version (Prigerson & Maciejewski, 2008) in a predeath sample of caregivers.

**A dementia-specific model for caregivers.** Meuser and Marwit (2001) conducted focus groups of dementia caregivers and identified important aspects of grief in this population, such as frustration and anger about the demands of caregiving, a longing for a time when the care recipient was healthy, and a sense of confusion and anxiety about the future. They then developed a conceptual model of grief that is specific to predeath dementia caregivers (Meuser et al., 2004). In their model predeath grief is a normal experience for caregivers, but certain caregivers may experience high levels of grief that have a negative effect on their lives due to both individual difference characteristics, such as poor coping resources, and situational factors, such as a lack of social support. Meuser and colleagues contend that treatment for grief will also affect stress, burden, depression, and well-being.

Marwit and Meuser (2002) developed a self-report instrument of predeath caregiver grief. They provided a sample of 166 caregivers with a 184-item measure consisting of direct or paraphrased quotes from the prior focus groups. A series of principal components and exploratory factor analyses of these items resulted in the 50-item Marwit-Meuser Caregiver Grief Inventory (MM-CGI). In particular, after removing 20 items with skewness greater than 1.0, the authors completed a principal components analysis with varimax rotation and concluded that the measure consisted of three distinct
factors. Sixty-four items with partial correlations and/or residuals greater than 0.2 were then dropped, and a second principal components analysis restricted to three factors was conducted. Another 33 items with factor loadings less than .4 in this analysis were removed from the measure. Principal axis factoring with oblique rotation was conducted on the remaining 69 items, and all but two double-loaded items were dropped for a final count of 50 items. This measure consists of three subscales, which also can be summed to create a total score. The first subscale, Personal Sacrifice Burden, refers to the things a person may have been forced to give up as a caregiver, including health, free time, and independence. The second subscale, Heartfelt Sadness and Longing, reflects aspects of separation distress and emotional responses to caregiving, such as yearning for the prior relationship with the care recipient. The third subscale, Worry and Felt Isolation, refers to social isolation and anxiety about disease progression.

An 18-item version of the MM-CGI was later developed using items with the highest mean intercorrelations within their subscale and the lowest mean intercorrelations with items from the other subscales (Marwit & Meuser, 2005). The short form (MM-CGI-SF) contains six items from each subscale. A total grief score also can be calculated with higher scores indicating more severe grief. Of note, a confirmatory factor analysis has not yet been conducted on either the 18-item or the 50-item version of the MM-CGI.

Each MM-CGI-SF subscale has a distinctive pattern of correlations with other caregiver outcomes, including depression, strain, well-being, and perceived family support (Marwit & Meuser, 2005). For example, Personal Sacrifice Burden is highly correlated with measures of depression, well-being, and strain (rs = .53 to .68), whereas
Heartfelt Sadness and Longing is highly correlated with depression ($r = .50$), but more modestly correlated with strain and well-being ($rs = .26$ to .38). Worry and Felt Isolation is highly correlated with perceived family support ($r = -.54$), whereas Personal Sacrifice Burden is more modestly correlated with family support ($r = -.34$), and Heartfelt Sadness and Longing is not significantly associated with this measure ($r = -.01$). The MM-CGI has been used to assess grief in other caregiving populations including cancer and acquired brain injury caregivers (Marwit, Chibnall, Dougherty, Jenkins, & Shawgo, 2008; Marwit & Kaye, 2006). In each case, the measure had a similar pattern of correlations with depression, well-being, strain, and perceived social support, providing evidence for the construct validity of the measure in these populations.

Marwit and Meuser (2002, 2005) identify caregivers as potentially in need of formal intervention if they fall one standard deviation above the sample mean on any of the subscales or on the total score. Based on this recommendation, studies have found 15% to 26% of dementia caregivers may be in need of intervention (Ott, Sanders, & Kelber, 2007; Sanders et al., 2008). Because this method is different than Prigerson and colleagues’ (2008) focus on diagnostic criteria outlined in Table 1, rates of caregivers identified as in need of intervention may vary across the two measures. This difference, however, has not been established empirically. Another way of identifying areas of overlap and disjunction between the PG-12 and the MM-CGI-SF is to investigate if these measures have similar patterns of association with demographic and care-related variables.
Risk and Protective Factors for Predeath Grief Among Dementia Caregivers

In other predeath samples of caregivers, a variety of characteristics of caregivers and of the caregiving situation have been shown to be associated with grief, including gender, relationship to the care recipient, length of time spent caregiving, severity of cognitive impairment, and living situation (Beery et al., 1997; Meuser & Marwit, 2001; Ott et al., 2007; Rudd et al., 1999). Additionally, Ott and colleagues reported an interaction between relationship to the care recipient and living situation. In particular, spouses endorsed more grief than adult children when they were not living with care recipients, but there was no difference in grief between spousal and adult child caregivers when they lived with care recipients. These variables may also be considered risk or protective factors. Identifying their associations with predeath grief is important for several reasons. First, researchers have speculated about the etiology of prolonged grief based on certain risk or protective factors. For example, finding that a longer period of caregiving is associated with more postdeath prolonged grief symptoms has led researchers to hypothesize that grief is, in part, caused by a wearing down of caregivers’ coping systems (Bodnar & Kiecolt-Glaser, 1994; Schulz, Newsom, Fleissner, Decamp, & Nieboer, 1997). Pragmatically, information on risk factors helps researchers and clinicians identify which caregivers are most susceptible to problematic grief reactions. Finally, risk and protective factors may have treatment implications. For example, lack of preparation for death is associated with postdeath prolonged grief among all types of caregivers and among dementia caregivers in particular (Hebert, Dang, & Schulz, 2006; Schulz et al.). Based on these data, researchers have proposed that effective interventions
may include providing caregivers with information about the final stages of the disease and helping caregivers accept the reality of eventual death (Schulz et al.). The current study is unique in its investigation of two other potentially important characteristics, self-reported personality traits and positive aspects of caregiving.

**Personality traits.** Prior research suggests that some personality characteristics may serve as risk factors, whereas others are protective factors in the experience of grief. For instance, low internal control beliefs (Stroebe, Stroebe, & Domittner, 1988) and emotion-oriented coping (Meuser & Marwit, 1999; Robinson & Marwit, 2006) may be risk factors for greater postdeath grief. In contrast, task-oriented coping (e.g., learning how to manage household finances) may protect people against prolonged grief responses (Meuser & Marwit), but results are mixed (Robinson & Marwit). Two studies have focused on personality traits. In each case high neuroticism as measured by the Eysenck Personality Questionnaire (Eysenck, 1975) was associated with higher levels of distress during bereavement (Middleton, Raphael, Burnett, & Martin, 1997; Robinson & Marwit). In the two studies that have investigated predeath grief, insecure attachment style (van Doorn et al., 1998) and pessimistic thinking (Tomarken et al., 2008) were associated with symptoms of prolonged grief in mixed and cancer caregiver samples.

To my knowledge, no studies have investigated the relationship between predeath grief and all of the Big Five personality traits (neuroticism, extraversion, openness, agreeableness, and conscientiousness; Costa & McCrae, 1992b). Some of these traits may have important associations with grief. For instance, a significant positive association between neuroticism and predeath prolonged grief might be predicted given
the relationship between neuroticism and postdeath bereavement distress (Middleton et al., 1997; Robinson & Marwit, 2006) and the associations between high neuroticism and insecure attachment, depressive symptoms, and anxiety symptoms (Shaver & Brennan, 1992; Weinstock & Whisman, 2006). Additionally, based on the significant negative correlation between extraversion and depressive symptoms (Clark, Watson, & Mineka, 1994; Farmer et al., 2002), there may be a negative association between predeath grief and extraversion. The potential relationships between grief and openness, agreeableness, and conscientiousness are less clear.

Positive aspects of caregiving. Although the negative consequences of caregiving have been a focus of much empirical study, the majority of caregivers also describe positive aspects of their caregiving experience. For instance, many caregivers view the sacrifices they make as reciprocating earlier sacrifices made by the care recipient (Cohen, Colantonio, & Vernich, 2002). People also describe the caregiving experience as a source of personal growth in that it enhances their relationships with others and helps them find meaning in life (Farran et al., 1991; Ott et al., 2007; Tarlow et al., 2004). These positive feelings about caregiving may have an effect on the grief that a caregiver experiences.

In the postdeath literature, Boerner, Schulz, and Horowitz (2004) found that people who reported benefits from caregiving were more likely to experience postdeath grief and depression even after controlling for demographic factors and burden. They explained that caregivers who are closer to the care recipient are more likely to report positive aspects of caregiving and to suffer more following the loss. It may also be that
certain positive aspects of caregiving (e.g., feeling useful and competent) protect caregivers from grief prior to the death of the care recipient but place people at risk for prolonged grief disorder once the caregiving role is lost. In contrast, other positive aspects of caregiving such as finding new meaning in life could continue throughout the caregiving process and even after death, reducing a person’s susceptibility to grief.

In the few studies conducted prior to the death of the care recipient, personal growth during caregiving was associated with increased well-being, better self-reported health, and decreased burden (Ott et al., 2007; Tarlow et al., 2004). Consequently, an ability to identify positive aspects of caregiving may be associated with less self-reported predeath grief.

**Research Goals**

The purpose of the current study was to investigate methods for assessing grief among caregivers of persons with dementia, prior to care recipient death. In specific, one of my goals was to study the psychometric properties of two grief measures within a population of dementia caregivers and to confirm the factor structure of each measure. The first measure, the PG-12, has been used extensively with postdeath but minimally with predeath samples. The second measure, the MM-CGI-SF was developed with dementia caregivers, but its factor structure has not been confirmed. Including both measures in the same sample allowed me to identify similarities and differences between the measures. I compared the measures in terms of the number of caregivers they identified as potentially in need of intervention. I also investigated areas of overlap and
disjunction based on how each measure was related to depressive symptoms, characteristics of caregivers, and characteristics of the caregiving situation.

Method

Participants

Based on prior Monte Carlo simulation studies (Flora & Curran, 2004), a sample size of at least 200 was recommended to obtain accurate parameter estimates and standard errors for the planned item-level confirmatory factor analyses using robust weighted least squares estimation (Muthen & Muthen, 1998-2010). A total of 202 spousal and adult child caregivers of people with dementia completed questionnaires. Caregivers were recruited from the Charles F. and Joanne Knight Alzheimer's Disease Research Center (Knight ADRC); the Washington University Memory Diagnostic Center; the St. Louis, Mid-Missouri, Southwest Missouri, and Heart of America chapters of the Alzheimer’s Association; and other local organizations with services for dementia caregivers. English-speaking caregivers of family members who had any dementia diagnosis for at least 6 months were included.

Measures

Demographic variables. Caregivers answered questions about their relationship to the care recipient (i.e., spouse or child), age, gender, race, years of education, and the number of hours per day they spent providing care. Caregivers also provided information about the care recipient including age, gender, primary dementia diagnosis, living situation (i.e., living with the care recipient or not living with the care recipient), and length of time since formal diagnosis.
Predeath grief.

Prolonged Grief Disorder Inventory (PG-12). The PG-12 (Prigerson & Maciejewski, 2008) is a 12-item scale whose predeath grief items were adapted from the postdeath Inventory of Complicated Grief (ICG; Prigerson, Maciejewski et al., 1995). In the first section of the scale (4 items), participants reported how often they experienced specific symptoms in the past month (e.g., “Longing or yearning for the patient to be healthy again.”) on a scale from 1 (not at all) to 5 (several times a day). In the second section (7 items), participants responded to questions about their grief experience based on how they currently felt (e.g., “Have you had trouble accepting [the patient’s] illness?”) on a scale from 1 (not at all) to 5 (overwhelmingly). Participants then answered a final yes/no question, “Have you experienced a significant reduction in social, occupational, or other important areas of functioning (e.g., domestic responsibilities)?”

The PG-12 can be used to assess the presence of prolonged grief disorder based on the criteria outlined by Prigerson and Maciejewski (2008). To receive a diagnosis respondents must report that they experience at least one symptom of separation distress (items 1 and 2) daily; endorse 5 of the 9 cognitive, emotional, and behavioral symptoms (items 3 through 11) at least daily or “quite a bit”; and report impairment in functioning (item 12). As in previous studies (Kiely et al., 2008), items 1 through 11 were summed in the current study to obtain a measure of grief intensity with higher scores indicating more severe symptoms.

Because the PG-12 was developed based on the recently updated diagnostic criteria for prolonged grief disorder, it has not been used in any published studies with
caregivers. The internal consistency reliability of the PG-12 in a sample of 39 cancer caregivers was .78 in a previous unpublished study (Prigerson, personal communication, November 3, 2008) and .87 in the current sample. Other versions of this instrument varying in length from 4 to 19 items have been used with caregiver samples and have provided evidence for the discriminant validity of this measure (Beery et al., 1997; Kiely et al., 2008; Prigerson et al., 2003; Tomarken et al., 2008; van Doorn et al., 1998).

Prolonged grief symptoms and depression formed separate factors in an exploratory factor analysis (Kiely et al.). Moreover, in comparison with depression, prolonged grief was associated with unique predictors including insecure attachment style (van Doorn et al.) and duration of caregiving (Beery et al.).

**Marwit-Meuser Caregiver Grief Inventory Short Form (MM-CGI-SF).** The MM-CGI-SF (Marwit & Meuser, 2005) contains 18 items about caregiver feelings and experiences on a scale of 1 (*strongly disagree*) to 5 (*strongly agree*). Items are summed to create both a total score and three subscale scores: Personal Sacrifice Burden (6 items; e.g., “I’ve had to give up a great deal to be a caregiver.”), Heartfelt Sadness and Longing (6 items, e.g., “I long for what was, what we had and shared in the past.”), and Worry and Felt Isolation (6 items, e.g., “My friends simply don’t understand what I’m going through.”). Higher scores indicate more severe grief. Participants are considered to be in need of intervention for their grief if their total score or any one subscale score falls one standard deviation or greater above the mean based on the descriptive information from the original validation sample (Marwit & Meuser).
The total score and all subscale scores had good internal consistency reliability in both a past study (alphas ranging from .80 to .90; Marwit & Meuser, 2005) and in the current sample (alphas ranging from .82 to .91). Based on previous studies, the short-form subscales are all highly correlated with their corresponding subscales from the 50-item MM-CGI (r = .92 for Personal Sacrifice Burden, .93 for Heartfelt Sadness and Longing, and .93 for Worry and Felt Isolation; Marwit & Meuser, 2005). Evidence for the construct validity of the scale is provided by the significant correlation (r = .76) between the total score and the Anticipatory Grief Scale (AGS; Theut, Jordan, Ross, & Deutsch, 1991), another measure designed specifically for dementia caregivers. Marwit and Meuser’s (2002, 2005) measure is preferable to the AGS, which was not empirically derived and was validated with a sample of 27 female caregivers. Evidence for the discriminant validity of the MM-CGI-SF is apparent in the moderate correlations between the total grief score and scores on other caregiver outcomes such as strain (rs = .38 to .68) and cross-sectional evidence that total MM-CGI scores increase as dementia progresses (Marwit & Meuser, 2002, 2005).

**Depressive symptoms.** The 21-item Beck Depression Inventory-II (BDI-II; Beck, Steer, & Brown, 1996) was used to assess emotional, cognitive, and physical symptoms of depression. Participants respond to items on a scale from 0 to 3 (e.g., 0 = *I do not feel sad*, 1 = *I feel sad much of the time*, 2 = *I am sad all the time*, 3 = *I am so sad or unhappy that I can’t stand it*). Items are summed, and higher scores indicate more depressive symptoms. An older version of the instrument, the BDI (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) had good reported internal consistency in a sample
of dementia caregivers (alpha = .87; Marwit & Meuser, 2002). The internal consistency reliability of the BDI-II in the current sample was .88.

**Personality traits.** The 120-item version of the International Personality Item Pool (IPIP; Goldberg, 1999) was used to assess personality. This instrument is designed to measure the Big Five personality traits (NEO-PI-R; Costa & McCrae, 1992a): neuroticism, extraversion, openness, agreeableness, and conscientiousness. Participants rate how accurately each item describes them on a scale from 1 (*very inaccurate*) to 5 (*very accurate*). Participants respond to a total of 24 items per personality trait, and items are summed to create trait scores, with higher scores indicating more of a given trait. The trait scores had acceptable internal consistency reliability in both a previous sample of college students (alphas ranging from .78 to .90; Donnellan, Oswald, Baird, & Lucas, 2006) and in the current sample (alphas ranging from .80 to .89). Although there are no studies of the association between the 120-item IPIP and the NEO-PI-R, facets from a 300-item version of the IPIP (Goldberg) were all significantly correlated with the corresponding NEO-PI-R facets ($r$s = .60 to .81).

**Positive aspects of caregiving.** The 9-item Positive Aspects of Caregiving Scale (Tarlow et al., 2004) was used to measure benefits of caregiving. This measure was developed as part of the Resources for Enhancing Alzheimer’s Caregiver Health (REACH) project (Wisniewski et al., 2003). Participants respond to statements about the benefits of caregiving on a scale from 1 (*disagree a lot*) to 5 (*agree a lot*). Based on a principal components analysis and a confirmatory factor analysis, the measure consists of two factors: Self-affirmation (6 items; e.g., “Providing help to the care recipient has made
me feel more useful.”), and Outlook on Life (3 items; e.g., “Providing help to the care recipient has enabled me to develop a more positive attitude toward life.”). Because the two components are highly correlated \((r = .69)\), Tarlow and colleagues recommend summing all of the items into a total score, with higher scores indicating a more positive feeling about the consequences of caregiving. The internal consistency reliability for the total score was .89 in Tarlow and colleagues’ study and .88 in the current sample.

**Procedure**

Caregivers were recruited in a variety of ways. In some cases, organizations provided a list of potential research participants that I contacted by telephone. If caregivers were interested and met the inclusion criteria, I mailed them questionnaire packets. I also attended a series of support groups sponsored by the Alzheimer’s Association at which I explained the project and distributed questionnaire packets to interested caregivers. In another case, an organization for caregivers sent out letters to their clients with information about the study, and caregivers contacted me if they were interested. All packets included information sheets detailing the research process, the questionnaires, a list of local resources for caregivers, and a stamped return envelope. Participants were allowed to strike through questions they did not wish to answer, but they were telephoned regarding any questions that were skipped.

**Data Analysis**

Item-level confirmatory factor analyses using robust weighted least squares (referred to as WLSMV in Mplus; Muthen & Muthen, 1998-2010) were conducted in Mplus Version 6 to test the factor structure of both the PG-12 and the MM-CGI-SF. For
the factor analyses, missing data estimation in Mplus was used for items that participants struck through or skipped. Model fit was evaluated using recommendations proposed by Hu and Bentler (1999) and Muthen and Muthen for the root mean square error of approximation (RMSEA; Steiger, 1990), the Tucker-Lewis Index (TLI; Tucker & Lewis, 1973), the comparative fit index (CFI; Bentler, 1990), and the weighted root mean square residual (WRMR; Muthen & Muthen). Models were compared using chi-square difference tests (Muthen & Muthen).

Descriptive statistics were calculated for each demographic variable and for the measures of grief, depression, personality, and positive aspects of caregiving. When calculating total scores on these measures for correlational and regression analyses, I replaced missing data with the allowable value closest to the participant’s mean on the subscale. As mentioned previously, participants were contacted regarding any skipped items so, in most cases, data was missing because participants were allowed to strike through questions that they did not wish to answer. Approximately 20% of participants (n = 40) had at least one missing data point across all of the measures. Although a considerable number of participants were affected by missing data, the amount of data missing per person was fairly small (about 0.4 missing items per person). Additionally, of participants with missing data, most were missing data on only 1 item (58%; n = 23) or 2 items (18%; n = 7). Of note, a large proportion of the missing data was due to participants skipping 2 items on the MM-CGI-SF (19 participants struck through “It hurts to put her/him to bed at night and realize that she/he is gone.” and 8 participants struck through “I wish I had an hour or two to myself each day to pursue personal interests.”)
and 1 item on the IPIP (8 participants struck through “Tend to vote for liberal political candidates”). When these items were removed, approximately 12% of participants \((n = 25)\) had any missing data, and most had missing data on only 1 item \((64; n = 16)\) or two items \((20%; n = 5)\). I compared the mean imputation technique for the missing data with other methods (e.g., listwise deletion), and the descriptive and correlational results were similar.

A series of Kolmogorov–Smirnov (Kolmogorov, 1941) tests were used to assess the normality of the measures of grief, depression, personality, and positive aspects of caregiving. Pearson product-moment correlations were calculated between the total score on the PG-12 and both the total overall score and the three total subscales scores of the MM-CGI-SF. Pearson product-moment correlations were also calculated between all grief measures and the BDI-II. In all cases, differences in the magnitudes of correlations were tested using Meng, Rosenthal and Rubin’s (1992) Z test for correlated correlations.

I calculated the percentage of participants with a diagnosis of prolonged grief disorder based on the PG-12 using Prigerson and Maciejewski’s (2008) recommendations. Using the descriptive data from Marwit and Meuser’s (2005) study, I also calculated the percentage of participants who fell one standard deviation above the mean on the total MM-CGI-SF score or any of the subscales. Cohen’s kappa (1960) was calculated to determine the level of agreement between the two classification systems.

Pearson product-moment correlations were also calculated between grief as measured by the PG-12 and the MM-CGI-SF total and subscale scores and demographic characteristics (caregiver gender, age, and education, relationship to the care recipient,
hours per day of care, care recipient age, living situation, and length of time since diagnosis), personality traits, and positive aspects of caregiving. Variables that were significantly correlated at the bivariate level were entered into hierarchical linear regression analyses with demographic characteristics entered at the first step, personality traits and positive aspects of caregiving added at the second step, and an interaction term entered at the third step. In particular, because prior research identified a significant interaction between relationship to the care recipient and living situation (Ott et al., 2007), I added this term at the third step of each hierarchical regression. To reduce the effects of multicollinearity, all variables were standardized before being entered in the regression analyses. Five separate linear regressions were performed, with the PG-12, the three MM-CGI-SF subscales, and BDI-II as dependent variables. For the purpose of comparison, the same independent variables were used in each hierarchical linear regression. A Bonferroni correction was used to control for the inflation of Type I error given these five separate regression analyses, such that the change in $R^2$ was only considered significant if $p < .01$.

**Results**

**Descriptive Statistics**

**Demographic variables.** Of the 289 questionnaire packets distributed to caregivers, 202 completed packets were returned (70%). Of those caregivers who returned packets, 63% were spouses and 37% were adult children. Refer to Table 2 for descriptive information about the sample and comparisons between spousal and adult child caregivers. Overall, the sample was mostly female (73%) and Caucasian (95%),
consistent with other research with dementia caregivers (e.g., Marwit & Meuser, 2005). Per caregiver report, care recipients had been diagnosed with dementia for about 5 years on average, and the majority had a primary diagnosis of Alzheimer’s disease (80%). In comparison to adult children, spouses were significantly older, less educated, and less racially diverse. In addition, spouses were more likely to be living with care recipients, provided more hours per day of care on average, and served as caregivers for younger care recipients who were more likely to be men.

Measures of predeath grief, depressive symptoms, positive aspects of caregiving, and personality. Table 3 provides descriptive statistics and internal consistency reliability for the measures of predeath grief, depressive symptoms, positive aspects of caregiving, and personality. Of note, many caregivers did endorse positive aspects of caregiving ($M = 30.16, SD = 7.35$ out of a possible range of 9-45). Based on descriptive information about skew and kurtosis and the results of a series of Kolmogorov–Smirnov tests, data on most measures were approximately normally distributed (all $p > .05$). The exceptions were the BDI-II and the conscientiousness scale of the IPIP, which were both significantly different from normality based on the Kolmogorov-Smirnov test ($p < .05$ and $p < .01$, respectively). A square root transformation was used for the BDI-II and the transformed values were approximately normally distributed ($p > .05$ on the Kolmogorov-Smirnov test). The conscientiousness values were squared and the distribution of these transformed values was also approximately normally distributed ($p > .05$ on the Kolmogorov-Smirnov test). Both the original and transformed variables were used in subsequent correlational and regression
analyses. Nearly all of the results for the untransformed and transformed BDI-II were identical. In the cases where the correlational results were different, the results based on both the original and the transformed variable are reported below. In the cases where the results were identical, only the results using the original BDI-II are reported. For conscientiousness, the results were identical so I report only the results based on the original, untransformed variable.

**Prolonged Grief Disorder Inventory (PG-12).** Scores on PG-12 items 1 through 11 were summed to create a measure of total grief. Because item 12 is a yes/no question regarding functional impairment, it was not included in this total calculation. There was a fair amount of variability in total grief scores across participants ($M = 25.00, SD = 8.64$ out of a possible range of 11-55). Spousal caregivers endorsed significantly more grief on the PG-12 ($M = 26.24, SD = 8.92$) in comparison to adult children ($M = 22.85, SD = 7.72$), $t(200) = 2.73, p < .001$. Because a version of the PG-12 this length has not been used in prior published studies, scores on items 1 through 11 were also averaged to create an item-based mean for the purpose of comparison across samples. Caregivers in the current study endorsed more severe symptoms than another sample of dementia caregivers who completed a 10-item version of the Prolonged Grief Disorder Inventory (overall item $M = 2.27$ in the current study versus 1.50 in Kiely et al., 2008). None of Kiely and colleagues’ participants lived with care recipients and their sample had a much larger proportion of adult children than the current study (68% versus 37%, respectively), both of which may explain this difference in grief intensity. The item mean of 2.27 in the current study implies that caregivers reported that grief symptoms occurred, on average,
between at least once per month/slightly (2) and at least once per week/somewhat (3). There was some variability in how often caregivers endorsed individual items. The most frequently endorsed item was “In the past month, how often have you felt yourself longing or yearning for the care recipient to be healthy again?” (item $M = 3.39, SD = 1.30$) and the least frequently endorsed item was “Has it been hard for you to trust others since the care recipient’s illness?” (item $M = 1.55, SD = 0.96$).

**Marwit-Meuser Caregiving Grief Inventory-Short Form (MM-CGI-SF).** Items were summed to create subscale and total scores on the MM-CGI-SF. These scores were comparable to Marwit and Meuser’s (2005) original validation study in terms of both mean and standard deviation values, although the mean Worry and Felt Isolation score was slightly lower in this sample (15.73 in the current sample compared to 16.6). In the current sample, there was some variability in item endorsement. On a scale from 1 (disagree a lot) to 5 (agree a lot), the most frequently endorsed item was “I feel very sad about what this disease has done.” (item $M = 4.07, SD = 1.00$) and the least frequently endorsed item was “I have nobody to communicate with.” (item $M = 2.20, SD = 1.02$). Similar to the PG-12, spouses reported significantly more Heartfelt Sadness and Longing ($M = 20.59, SD = 5.51$) than adult children ($M = 18.64, SD = 5.09$), $t(200) = 2.49, p < .05$. There were no significant differences between spouses and adult children on the other MM-CGI-SF subscales or on the measures of depressive symptoms, personality traits, or positive aspects of caregiving.
Confirmatory Factor Analyses

Factor structure of the PG-12. All factor loadings were significant for the proposed one-factor model of the PG-12 and the fit indices were acceptable (CFI = .94, TLI = .93, RMSEA = .10, WRMR = 1.04). Because this fit was neither good nor excellent, an alternative model was tested. In particular, because the response options are distinct for the first four items on the PG-12 (i.e., caregivers are asked how often they experienced symptoms in the past month for the first four items versus how they currently feel for the remaining items), an alternative model was fitted with these items loading on a second uncorrelated method factor. The alternative model, referred to as the grief factor + method factor model provided good fit (CFI = .97, TLI = .97, RMSEA = .07, WRMR = .75). Additionally, adding the method factor significantly improved fit over the proposed one-factor model based on the chi-square difference test, $\chi^2(4, N = 202) = 46.89, p < .001$. All standardized factor loadings were significant for the grief factor + method factor model and can be found in Table 4.

A series of analyses were conducted that provided evidence that the method factor is not a separate substantive factor because convergent grief measures correlated more strongly with the PG-12 grief factor than the method factor. Within a structural equation modeling framework, the correlations between the PG-12 grief factor and each MM-CGI-SF subscale factor were stronger than the correlations between the PG-12 method factor and each MM-CGI-SF subscale factor ($r = .63$ versus $r = -.12$ for Personal Sacrifice Burden; $r = .71$ versus $r = .30$ for Heartfelt Sadness and Longing; $r = .82$ versus $r = .05$ for Worry and Felt Isolation). To demonstrate that the correlations
between the PG-12 grief factor and each subscale factor were different from the correlations between the PG-12 method factor and each subscale factor, a series of models were fitted in which each pair of correlations was constrained to be equal. The unconstrained model was a significantly better fit than the model that constrained the pair of correlations with Personal Sacrifice Burden to be equal, \( \chi^2 (1, N = 202) = 15.45, p < .001 \). It was also a significantly better fit than the model that constrained the pair of correlations with Heartfelt Sadness and Longing to be equal, \( \chi^2 (1, N = 202) = 21.21, p < .001 \) and the model that constrained the pair of correlations with Worry and Felt Isolation to be equal, \( \chi^2 (1, N = 202) = 42.03, p < .001 \).

**Factor structure of the MM-CGI-SF.** The fit for the proposed three-factor model of the MM-CGI-SF was acceptable (CFI = .94, TLI = .93, RMSEA = .09, WRMR = 1.09), and all factor loadings were significant. Because this fit was neither good nor excellent, alternative models were tested. Some items on the MM-CGI-SF have similar wording (e.g., “I feel I am losing my freedom.” and “Independence is what I’ve lost…I don’t have the freedom to go and do what I want.”). For this reason, a second three-factor model was fitted in which the errors for these items (items 4 and 11; 7 and 14; 2 and 16; 5 and 13) were allowed to covary. This model, referred to as the three-factor covariance model, was an improvement based on its good fit indices (CFI = .96, TLI = .96, RMSEA = .07, WRMR = .89). The three factors were all significantly correlated with each other (\( r = .56 \) for Personal Sacrifice Burden and Heartfelt Sadness and Longing; \( r = .75 \) for Personal Sacrifice Burden and Worry and Felt Isolation; \( r = .80 \) for Heartfelt Sadness and Longing and Worry and Felt Isolation, all \( p < .001 \)). Given the
magnitude of these correlations, one and two-factor models in which the same errors were allowed to covary were also tested. The three-factor covariance model was a better fit than a one-factor covariance model, as evidenced by the chi-square difference test, $\chi^2(3, N = 202) = 103.80, p < .001$. Additionally, it was a significantly better fit than the two-factor covariance models that combined highly correlated subscales: for the model that combined Personal Sacrifice Burden and Worry and Felt Isolation, $\chi^2(2, N = 202) = 52.97, p < .001$; for the model that combined Heartfelt Sadness and Longing and Worry and Felt Isolation, $\chi^2(2, N = 202) = 35.03, p < .001$. All standardized factor loadings for the three-factor covariance model were significantly different from 0 and can be found in Table 5.

**Factor structure of a higher order grief model.** A model was fitted in which the PG-12 grief factor and the three MM-CG-SF factors loaded on a higher-order grief factor. The PG-12 method factor and the MM-CG-SF item covariances were also included in this higher-order grief model. The fit for this model was good (CFI = .95, TLI = .95, RMSEA = .06, WRMR = 1.0). However, a comparable model that did not include a higher-order factor (did include PG-12 grief and method factors, three MM-CGI-SF factors, and item covariances) had significantly better fit, $\chi^2(5, N = 202) = 25.4, p < .001$; CFI = .96, TLI = .95, RMSEA = .06, WRMR = .94.

**Correlations Between Measures of Predeath Grief and Depressive Symptoms**

Table 6 includes bivariate correlations among total scores on the PG-12, the MM-CGI-SF subscales, and the BDI-II. The PG-12 was significantly correlated with all MM-CGI-SF subscales, although the correlations varied in magnitude (range = .49 – .71).
Meng and colleagues’ (1992) Z test for correlated correlations was used to determine if some correlations were greater than others. The PG-12 was significantly more strongly correlated with both Heartfelt Sadness and Longing ($r = .66$) and Worry and Felt Isolation ($r = .66$) than with Personal Sacrifice Burden ($r = .49$; $z = 2.04$, $p < .01$ and $z = 3.52$, $p < .001$, respectively).

Similarly, correlations between the measures of grief and depressive symptoms were all statistically significant, but some were stronger than others (range $= .42 – .61$). The correlation between the PG-12 and the BDI-II ($r = .61$) was significantly larger than both the correlation between Personal Sacrifice Burden and the BDI-II ($r = .43$; $z = 3.11$, $p < .01$) and the correlation between Heartfelt Sadness and Longing and the BDI-II ($r = .42$; $z = 3.94$, $p < .001$). Additionally, the correlation between Worry and Felt Isolation and the BDI-II ($r = .53$) was significantly greater than the correlation between Heartfelt Sadness and Longing and the BDI-II ($r = .42$; $z = 2.11$, $p < .05$). However, this difference was no longer significant for the transformed BDI-II variable. In particular, the correlation between Worry and Felt Isolation and the transformed BDI-II ($r = .52$) was not significantly different from the correlation between Heartfelt Sadness and Longing and the transformed BDI-II ($r = .44$; $z = 1.54$, $p = .12$).

**Identification of Caregivers Potentially in Need of Intervention**

Seven percent of caregivers ($n = 15$) met diagnostic criteria for Prolonged Grief Disorder based on Prigerson and Maciejewski’s (2008) recommendations. A larger proportion of caregivers (27%, $n = 54$) were identified as potentially in need of intervention based on scoring at least one standard deviation above the mean on any
subscale using data from Marwit and Meuser’s (2005) original validation study. Based on Cohen’s kappa (1960), there was only fair agreement between these diagnostic classification systems ($\kappa = .30$). Of the caregivers who met diagnostic criteria for Prolonged Grief Disorder, 87% ($n = 13$ out of 15) were also considered in need of intervention using Marwit and Meuser’s recommendations. Of the caregivers who met criteria for intervention based on Marwit and Meuser’s recommendations, 24% ($n = 13$ out of 54) met diagnostic criteria for Prolonged Grief Disorder.

**Predicting Grief and Depressive Symptoms from Characteristics of Caregivers and of the Caregiving Situation**

Table 7 contains bivariate correlations among the measures of grief and depressive symptoms and the measures of personality traits and positive aspects of caregiving. As expected, the PG-12, all MM-CGI-SF subscales and the total score, and the BDI-II were significantly correlated with neuroticism. Only the PG-12 and the BDI-II were significantly associated with extraversion. Conscientiousness was significantly correlated with depressive symptoms, but not with any of the grief measures. The other personality characteristics (openness, agreeableness) were not significantly associated with any measure of predeath grief or the BDI-II. The Positive Aspects of Caregiving Scale (PAC) was not significantly associated with any measure of predeath grief. It was correlated with the BDI-II ($r = -.16, p < .05$), but this association was no longer significant with the transformed BDI-II ($r = -.10, p = .17$). Finally, PAC was significantly associated with neuroticism and extraversion.

Pearson product-moment correlations were also calculated among the measures of
grief and depressive symptoms and characteristics of caregivers and of the caregiving (Table 8). At the bivariate level, spousal relationship with the care recipient was associated with the PG-12 and Heartfelt Sadness and Longing scores, and care recipient age was negatively correlated with all of the grief measures (PG-12, Personal Sacrifice Burden, Heartfelt Sadness and Longing, and Worry and Felt Isolation). Additionally, education was negatively associated with PG-12, Heartfelt Sadness and Longing, and Worry and Felt Isolation scores. Living with the care recipient was positively correlated with Personal Sacrifice Burden and negatively correlated with Heartfelt Sadness and Longing scores. Finally, hours per day of care was only associated with Personal Sacrifice Burden and female gender was only associated with BDI-II scores. Of note, length of time since diagnosis was not significantly correlated with any measure of grief or the BDI-II.

In order to test if personality traits were predictive of grief above and beyond the effects of demographic variables, variables that were significantly correlated with any measure of grief or depression at the bivariate level were entered into hierarchical linear regression analyses, with demographic characteristics entered at the first step and personality traits added at the second step. Because an interaction between relationship to the care recipient and living situation was found in a prior study (Ott et al., 2007), this interaction was also tested at the third step of each regression analysis. Only the two significant interactions are reported. Five separate linear regressions were performed, with PG-12, the three MM-CGI-SF subscales, and BDI-II as dependent variables. For the purpose of comparison, the same independent variables were used in each hierarchical
linear regression. Tables 9 through 13 contain results from these regression analyses.

In combination, the demographic characteristics added at the first step accounted for a significant proportion of the variance across all grief measures (11% for the PG-12, 10% for Personal Sacrifice Burden, 19% for Heartfelt Sadness and Longing, and 10% for Worry and Felt Isolation). These variables accounted for 6% of the variance in the transformed BDI-II scores, \( p = .07 \). At the final step in each model, education was significantly negatively associated with PG-12, Heartfelt Sadness and Longing, and Worry and Felt Isolation scores. Age of the care recipient was significantly negatively associated with Heartfelt Sadness and Longing and Worry and Felt Isolation. Time spent providing care was significantly associated with Personal Sacrifice Burden. Once personality characteristics were added to the model, none of the other demographic or care-related variables were significantly related to depressive symptoms.

Adding neuroticism, extraversion and conscientiousness accounted for a significant additional proportion of the variance in all five dependent variables (an additional 21% for the PG-12, 12% for Personal Sacrifice Burden, 7% for Heartfelt Sadness and Longing, 20% for Worry and Felt Isolation, and 23% for the BDI-II). Notably, these results were driven mainly by neuroticism, which was the only independent variable that was significantly associated with all of the dependent variables. Conscientiousness was also significantly associated with Personal Sacrifice Burden, Heartfelt Sadness and Longing, and Worry and Felt Isolation, but not with PG-12 or BDI-II scores. Extraversion was not significantly associated with any dependent measure in the regression analyses.
The zero-order correlations for the relationships between conscientiousness and all of the grief measures (PG-12; Personal Sacrifice Burden; Heartfelt Sadness and Longing; Worry and Felt Isolation) were smaller and/or opposite in sign in comparison to the standardized regression coefficients and part correlations. A similar suppression effect also occurred for neuroticism. Additional regression analyses for each dependent variable were conducted to identify the primary variables involved in this suppression effect by entering the personality traits and demographic characteristics one at a time. Suppression occurred when neuroticism and conscientiousness were added to the regression equations together. Based on these analyses, neuroticism and conscientiousness are suppressing variance in each other, thereby enhancing the relationship between these personality traits and the dependent variables that measure grief (PG-12, Personal Sacrifice Burden, Heartfelt Sadness and Longing, and Worry and Felt Isolation). This effect makes sense given the significant negative correlation between conscientiousness and neuroticism ($r = -.43, p < .01$). For more information, a table with the bivariate correlations between the personality traits and the demographic characteristics is included in Appendix A.

Adding the interaction between relationship to the care recipient and living situation accounted for an additional 2% of the variance of both the PG-12 and Heartfelt Sadness and Longing. Although the interactions are considered significant at the level of $p < .05$, they are not significant at the Bonferroni corrected value of $p < .01$. For the purpose of description, the interaction terms were explored further. For both measures, spouses and adult children did not differ significantly on grief when they lived with the care
recipient. When they did not live with the care recipient, however, spouses endorsed significantly more grief on both the PG-12 and Heartfelt Sadness and Longing. Please refer to Table 14 for more details.

**Discussion**

This study examined two methods for assessing predeath grief among family caregivers of people with dementia, one measure adapted from the postdeath literature and one designed specifically for dementia caregivers. My first goal was to investigate if each measure was appropriate for use with a predeath sample, based on caregivers’ endorsement of grief items as well as psychometric properties and fit indices in confirmatory factor analyses. This information is especially important for the Prolonged Grief Disorder Inventory (PG-12) because it has been used only minimally with predeath populations.

Grief does seem to be an important component of the caregiving experience for many people given their endorsement of items on both measures. For example, in the case of the PG-12, on average caregivers reported experiencing grief symptoms somewhere between at least once per month/slightly and at least once per week/somewhat. Based on the variability of both measures, some participants experienced substantial grief in their role as caregivers. Across the measures, caregivers were most likely to endorse items related to separation distress and sadness. They were least likely to endorse items related to problems with interpersonal relationships (e.g., inability to trust others, feeling that friends do not understand the caregiving situation).
Interestingly, many participants also reported positive aspects of caregiving, but endorsement of these items was unrelated to the grief experience.

Participants responded consistently across all items on the PG-12. Additionally, caregivers responded consistently across items on each of the three MM-CGI-SF subscales. These findings provide evidence that both of these measures can be used reliably with caregivers prior to the death of their family members. In combination with the results of confirmatory factor analyses, they also support the one-dimensional nature of the PG-12 and the three-dimensional nature of the MM-CGI-SF. The best fitting model for the PG-12 accounted for the distinct response format of the first four items. The PG-12 may be improved in the future by keeping the response format consistent across all of the items, in particular because the diagnostic criteria for prolonged grief disorder requires that symptoms be present daily or to an intense or disruptive degree.

Although prior pre- and postdeath exploratory analyses support a one-factor structure for the PG-12 (Kiely et al., 2008; Prigerson, Maciejewski et al., 1995), this study is the first to confirm this structure in a predeath sample. The best fitting model for the MM-CGI-SF had three factors but allowed items with similar wording to covary, which is consistent with the three-factor structure proposed based on exploratory analyses (Marwit & Meuser, 2002). These three MM-CGI-SF factors appear to be related but not identical. To my knowledge, this confirmatory factor analysis is the first one conducted with the MM-CGI-SF.

This study also supported the validity of each grief measure. The large, significant correlations between the PG-12 and each of the MM-CGI-SF subscales
provide evidence for the convergent validity of each measure. In addition, the grief
measures were significantly, though moderately, correlated with a measure of depressive
symptoms. Based on these associations, grief as measured by the PG-12 is the most
similar to depressive symptoms. However, across measures grief was distinct from
depression in the multiple regression analyses: with the exception of neuroticism,
depressive symptoms and grief had unique patterns of association with characteristics of
caregivers and the caregiving situation. The neuroticism results were consistent with
previous studies that have identified this personality trait as a risk factor for postdeath
grief in bereaved mothers (Robinson & Marwit, 2006) as well as depressive symptoms
(Berlanga, Heinze, Torres, Apiquian, & Caballero, 1999; Farmer et al., 2002). The
moderate correlations between grief and depression and dissimilar regression results
provide evidence for the discriminant validity of each grief measure. These findings are
similar to previous studies, in which grief was correlated with, but distinct from,
depression in both predeath (Beery et al., 1997; Kiely et al., 2008; Prigerson et al., 2003;
Tomarken et al., 2008; van Doorn et al., 1998) and postdeath samples (see Zhang et al.,
2006 for review).

A second goal of the study was to identify areas of overlap and disjunction
between the two grief measures, as this study is the first to include both the PG-12 and
the MM-CGI-SF in the same sample. In comparison to Personal Sacrifice Burden, the
Heartfelt Sadness and Longing and Worry and Felt Isolation subscales of the MM-CGI-
SF overlapped more with the PG-12 and with each other, based on the magnitude of the
correlations between the grief measures and results from the multiple regression analyses.
In particular, the correlations between the PG-12 and both the Heartfelt Sadness and Longing subscale and the Worry and Felt Isolation subscale were significantly stronger than the correlation between the PG-12 and the Personal Sacrifice Burden subscale. Additionally, less educated caregivers endorsed more grief as measured by the PG-12 and both Heartfelt Sadness and Longing and the Worry and Felt Isolation subscales. This finding is consistent with previous studies that identified education as a protective factor for psychological distress among dementia caregivers (e.g., Alspaugh, Stephens, Townsend, Zarit, & Greene, 1999) and for postdeath grief in a sample of cancer caregivers (Goldsmith et al., 2008). Education may be a proxy for general socioeconomic factors such as access to healthcare, services including home health and caregiver support groups, and reduced financial strain. These factors may alleviate caregivers’ concerns about the future, reduce their sense of isolation, and provide them with more resources for coping with sadness.

The PG-12 and the Heartfelt Sadness and Longing subscales also had similar conditional relationships between living situation and relationship with the care recipient. In particular, spousal caregivers were more susceptible to predeath grief than adult children when they were living apart from care recipients, but there were no differences in grief between spouses and adult children who lived with care recipients. This finding, which is consistent with another predeath study of dementia caregivers (Ott et al., 2007), may be partially explained by adult child caregivers experiencing a sense of relief following placement of their parents in long-term care whereas spouses feel more sadness, separation distress, and guilt once their partner is no longer present in the home.
(Meuser & Marwit, 2001; Rudd et al., 1999). Also in keeping with previous research (Kiely et al., 2008), younger care recipient age was a risk factor for grief in the current study, perhaps because of the tendency for dementia to progress more quickly in early onset cases (Jacobs et al., 1994) and because of family members’ lack of preparation for these declines (Hebert et al., 2006).

Based on item content alone, it makes sense that the PG-12 overlaps more with Heartfelt Sadness and Longing and Worry and Felt Isolation versus Personal Sacrifice Burden. In particular, Heartfelt Sadness and Longing includes items that are similar to the separation distress symptoms of prolonged grief disorder (e.g., “I long for what was, what we had and shared in the past.”). The Worry and Felt Isolation subscale includes items related to feelings of disconnection from friends and family, which are similar to PG-12 items related to bitterness over the loss, an inability to trust other people and difficulty moving on with other relationships. In contrast, the Personal Sacrifice Burden subscale is the most dementia-specific. It focuses on the things a person has given up as a caregiver more than the emotional experience of providing care for someone with dementia, and thus it is associated with more hours per day spent providing care and greater conscientiousness. Conscientious individuals may view caregiving as their own responsibility, making them less likely to rely on other family members or professional organizations for assistance with care. Without this help they may ultimately feel greater burden and social isolation.

Across all MM-CGI-SF subscales, one area of disjunction with the PG-12 is the number of caregivers identified as potentially in need of intervention. As expected, a
significantly smaller proportion of the caregivers met diagnostic criteria for prolonged grief disorder a la the PG-12 versus Marwit and Meuser’s (2005) less rigorous criterion of scoring at least one standard deviation above the mean on any of the subscales or the total score. The numbers, however, are fairly consistent with previous studies, as 7% of participants met the diagnostic criteria for prolonged grief in the current study and 8% met diagnostic criteria in a prior predeath sample of caregivers of people with cancer (Prigerson et al., 2003). The 27% of participants identified as potentially in need of intervention based on Marwit and Meuser’s recommendations is also similar to rates found in previous research with dementia caregivers, which have ranged from 15% to 26% (Ott et al., 2007; Sanders et al., 2008). Although there was only fair agreement between these diagnostic classification systems, there is some overlap across the measures, as 87% of the caregivers who met the diagnostic criteria for prolonged grief disorder were also identified as potentially in need of intervention using the MM-CGI-SF subscales. The PG-12 may be a less sensitive and more specific measure than the MM-CGI-SF, but it is difficult to test this hypothesis in the absence of a gold standard measure for caregiver grief. Future studies could examine whether one measure or the other is more predictive of longitudinal distress for caregivers as well as responses to treatment.

Indeed, the cross-sectional nature of this study is one of its limitations. Longitudinal studies may highlight areas of overlap and disjunction between the two grief measures and between each grief measure and depressive symptoms, based on changes in these variables over time as well as associations with long-term dysfunction. Postdeath studies may serve as models for this type of research, as they have examined longitudinal
relationships between grief and mental health outcomes, controlling for variables such as depressive symptoms at baseline (e.g., Prigerson, Frank et al., 1995).

Another limitation of the current study is that many participants had missing data on at least one item across the measures of interest. Fortunately, Mplus Version 6 was able to estimate this missing data for the factor analyses so this is only an issue for the correlational and regression results. Additionally, the average amount of missing data per person was fairly small and the results were similar across the mean imputation technique used and other methods (e.g., listwise deletion). Given that participants were allowed to strike through questions that they did not wish to answer, the finding that participants tended to skip two of the MM-CGI-SF items and one of the IPIP items more frequently than others implies that data may not be missing at random. Multiple imputation for missing data could be used in future analyses, but this technique would not account for data that is not missing at random (Schafer & Graham, 2002).

Although this research provides evidence for the reliability and validity of both grief measures, another limitation is that other psychometric properties were not examined (e.g., predictive validity, sensitivity). Additionally, caregiver reported length of time since diagnosis may be an imperfect measure of dementia severity and a more rigorous measure could be included in future research (e.g., Clinical Dementia Rating; Morris, 1993). Finally, similar analyses should be conducted in more diverse samples, as approximately 95% of the current sample was Caucasian and experiences of grief as well as reactions to caregiving may vary across different ethnic and cultural groups (Goldsmith et al., 2008; Pinquart & Sorensen, 2005).
In spite of these limitations, this study is an important first step in understanding the grief experienced by family caregivers of people with dementia. In particular, these results confirm that many caregivers do experience grief prior to the death of their family members, a finding that can be explained based on the series of losses caregivers experience as dementia progresses. Additionally, this grief is related to, but distinct from, depressive symptoms.

Based on the psychometric properties of the PG-12 and the MM-CGI-SF, this study supports the use of both measures as methods for assessing predeath grief. The MM-CGI-SF is more inclusive both in terms of its item content (e.g., items related to burden) and in the number of caregivers it identifies as potentially in need of intervention. One could make an argument that this measure is preferable because it takes into account the uniqueness of the dementia caregiving population and provides a more comprehensive picture of the variety of losses experienced by caregivers, ranging from the loss of the relationship to the loss of independence. Certain items, however, may reflect strain and burden rather than grief (e.g., “I wish I had an hour or two to myself each day to pursue personal interests.”), a possibility that may be tested by including measures of these variables in future studies. An additional criticism of this measure is that a substantial proportion of participants chose not to answer two of the items. Although participants did not indicate why they struck through items, it is possible that they did not understand the wording or they felt the questions did not apply to them. For example, the 19 participants who skipped “It hurts to put her/him to bed at night and realize that she/he is ‘gone.’” may have been unsure how to interpret the word “gone” or
they may have been living apart from the care recipient and thus not putting her or him to bed. In contrast, the PG-12 may be preferable because it allows for a more parsimonious model in which predeath and postdeath grief are potentially the same construct and in which caregivers can be diagnosed with prolonged grief disorder prior to the deaths of their family members. As in the postdeath literature (Stroebe, Schut, & Finkenauer, 2001), it could be argued that the use of this diagnosis transforms a normal grief reaction into a pathology and may stigmatize people. Although grief seems to be a universal experience for dementia caregivers, it is possible that prolonged grief disorder represents a point on the continuum of grief at which symptoms cause significant distress and impairment because they are more severe than is typical for most people (Prigerson et al., 2008). In this sense prolonged grief disorder may be similar to major depressive disorder in that all people may experience some symptoms of depression, but people are diagnosed with the disorder if they experience a certain number of symptoms over an extended period of time, and these symptoms cause distress and/or impairment.

Based on the correlational results, grief as measured by the PG-12 is most similar to depressive symptoms, which makes sense given some similarities in item content (e.g., loss of interest). Latent variable analyses including both grief and depressive symptoms may provide more information about this relationship. Given the advantages and disadvantages of both measures, future analyses may also involve creating a composite measure using items from both the MM-CGI-SF and the PG-12. Ultimately it will be important to determine if one measure and/or one method for identifying which
caregivers are in need of intervention is predictive of dysfunction in the context of longitudinal studies.

Grief may fit into the larger framework of the stress-process model of dementia caregiving (Pearlin, Mullan, Semple, & Skaff, 1990), which contends that objective demands of caregiving (e.g., problem behaviors), situational stressors (e.g., financial limitations), coping resources (e.g., social support), and coping limitations (e.g., history of depression) may all influence a caregiver’s level of distress. In particular, researchers have suggested that grief may be a causal factor for various types of emotional distress, such as depression, stress, and burden (Holley & Mast, 2009; Meuser et al., 2004). Although longitudinal studies are needed to clarify these relationships, interventions for grief may also improve these other caregiver outcomes.

Determining a way to measure grief is a crucial first step in identifying caregivers who might benefit from interventions for grief, which may supplement existing interventions focused on stress and burden. Although interventions focused specifically on grief have not been evaluated with predeath dementia caregivers, one could imagine adapting existing strategies for postdeath prolonged grief (Shear et al., 2005; Wagner et al., 2006). For example, clinicians could encourage caregivers to tell the story of the losses they have experienced, discuss new ways of feeling close with the care recipient (e.g., using physical touch) and of honoring the life of the person with dementia (e.g., looking through pictures, passing on positive memories to other family members), and problem solve regarding ways for caregivers to maintain their relationships with other people (Sanders, Marwit, Meuser, & Harrington, 2007; Sanders & Sharp, 2004). In the
case of the MM-CGI-SF, interventions could be targeted based on which subscales are elevated (e.g., support groups for caregivers who endorse extensive Worry and Felt Isolation). As measures and interventions for grief continue to be developed and evaluated, the most important thing clinicians can do is to acknowledge that grieving prior to the death a family member is a common occurrence and help caregivers to process their feelings related to these losses.
References


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Table 1

*Proposed Diagnostic Criteria for Prolonged Grief Disorder for DSM-V*

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Criterion A: Bereavement</td>
<td>The reaction follows the loss of a significant other.</td>
</tr>
<tr>
<td>Criterion B: Separation</td>
<td>The bereaved person experiences at least 1 of the following 3 symptoms daily or to an intense or disruptive degree:</td>
</tr>
<tr>
<td>Distress</td>
<td>1. Intrusive thoughts related to the deceased.</td>
</tr>
<tr>
<td></td>
<td>2. Intense pangs of separation distress.</td>
</tr>
<tr>
<td></td>
<td>3. Distressingly strong yearnings for that which was lost.</td>
</tr>
<tr>
<td>Criterion C: Cognitive,</td>
<td>The bereaved person experiences 5 of the following 9 symptoms daily or to an intense or disruptive degree:</td>
</tr>
<tr>
<td>Emotional, Behavioral</td>
<td>1. Confusion about one’s role in life or diminished sense of self (e.g., feeling that part of oneself has died).</td>
</tr>
<tr>
<td>Symptoms</td>
<td>2. Difficulty accepting the loss.</td>
</tr>
<tr>
<td></td>
<td>3. Avoidance of reminders of the reality of the loss.</td>
</tr>
<tr>
<td></td>
<td>4. An inability to trust others since the loss.</td>
</tr>
<tr>
<td></td>
<td>5. Bitterness or anger related to the loss.</td>
</tr>
<tr>
<td></td>
<td>6. Difficulty moving on with life (e.g., making new friends, pursuing interests).</td>
</tr>
<tr>
<td></td>
<td>7. Numbness (absence of emotion) since the loss.</td>
</tr>
<tr>
<td></td>
<td>8. Feeling that life is unfulfilling, empty, and meaningless since the loss.</td>
</tr>
<tr>
<td></td>
<td>9. Feeling stunned, shocked or dazed by the loss.</td>
</tr>
<tr>
<td>Criterion D: Duration</td>
<td>Duration of at least 6 months from the onset of separation distress.</td>
</tr>
<tr>
<td>Criterion E: Impairment</td>
<td>The symptomatic disturbance must cause clinically significant distress or impairment in social, occupational, or other important areas of functioning (e.g., domestic responsibilities).</td>
</tr>
</tbody>
</table>

*Note.* Adapted from Prigerson et al., 2008.
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total sample (N = 202)</th>
<th>Spouses (n = 128)</th>
<th>Adult children (n = 74)</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td></td>
</tr>
<tr>
<td>Caregiver age (yrs.)</td>
<td>67.57 (11.52)</td>
<td>73.01 (9.00)</td>
<td>58.03 (9.01)</td>
<td>11.35***</td>
</tr>
<tr>
<td>Care recipient age (yrs.)</td>
<td>78.93 (9.27)</td>
<td>75.62 (9.15)</td>
<td>84.66 (6.21)</td>
<td>-8.35***</td>
</tr>
<tr>
<td>Education (yrs.)</td>
<td>15.03 (3.11)</td>
<td>14.72 (3.42)</td>
<td>15.57 (2.42)</td>
<td>-2.06*</td>
</tr>
<tr>
<td>Years since diagnosis</td>
<td>4.79 (3.21)</td>
<td>5.00 (3.18)</td>
<td>4.45 (3.24)</td>
<td>1.18</td>
</tr>
<tr>
<td>Hours per day of care</td>
<td>9.99 (8.89)</td>
<td>12.00 (8.93)</td>
<td>6.49 (7.69)</td>
<td>4.50***</td>
</tr>
<tr>
<td>Caregiver gender:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>female</td>
<td>73.3 (148)</td>
<td>68.8 (88)</td>
<td>81.1 (60)</td>
<td>3.64</td>
</tr>
<tr>
<td>Care recipient gender:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>female</td>
<td>51.0 (103)</td>
<td>31.3 (40)</td>
<td>85.1 (63)</td>
<td>54.48***</td>
</tr>
<tr>
<td>Living with care recipient</td>
<td>55.4 (112)</td>
<td>71.9 (92)</td>
<td>27.0 (20)</td>
<td>38.18***</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>94.5 (190)</td>
<td>97.7 (125)</td>
<td>89.0 (65)</td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>5.5 (11)</td>
<td>2.3 (3)</td>
<td>11.0 (8)</td>
<td></td>
</tr>
<tr>
<td>Primary diagnosis</td>
<td>80.0 (148)</td>
<td>79.7 (98)</td>
<td>80.6 (50)</td>
<td>.02</td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>20.0 (37)</td>
<td>20.3 (25)</td>
<td>19.4 (12)</td>
<td></td>
</tr>
</tbody>
</table>

*Note. *A chi-square test could not be used for race because the expected value of one cell was less than 5. Fisher’s exact test was used instead and it was significant, p < .05. **N = 185 for this variable because 5 spouses and 12 adult children did not know their care recipient’s primary diagnosis.

*p < .05, **p < .01, ***p < .001.
Table 3
Descriptive Statistics and Internal Consistency For Measures of Predeath Grief, Depressive Symptoms, Personality, and Positive Aspects of Caregiving

<table>
<thead>
<tr>
<th>Measure</th>
<th>M</th>
<th>SD</th>
<th>α</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prolonged Grief Disorder Inventory (PG-12)</td>
<td>25.00</td>
<td>8.64</td>
<td>.87</td>
</tr>
<tr>
<td>Marwit-Meuser Caregiver Grief Inventory (MM-CGI-SF)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal Sacrifice Burden (PSB)</td>
<td>19.75</td>
<td>5.06</td>
<td>.85</td>
</tr>
<tr>
<td>Heartfelt Sadness and Longing (HSL)</td>
<td>19.87</td>
<td>5.43</td>
<td>.87</td>
</tr>
<tr>
<td>Worry and Felt Isolation (WFI)</td>
<td>15.73</td>
<td>5.01</td>
<td>.82</td>
</tr>
<tr>
<td>Total Score</td>
<td>55.35</td>
<td>13.10</td>
<td>.91</td>
</tr>
<tr>
<td>Beck Depression Inventory (BDI-II)</td>
<td>11.40</td>
<td>7.60</td>
<td>.88</td>
</tr>
<tr>
<td>International Personality Item Pool (IPIP)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neuroticism</td>
<td>61.92</td>
<td>12.60</td>
<td>.84</td>
</tr>
<tr>
<td>Extraversion</td>
<td>79.35</td>
<td>13.13</td>
<td>.87</td>
</tr>
<tr>
<td>Openness</td>
<td>75.81</td>
<td>11.93</td>
<td>.80</td>
</tr>
<tr>
<td>Agreeableness</td>
<td>99.13</td>
<td>8.93</td>
<td>.80</td>
</tr>
<tr>
<td>Conscientiousness</td>
<td>96.74</td>
<td>12.56</td>
<td>.89</td>
</tr>
<tr>
<td>Positive Aspects of Caregiving Scale (PAC)</td>
<td>30.16</td>
<td>7.35</td>
<td>.88</td>
</tr>
</tbody>
</table>

Note. The range of possible scores is 11-55 for the PG-12, 6-30 for the MM-CGI-SF subscales, 18-90 for the MM-CGI-SF total score, 0-63 for the BDI-II, 24-120 for the IPIP trait scores, and 9-45 for the PAC.
<table>
<thead>
<tr>
<th>Item</th>
<th>Grief factor</th>
<th>Method factor</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. In the past month, how often have you felt yourself longing or yearning for your family member to be healthy again?</td>
<td>.60</td>
<td>.42</td>
</tr>
<tr>
<td>2. In the past month, how often have you had intense feelings of emotional pain, sorrow, or pangs of grief related to the your family member’s illness?</td>
<td>.68</td>
<td>.62</td>
</tr>
<tr>
<td>3. In the past month, how often have you tried to avoid reminders that your family member is ill?</td>
<td>.49</td>
<td>.40</td>
</tr>
<tr>
<td>4. In the past month, how often have you felt stunned, shocked, or dazed by the illness?</td>
<td>.58</td>
<td>.49</td>
</tr>
<tr>
<td>5. Do you feel confused about your role in life or feel like you don’t know who you are (i.e., feeling that a part of yourself has died)?</td>
<td>.77</td>
<td>.85</td>
</tr>
<tr>
<td>6. Have you had trouble accepting your family member’s illness?</td>
<td>.67</td>
<td>.85</td>
</tr>
<tr>
<td>7. Has it been hard for you to trust others since your family member’s illness?</td>
<td>.48</td>
<td>.56</td>
</tr>
<tr>
<td>8. Do you feel bitter over your family member’s illness?</td>
<td>.66</td>
<td>.85</td>
</tr>
<tr>
<td>9. Do you feel that moving on would be difficult for you now?</td>
<td>.58</td>
<td>.56</td>
</tr>
<tr>
<td>10. Do you feel emotionally numb since your family member’s illness?</td>
<td>.60</td>
<td>.40</td>
</tr>
<tr>
<td>11. Do you feel that life is unfulfilling, empty or meaningless since the illness?</td>
<td>.58</td>
<td>.40</td>
</tr>
<tr>
<td>12. Have you experienced a significant reduction in social, occupational, or other important areas of functioning (e.g., domestic responsibilities)?</td>
<td>.85</td>
<td>.85</td>
</tr>
</tbody>
</table>

Note. All factor loadings were statistically significant at $p < .001$. 
Table 5  
Confirmatory Factor Analysis of the Marwit-Meuser Caregiver Grief Inventory-Short Form (MM-CGI-SF)

<table>
<thead>
<tr>
<th>Item</th>
<th>Standardized factor loading</th>
<th>Standard error</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Personal Sacrifice Burden</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. I’ve had to give up a great deal to be a caregiver.</td>
<td>.80</td>
<td>.04</td>
</tr>
<tr>
<td>2. I feel I am losing my freedom.</td>
<td>.84</td>
<td>.03</td>
</tr>
<tr>
<td>10. I will be tied up with this for who knows how long.</td>
<td>.65</td>
<td>.06</td>
</tr>
<tr>
<td>16. Independence is what I’ve lost… I don’t have the freedom to go</td>
<td>.80</td>
<td>.03</td>
</tr>
<tr>
<td>and do what I want.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. I wish I had an hour or two to myself each day to pursue</td>
<td>.72</td>
<td>.04</td>
</tr>
<tr>
<td>personal interests.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. I’m stuck in this caregiving world and there’s nothing I can do</td>
<td>.70</td>
<td>.04</td>
</tr>
<tr>
<td>about it.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Heartfelt Sadness and Longing</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I have this empty, sick feeling knowing that my loved one is</td>
<td>.80</td>
<td>.03</td>
</tr>
<tr>
<td>“gone”.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. I long for what was, what we had and shared in the past.</td>
<td>.79</td>
<td>.04</td>
</tr>
<tr>
<td>9. I could deal with other serious disabilities better than this.</td>
<td>.68</td>
<td>.05</td>
</tr>
<tr>
<td>11. It hurts to put her/him to bed at night and realize that she/he</td>
<td>.79</td>
<td>.04</td>
</tr>
<tr>
<td>is “gone”.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. I feel very sad about what this disease has done.</td>
<td>.76</td>
<td>.04</td>
</tr>
<tr>
<td>15. I’ve lost other people close to me, but the losses I am</td>
<td>.80</td>
<td>.03</td>
</tr>
<tr>
<td>experiencing now are more troubling.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Worry and Felt Isolation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I have nobody to communicate with.</td>
<td>.65</td>
<td>.05</td>
</tr>
<tr>
<td>5. I spend a lot of time worrying about the bad things to come.</td>
<td>.75</td>
<td>.04</td>
</tr>
<tr>
<td>6. Dementia is like a double loss…I’ve lost the closeness with my</td>
<td>.76</td>
<td>.04</td>
</tr>
<tr>
<td>loved one and connectedness with my family.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. My friends simply don’t understand what I’m going through.</td>
<td>.56</td>
<td>.06</td>
</tr>
<tr>
<td>13. I lay awake most nights worrying about what’s happening and</td>
<td>.66</td>
<td>.04</td>
</tr>
<tr>
<td>how I’ll manage tomorrow.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. The people closest to me do not understand what I’m going</td>
<td>.68</td>
<td>.05</td>
</tr>
<tr>
<td>through.</td>
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</table>

*Note.* For items with similar wording (items 4 and 11; items 7 and 14; items 2 and 16; items 5 and 13), errors were allowed to covary. All factor loadings were statistically significant at \(p < .001\).
Table 6
*Bivariate Correlations Between Measures of Predeath Grief and Depressive Symptoms*

<table>
<thead>
<tr>
<th>Scale</th>
<th>PG-12</th>
<th>BDI-II</th>
</tr>
</thead>
<tbody>
<tr>
<td>MM-CGI-SF</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal Sacrifice Burden</td>
<td>.49</td>
<td>.43</td>
</tr>
<tr>
<td>Heartfelt Sadness and Longing</td>
<td>.66</td>
<td>.42</td>
</tr>
<tr>
<td>Worry and Felt Isolation</td>
<td>.66</td>
<td>.54</td>
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<tr>
<td>Total Score</td>
<td>.71</td>
<td>.56</td>
</tr>
<tr>
<td>PG-12</td>
<td></td>
<td>.61</td>
</tr>
</tbody>
</table>

*Note.* MM-CGI-SF = Marwit-Meuser Caregiver Grief Inventory-Short Form; PG-12 = Prolonged Grief Disorder Inventory; BDI-II = Beck Depression Inventory-II. All correlations were significant at $p < .001$. 
Table 7
Bivariate Correlations Between Measures of Predeath Grief and Depressive Symptoms and Measures of Personality Traits and Positive Aspects of Caregiving

<table>
<thead>
<tr>
<th>Scale</th>
<th>Neuroticism</th>
<th>Extraversion</th>
<th>Openness</th>
<th>Agreeableness</th>
<th>Conscientiousness</th>
<th>PAC</th>
</tr>
</thead>
<tbody>
<tr>
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<td>MM-CGI-SF</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PSB</td>
<td>.29***</td>
<td>-.06</td>
<td>.01</td>
<td>-.08</td>
<td>.10</td>
<td>-.02</td>
</tr>
<tr>
<td>HSL</td>
<td>.27***</td>
<td>-.06</td>
<td>.01</td>
<td>-.02</td>
<td>-.04</td>
<td>.11</td>
</tr>
<tr>
<td>WFI</td>
<td>.41***</td>
<td>-.11</td>
<td>-.06</td>
<td>-.11</td>
<td>.06</td>
<td>-.01</td>
</tr>
<tr>
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<td>-.02</td>
<td>-.07</td>
<td>.04</td>
<td>.04</td>
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<tr>
<td>BDI-II</td>
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<td>-.05</td>
<td>-.03</td>
<td>-.21**</td>
<td>-.16*</td>
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<tr>
<td>PAC</td>
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<td>.21**</td>
<td>.09</td>
<td>.12</td>
<td>.06</td>
<td></td>
</tr>
</tbody>
</table>

Note. PG-12 = Prolonged Grief Disorder Inventory; MM-CGI-SF = Marwit-Meuser Caregiver Grief Inventory-Short Form; PSB = Personal Sacrifice Burden; HSL = Heartfelt Sadness and Longing; WFI = Worry and Felt Isolation; BDI-II = Beck Depression Inventory-II; PAC = Positive Aspects of Caregiving Scale. Neuroticism, Extraversion, Openness, Agreeableness, and Conscientiousness were measured using the International Personality Item Pool.

*When the transformed BDI-II values were used, this relationship was no longer significant (r = -.10, p = .17).

*p < .05, *p < .01, ***p < .001.
### Table 8

**Bivariate Correlations Between Measures of Predeath Grief and Depressive Symptoms and Demographic and Care-Related Characteristics**

<table>
<thead>
<tr>
<th>Scale</th>
<th>Spousal relationship</th>
<th>Care recipient age</th>
<th>Female gender</th>
<th>Living with care recipient</th>
<th>Education</th>
<th>Hours per day of care</th>
<th>Years since diagnosis</th>
</tr>
</thead>
<tbody>
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<td>-.02</td>
<td>.02</td>
<td>-.19**</td>
<td>.06</td>
<td>.00</td>
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<td>MM-CGI-SF</td>
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<td></td>
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<tr>
<td>PSB</td>
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<td>.00</td>
<td>.17*</td>
<td>.00</td>
<td>.27***</td>
<td>.03</td>
</tr>
<tr>
<td>HSL</td>
<td>.17*</td>
<td>-.27***</td>
<td>-.07</td>
<td>-.17*</td>
<td>-.17*</td>
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<td>.12</td>
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<tr>
<td>WFI</td>
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<td>-.05</td>
<td>-.01</td>
<td>-.19**</td>
<td>.06</td>
<td>.05</td>
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<td>-.01</td>
<td>-.14*</td>
<td>.10</td>
<td>.08</td>
</tr>
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<td>BDI-II</td>
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<td>.15*</td>
<td>.02</td>
<td>-.14</td>
<td>.07</td>
<td>.02</td>
</tr>
</tbody>
</table>

*Note.* PG-12 = Prolonged Grief Disorder Inventory; MM-CGI-SF = Marwit-Meuser Caregiver Grief Inventory-Short Form; PSB = Personal Sacrifice Burden; HSL = Heartfelt Sadness and Longing; WFI = Worry and Felt Isolation; BDI-II = Beck Depression Inventory-II.

* *p < .05, * * *p < .001.
Table 9
Predicting Prolonged Grief Disorder (PG-12) Symptoms from Individual Difference Characteristics

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>ΔR²</th>
<th>β</th>
<th>Part r</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td>.11**</td>
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<td></td>
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<tr>
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<td>.11</td>
<td>.08</td>
<td></td>
</tr>
<tr>
<td>Care recipient age</td>
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<td>-.19**</td>
<td></td>
</tr>
<tr>
<td>Female gender</td>
<td>.05</td>
<td>.05</td>
<td></td>
</tr>
<tr>
<td>Living with care recipient</td>
<td>-.13</td>
<td>-.10</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>-.17*</td>
<td>-.18*</td>
<td></td>
</tr>
<tr>
<td>Care hours per day</td>
<td>.06</td>
<td>.05</td>
<td></td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td>.21***</td>
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<td></td>
</tr>
<tr>
<td>Spousal relationship</td>
<td>.16*</td>
<td>.13*</td>
<td></td>
</tr>
<tr>
<td>Care recipient age</td>
<td>-.12</td>
<td>-.10</td>
<td></td>
</tr>
<tr>
<td>Female gender</td>
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<td>-.05</td>
<td></td>
</tr>
<tr>
<td>Living with care recipient</td>
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<td>-.08</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>-.13*</td>
<td>-.13*</td>
<td></td>
</tr>
<tr>
<td>Care hours per day</td>
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<td>.02</td>
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<td>.43***</td>
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<td>.05</td>
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<td>Conscientiousness</td>
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<td>.10</td>
<td></td>
</tr>
<tr>
<td><strong>Step 3</strong></td>
<td>.02*</td>
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<td></td>
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<tr>
<td>Spousal relationship</td>
<td>.13</td>
<td>.10</td>
<td></td>
</tr>
<tr>
<td>Care recipient age</td>
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<td>-.11</td>
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<tr>
<td>Female gender</td>
<td>-.05</td>
<td>-.05</td>
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<tr>
<td>Living with care recipient</td>
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<td>-.07</td>
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</tr>
<tr>
<td>Education</td>
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<td>-.12*</td>
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</tr>
<tr>
<td>Care hours per day</td>
<td>.01</td>
<td>.00</td>
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</tr>
<tr>
<td>Neuroticism</td>
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<td>.43***</td>
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<tr>
<td>Extraversion</td>
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<td>.04</td>
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<tr>
<td>Conscientiousness</td>
<td>.13</td>
<td>.11</td>
<td></td>
</tr>
<tr>
<td>Interaction: Relationship by living</td>
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<td>-.12*</td>
<td></td>
</tr>
</tbody>
</table>

\[ R^2 = .34, \ p < .001 \]

*Note. *p < .05, *p < .01, ***p < .001.
Table 10
Predicting Personal Sacrifice Burden (PSB) from Individual Difference Characteristics

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>Personal Sacrifice Burden</th>
<th>( \Delta R^2 )</th>
<th>( \beta )</th>
<th>Part ( r )</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
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<td></td>
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<tr>
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<td>-.06</td>
<td></td>
</tr>
<tr>
<td>Care recipient age</td>
<td></td>
<td>-.16*</td>
<td>-.14*</td>
<td></td>
</tr>
<tr>
<td>Female gender</td>
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<td>.03</td>
<td>.03</td>
<td></td>
</tr>
<tr>
<td>Living with care recipient</td>
<td></td>
<td>.02</td>
<td>.01</td>
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</tr>
<tr>
<td>Education</td>
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<td>.02</td>
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</tr>
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<td>Care hours per day</td>
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<td>.21**</td>
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<tr>
<td><strong>Step 2</strong></td>
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<td></td>
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<tr>
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<td>-.02</td>
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<td>Care recipient age</td>
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<td>-.08</td>
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<td>Female gender</td>
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<td>.00</td>
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<td>Care hours per day</td>
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<td>.24**</td>
<td>.19**</td>
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<td>.39***</td>
<td>.31***</td>
<td></td>
</tr>
<tr>
<td>Extraversion</td>
<td></td>
<td>.01</td>
<td>.01</td>
<td></td>
</tr>
<tr>
<td>Conscientiousness</td>
<td></td>
<td>.23**</td>
<td>.20**</td>
<td></td>
</tr>
</tbody>
</table>

\( R^2 = .21, p < .001 \)

*Note. *\( p < .05, *p < .01, ***p < .001. \)
Table 11
Predicting Heartfelt Sadness and Longing (HSL) from Individual Difference Characteristics

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>Heartfelt Sadness and Longing</th>
<th>AR²</th>
<th>β</th>
<th>Part r</th>
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<tbody>
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<td>Step 1</td>
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<td>.14</td>
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</tr>
<tr>
<td>Care recipient age</td>
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<td>-.26**</td>
<td>-.23**</td>
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<td>Female gender</td>
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<td>.02</td>
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<td>Education</td>
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<td>-.17*</td>
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<td>.17**</td>
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<td>-.17**</td>
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<td>.01</td>
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<td>.25***</td>
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<td>.01</td>
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<td>Conscientiousness</td>
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<td>Step 3</td>
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<td>.13*</td>
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<td>Care recipient age</td>
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<td>-.18**</td>
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<tr>
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<tr>
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<td>Care hours per day</td>
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<td>.26***</td>
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<td>.01</td>
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<tr>
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<td>Interaction: Relationship by living</td>
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<td>-.16*</td>
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\[ R^2 = .28, \ p < .001 \]

Note. *p < .05, *p < .01, ***p < .001.
### Table 12

*Predicting Worry and Felt Isolation (WFI) from Individual Difference Characteristics*

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>ΔR²</th>
<th>β</th>
<th>Part r</th>
</tr>
</thead>
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<tr>
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<td>-.10</td>
</tr>
<tr>
<td>Care recipient age</td>
<td></td>
<td>-.27**</td>
<td>-.24**</td>
</tr>
<tr>
<td>Female gender</td>
<td></td>
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<td>-.02</td>
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<tr>
<td>Living with care recipient</td>
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</tr>
<tr>
<td>Education</td>
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<td>-.19**</td>
</tr>
<tr>
<td>Care hours per day</td>
<td></td>
<td>.08</td>
<td>.06</td>
</tr>
<tr>
<td>Step 2</td>
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</tr>
<tr>
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<td>-.06</td>
<td>-.04</td>
</tr>
<tr>
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<td>-.18*</td>
<td>-.15*</td>
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<td>-.10</td>
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<tr>
<td>Living with care recipient</td>
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<td>-.09</td>
<td>-.07</td>
</tr>
<tr>
<td>Education</td>
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<td>-.15*</td>
</tr>
<tr>
<td>Care hours per day</td>
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<td>.00</td>
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<td>.24**</td>
</tr>
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</table>

R² = .30, p < .001

*Note.* *p < .05, *p < .01, ***p < .001.
Table 13
Predicting Depressive Symptoms from Individual Difference Characteristics

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>Beck Depression Inventory (BDI-II)</th>
<th>( \Delta R^2 )</th>
<th>( \beta )</th>
<th>Part r</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td>.06</td>
<td></td>
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</tr>
<tr>
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<td>.04</td>
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<td></td>
</tr>
<tr>
<td>Care recipient age</td>
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<td>-.08</td>
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</tr>
<tr>
<td>Female gender</td>
<td></td>
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<td>.18*</td>
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<tr>
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<td>-.07</td>
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<tr>
<td>Education</td>
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<td>-.12</td>
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<tr>
<td>Care hours per day</td>
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<td>.08</td>
<td>.07</td>
<td></td>
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<tr>
<td>Step 2</td>
<td></td>
<td>.23***</td>
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</tr>
<tr>
<td>Spousal relationship</td>
<td></td>
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<td>.39***</td>
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\( R^2 = .29, p < .001 \)

Note. *p < .05, *p < .01, ***p < .001
Table 14
Mean Grief Scores for Spousal and Adult Child Caregivers Based on Living Situation

<table>
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<tr>
<th></th>
<th>Spouses (n = 128)</th>
<th>Adult children (n = 74)</th>
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<td>8.52</td>
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<tr>
<td>HSL</td>
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<td>5.22</td>
<td>18.86</td>
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Note. PG-12 = Prolonged Grief Disorder Inventory; HSL = Heartfelt Sadness and Longing. Only the PG-12 and HSL are presented here because the interactions between relationship with the care recipient and living situation were not significant for the other measures of grief and depression. For living with care recipient, n = 92 for spouses and n = 20 for adult children; for not living with care recipient, n = 36 for spouses and n = 54 for adult children.

*p < .05, **p < .01, ***p < .001.
### APPENDIX A: Bivariate Correlations Between Measures of Personality Traits and Demographic Characteristics

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**Note.** Neuroticism, Extraversion, Openness, Agreeableness, and Conscientiousness were measured using the International Personality Item Pool.

* *p < .05, **p < .01, ***p < .001.