

The Role of Grief in Dementia Caregiving

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The literature examining issues of caregiver stress, burden, or depression has focused on the stress-process model of caregiving, which posits that there are characteristics inherent in dementia and in the course of caregiving for a person with dementia that can cause stress in the caregiver's life. A more recent literature has emerged that argues that issues of loss and grief play a significant role in a caregiver's ability to cope with the stressors of caregiving.

This article reviews the caregiver stress and grief literatures, and proposes a conceptual model of dementia caregiving that outlines pathways of stress and grief in dementia caregiving. Issues specific to caregiver grief are proposed for future research and intervention design.

Keywords: dementia; caregiving; grief; stress; caregiver support

Approximately 52 million adults in the United States care for an ill or disabled family member, and of these, almost 9 million are caregivers for a loved one with dementia.¹ It is well established that family members caring for a person with dementia are at high risk for serious physical illness, emotional strain, and mental health problems.²⁻⁵ For geriatric health care providers, comprehensively understanding the caregiving experience is essential to developing effective interventions for alleviating caregiver distress. Influenced by caregiver negative health outcomes, research aimed at intervention design has focused on the stress and burden encountered during the provision of care. Findings from these studies have identified

ways for the professional to efficiently assess and intervene to reduce caregiver burden and stress.³

The dominant conceptual framework that describes the experience of dementia caregiving is the stress-process model,⁶ which posits that stress is a product of the task demands associated with care provision and the personal resources available to the caregiver to meet those demands. In addition, there is a growing body of literature suggesting that other aspects of the caregiver role also impact well-being. These include the experience of grief in response to loss reported during the course of care. The caregiver grief literature, although not large, provides compelling evidence that there are significant issues of loss inherent in caring for a loved one with dementia.⁷⁻⁹ Not only must caregivers cope with the stressful demands of addressing the needs of a loved one who can no longer adequately care for him or herself, they must also cope with the interpersonal loss of a likely deeply meaningful relationship.

This article explores the phenomena of grief and loss within the context of dementia caregiving. First, we review the literature on caregiver stress—which is dominated by the stress-process model—as well as the literature on caregiver grief in an effort to understand how these 2 psychological states affect the caregiving experience. Then, we discuss the clinical implications of assessment and intervention. Finally, we propose an expanded grief-stress model of

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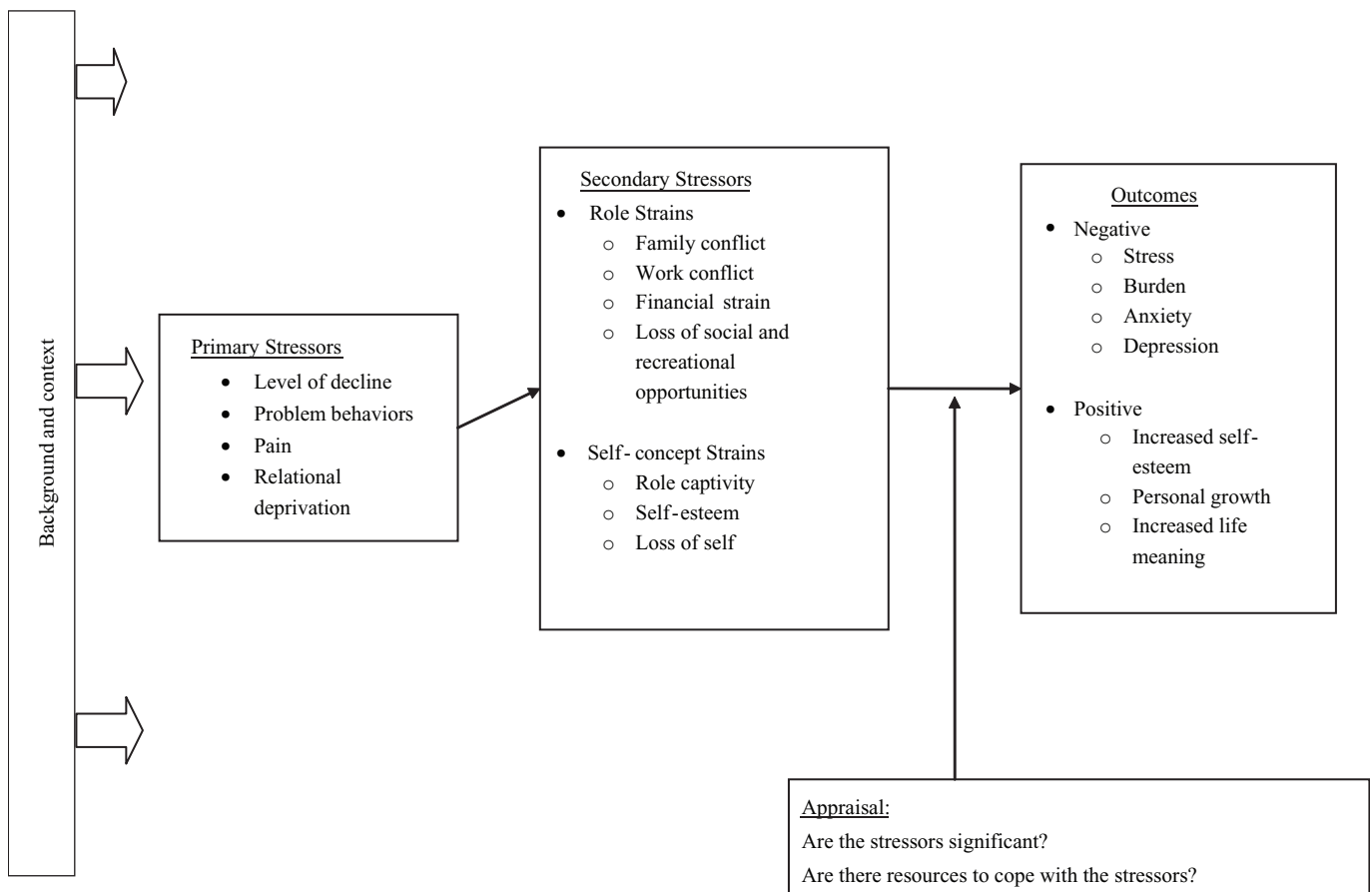


Figure 1. Stress-process model of dementia caregiving. Adapted from Pearlin et al⁶ and Hebert & Schulz.¹⁰

dementia caregiving to help professionals more precisely pinpoint assessment and intervention strategies to alleviate stress, depression, anxiety, burden, and grief in family members caring for persons with dementia.

Stress-Process Model of Caregiving

The stress-process or stress/health model of caregiving^{3,6,10} proposes that there are characteristics inherent in dementia and in the course of caring for a person with dementia that have the potential for causing stress in the caregiver's life. Pearlin et al⁶ describe 4 major stress-process domains. Figure 1 is an abbreviated adaptation of Pearlin's conceptual model that for the purpose of illustration summarizes aspects of these 4 major stress-process domains. First is the background and context of stress. This is captured by individual difference variables that include socioeconomic, demographic, health, personality, and interpersonal factors that are the context in which caregiving is rendered and which

influence every caregiving situation in unique ways. The second variable consists of stressors, additional demands that occur during the course of caregiving that can place strain on the caregiver. In this regard, Pearlin et al⁶ point to primary and secondary stressors. Primary stressors are a direct result of the care recipient's dementia and they are divided into objective and subjective indicators. Objective indicators include level of cognitive status of the care recipient, the ability to carry out activities of daily living and instrumental activities of daily living, as well as care recipient problem behaviors (such as aggression, agitation, repeating questions, wandering, or lethargy). Subjective indicators are indicators that affect caregiver appraisal of the process including the caregiver's perception of overload and relational deprivation. In addition to primary stressors, secondary stressors arise from primary stressors and include the conflict caregivers feel when other life roles (eg, as a parent, a worker, a spouse) are affected by caregiving as well as when the caregiver feels that his or her life is socially constricted because of the caregiving role. Third, the model implies that caregivers

appraise whether stressors pose a threat to their own well-being. This third component of the model underscores the importance of the role of caregiver subjective evaluation as an influencing factor underlying caregiver health.

Taken together, these 3 components yield a fourth domain labeled outcomes. If a caregiver does not possess adequate coping resources he or she may experience negative outcomes, such as depression, anxiety, anger, a poor caregiver-care recipient relationship, or physical health problems.³ However, a positive appraisal of stressors may result in increased caregiver self-esteem, feelings of personal growth and mastery, improved caregiver-care recipient relationship, or a greater sense of meaning associated with the caregiving experience.

Guided by Pearlin's stress-process model, substantial caregiving research has focused on outcomes and the effect these have on the caregiving process. In particular, the model has generated substantial research related to caregiving stress and interventions aimed at resolving stress-related symptoms. Issues of grief and relationship loss have been acknowledged in the dementia caregiving literature. Most notably, original stress-process model of Pearlin et al included the loss term "relational deprivation"⁶ as a potential stressor; however, since then, this variable has received little attention in relation to other objective and subjective indicators of stress. With respect to relational deprivation, no attempts have been made to refine or to operationalize it for further empirical study, or to develop interventions that would target the amelioration of relational deprivation, grief, and/or loss as a pathway for improving caregiver health. A central goal of this article is to further elucidate this concept and to argue that relational deprivation may be a descriptive label for the caregiver grief process.

Caregiver Grief

As a starting point, the general literature on grief, grieving, and bereavement offers an initial context as well as a broader theoretical perspective that may facilitate understanding the role that grief plays as a consequence of dementia caregiving. In their integrative review of grief and bereavement, Bonanno and Kaltman¹¹ summarize several psychological models that have attempted to capture the phenomenology of the grieving process. Germane to this discussion is the cognitive stress perspective which conceptualizes grief as a kind of permanent

interpersonal loss or stressor that threatens an individual's well-being and/or perceived sense of safety. Within the cognitive stress model of bereavement, when the magnitude of the stressor (in this case the loss of a loved one) is appraised as greater than one's intrapersonal resources for coping an individual will perceive that he or she is in imminent danger.

Meuser et al suggest that caregiver grief, which they define as "the caregiver's emotional, cognitive, and behavioral reactions to the recognition of personally significant loss" (p 175),¹² is an ever present stressor in caring for a person with dementia. They argue that it is "true grief" that is "relatively indistinguishable from post-death grief in personal impact and meaning" (p 174).¹² Further, these authors suggest that grief (in reaction to the many losses that caregivers face) may be an essential factor that is related to, but potentially distinct from, the symptoms of stress typically focused on in the caregiver literature.¹² It is the thesis of this review that the magnitude of stress, although distributed over a longer time interval, is equal to or greater than the stress that one experiences in postdeath grieving.

Related to the cognitive stress perspective of grief is the unpredictable and intermittent nature of the caregiver's sense of loss, especially as the care recipient progressively deteriorates as a result of dementia. This phenomenon is captured by Boss¹³ and Blieszner et al¹⁴ who used the term "ambiguous loss" to describe the kind of loss that a caregiver may experience as the care recipient fades in and out of realistic consciousness depending, more or less, on the severity and the course of the care recipient's dementing disease. It is this kind of unstable pattern of loss that makes applying coping resources to offset the impact of grief on the caregiver difficult. In some instances, the degree of ambiguity may be so great that it renders a dementia caregiver's coping resources less effective than a person who is engaged in postdeath grieving.

This notion of ambiguous loss can also explain the patterns of relationship changes that affect a caregiver's sense of connectedness to his or her loved one. Evidence for the salience of this issue was underscored in a qualitative study of 253 caregivers of individuals with Alzheimer's disease conducted by Sanders and Corley.⁹ In this study, based on participants' descriptions of loss experiences during the course of caregiving, 68% reported that they were in fact experiencing classic symptoms of grief including feelings of ambiguity toward the loved one, perceived loss due to changing roles in the relationship, loss of intimacy, and diminished

interpersonal connection with the care recipient.⁹ They also found, however, that themes of relationship loss were more prominent in the later stages of the care recipients' disease and, that as the disease worsened, increased stress associated with the caregiver-care recipient relationship ensued. For example, caregivers indicated that they could no longer communicate or participate in shared activities with their loved one and they lamented the apparent loss of their loved ones' defining attributes while at the same time, because of the unstable nature of the disease, caregivers held out the unrealistic hope that somehow a normal interpersonal relationship between the caregiver and the care recipient might return. The following excerpt taken from the Sanders and Corley⁹ study illustrates this point:

I grieve that things that have become impossible for my husband to do. I sit and wait for the next change to happen. Sometimes the changes happen quickly whereas other times I seriously think that he is starting to come back. My life has become a nightmare. I am always waiting for the bottom to drop. That is why I grieve—I want my life back. (p 46).

The phenomenology of this kind of loss gives greater dimensionality to the caregiver experience that is not fully captured in concepts like "relational deprivation." For example, care recipient diminished memory and attention associated with the progressive cognitive deterioration due to dementia can make it difficult for the care recipient to play the same role in relationship decision making, intimacy, and communication that was played in the past.^{7,9,15,16} However, in ambiguous loss, the intermittent nature of the phenomenon sets up a mixed set of expectations that creates a revolving door of hope followed by disappointment and then ending in despair and a sense of being trapped and helpless by one's own situation. This cycle may repeat itself many times during the course of caregiving.

The idea of ambiguous loss appears to be an especially relevant concept for understanding how caregivers perceive the changing nature of a loved one with dementia. Unlike the loss experienced by a widow(er), for the caregiver of a person with dementia, the care recipient is still physically present, but may no longer be psychologically aware or able to interpersonally engage the caregiver in any meaningful way.¹⁷ Caregivers have difficulty interpreting this kind of loss; thus, they may not recognize a personal grief reaction or allow themselves to grieve openly. Given this scenario, a caregiver may tend to

deny problems or withhold himself or herself from seeking help.^{17,18}

For caregiver spouses of persons with dementia, the nature of ambiguous loss may be especially difficult, as they may now be deprived of the communication, support, and intimacy that they had before their partner developed cognitive problems. In addition, the dynamic of the relationship may move away from one that is mutually supportive to a relationship in which one spouse is now dependent on the other.¹⁹ For couples who had a history of negative or conflicted relational patterns, caregivers may grieve the loss of hope for future reconciliation.²⁰

Paying attention to relationship losses and the unique nature of those losses depending on the type of filial (eg, child or spouse) and relational characteristics of the caregiver/care recipient dyad is important because there is evidence that coping with loss may be more challenging and complex than coping with the demands of actually providing care. For example, study of spousal dementia caregivers by Rankin et al found that spouses were more likely to display symptoms of depression and grief as a result of diminished intimacy with their care recipients than with providing assistance to negotiate instrumental activities of daily living.²⁰

In addition to relationship losses, other types of losses inherent in caregiving that may initiate a grief reaction have been noted. When Loos et al surveyed 68 caregivers for persons with Alzheimer's disease, they found the following themes: loss of social and recreational interaction, loss of control over life events (freedom to be their own person), loss of well-being (exhaustion, lack of sleep, restlessness, difficulty concentrating, worry, guilt), and loss of occupation.²¹ Other authors have pointed to a loss of future hopes and dreams and the caregiver's loss of personal identity.¹⁸

Clinical Implications: Assessment of Caregiver Grief

Given that grief appears to be a relevant component of the caregiving experience, quantifying the extent to which a caregiver experiences grief is a necessary precursor to developing grief-targeted interventions. Although there are a number of validated measures of grief,²² these instruments have not been developed specifically with caregiver grief in mind. To date, only 1 measure, the Marwit and Meuser Caregiver Grief Inventory (MM-CGI),²³ has been designed specifically to address caregiver grief. To

construct this measure, the researchers conducted a qualitative examination of 87 spouse and adult-child caregivers of dementia patients at varying stages of the disease.⁷ The findings from this study yielded a stage-sensitive model of grief in dementia caregiving. Guided by this conceptualization, 184 items were identified as essential descriptions of the grieving response.²³

Factor analysis of the 184 items administered to 166 adult child and spousal caregivers revealed that 50 items, representing 3 distinct factors, accounted for most of the explanatory variance. The first factor, Personal Sacrifice and Burden, measured the extent to which caregivers experienced personal losses of time, freedom, sleep, health, and so on due to caregiving duties. The second factor, Heartfelt Sadness and Longing, represented the emotional reaction to the loss of relationship with the demented care recipient and measured feelings such as powerlessness, sadness, and wishing for the way things used to be. The authors note that this factor has the least overlap with measures of depression, and thus is likely a measure of “true [caregiver] grief.” The third factor, Worry and Felt Isolation, addressed how caregivers perceive losing personal connections with others due to caregiving responsibilities and the worries they have about their current and future situation.²³ A short form of the Marwit and Meuser Caregiver Grief Inventory (MM-CGI-SF)²⁴ was developed to quickly gauge caregiver grief in clinical contexts. The short form may be especially useful in settings where only a brief screening is desired.

Several studies have used these instruments to examine patterns of caregiver grief. A study of 99 caregivers by Adams et al found that those caring for loved ones with severe dementia had higher reported levels of grief and depression than those caring for loved ones with mild or moderate levels of dementia.²⁵ In particular, those caring for persons in the late stage of dementia were concerned about issues of relationship loss versus instrumental caregiving responsibilities. These same authors also conducted a pilot study examining grief and depression in 122 caregivers of individuals with Alzheimer’s disease and found that grief scores as measured by the MM-CGI predicted 48% of the variance of caregivers’ scores on the geriatric depression scale.²⁶ This finding could be interpreted to mean that a large component of caregiver depression may be alternatively explained as a grief reaction. In addition, the authors found that the Heartfelt Sadness and Longing factor of the MM-CGI explained the majority of the predicted variance, suggesting that relationship

losses may be an especially important component of the caregiver experience.

More recently, the MM-CGI-SF was employed to examine grief and personal growth experiences of spousal and adult-child caregivers of persons with dementia.⁸ Level of grief increased with the severity of dementia of the care recipient and there was a significant relationship between higher levels of grief and reported symptoms of caregiver depression, burden, stress, and decreased well-being. In addition, participants who reported experiencing personal growth as a result of their caregiving duties experienced lower levels of grief and reported finding greater personal meaning in caregiving.^{8,27}

Clinical Implications: Treatment of Caregiver Grief

Clinical use of the MM-CGI and its short form has led to treatment recommendations for persons caring for loved ones with dementia. Meuser et al¹² recommended using the MM-CGI-SF in clinical settings to help the clinician develop targeted and individualized interventions. For example, a caregiver who scores high on the Heartfelt Sadness and Longing subscale may require a different intervention than someone who scores high on the Personal Sacrifice Burden subscale. They suggested that the most important intervention that therapists can provide for grieving dementia caregivers is to normalize these feelings, underscoring the fact that caregiver grief interventions do not necessarily need to focus on ameliorating a pathological condition. In other words, grieving may be a normal part of the process of caring for a loved one with dementia.

A more recent article proposing specific component strategies for treating grief in dementia caregivers advocated the use of the MM-CGI-SF to identify grief issues of concern.¹⁷ Specifically, very low scores (which may be indicative of denial) or high scores on any of the MM-CGI-SF’s 3 subscales would serve as a starting point for further exploration and multidimensional intervention that might include treatment for grief and/or depression. The authors outline several assessment issues and intervention strategies that are appropriate for modest elevations on each of the MM-SGI-SF subscales. For example, if a caregiver scores highly on the Heartfelt Sadness and Longing subscale, they recommend using the following critical question as a guide for assessment and intervention: “What changes in the care recipient or your relationship with him/her

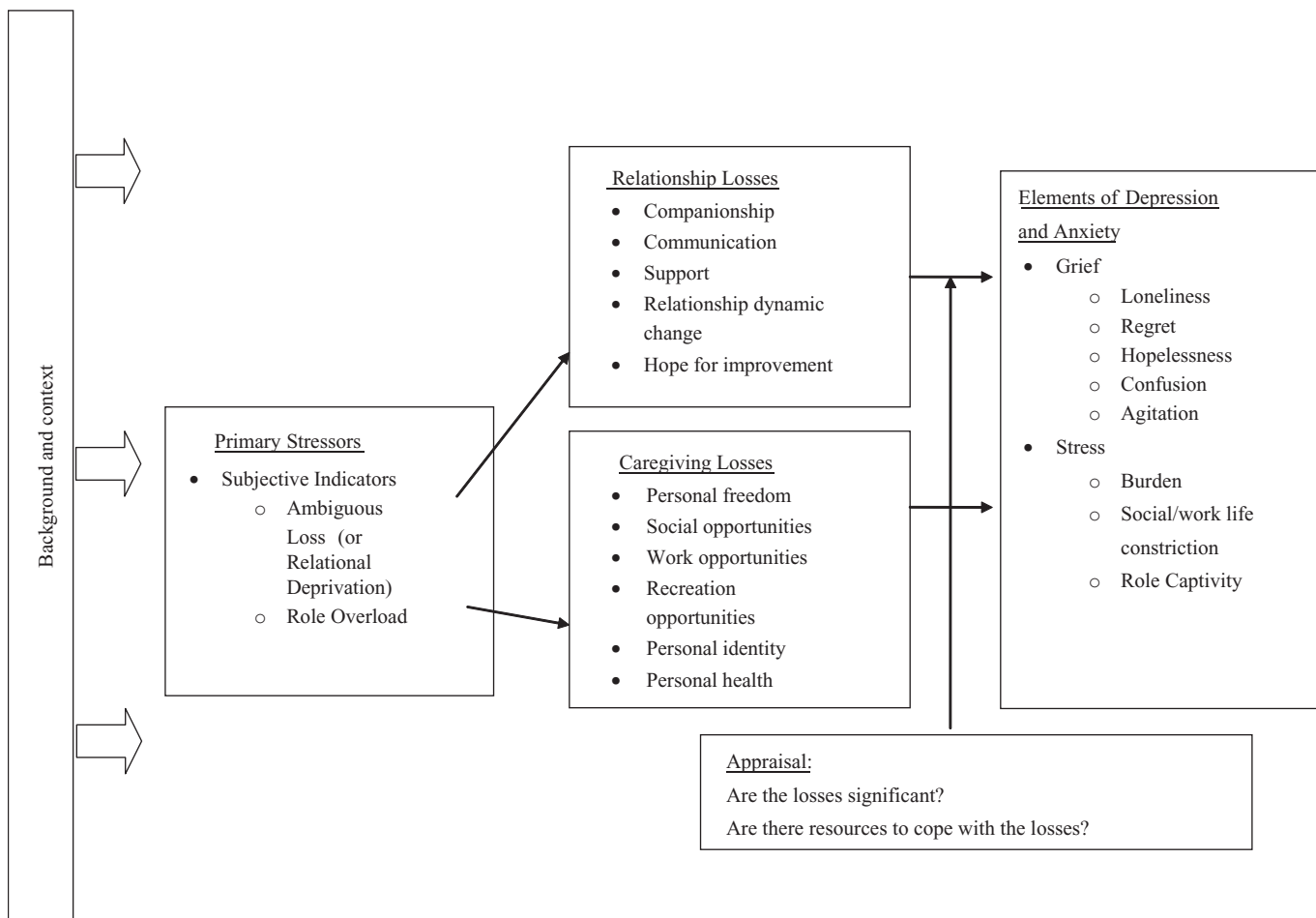


Figure 2. Grief-stress model of caregiving.

evoke feelings of sadness?” (p 55).¹⁷ A therapist may intervene by encouraging the caregiver to tell the story of the care recipient’s disease process, educating the caregiver on practices that will encourage a positive emotional connection with the care recipient, providing grief counseling, and making referrals to support groups. The authors make similar intervention recommendations based on caregiver scores on the MM-SGI-SF Personal Sacrifice and Burden and Worry and Felt Isolation subscales. Through this process, a therapist can help grieving caregivers begin to understand and accept losses inherent in their current circumstances.¹⁷

To date, there has been only 1 study that has empirically examined a broad-spectrum intervention strategy based on a theoretical model of treating dementia caregiver grief.²⁸ Based on a model of bereavement, this intervention consisted of a 5-session psychoeducational group curriculum that included topics such as: (1) an educational review of dementia middle- and late-stage dementia

symptoms; (2) spiritual views of death and mourning; (3) definitions, world views, predictors, and observances of grief and loss; (4) strategies for placement of loved one into a care facility; (5) coping mechanisms for loss; (6) identifying resources to assist with grief and loss issues; and (7) developing strategies for celebrating the life of the person with dementia. The researchers evaluated the effectiveness of their intervention through pre administration and postadministration of the MM-CGI to those who attended the 5-week intervention group. They also administered the measure once to a control group after they attended a typical (nongrief-focused) caregiver support group. The study group’s MM-CGI scores increased from pretest to posttest, although this increase did not reach statistical significance. Although the caregivers in the treatment group unanimously reported that they found the group to be beneficial, the authors reasoned that this unexpected finding was due to the effort to normalize and accept the caregivers’ grief experiences; therefore,

they felt freer to express their true reactions. Overall, the authors reported that the intervention was a useful method for helping caregivers learn about their grief symptoms, develop effective coping strategies, and find access to needed resources.²⁸ The unexpected findings also highlight the difficulty of designing treatments based on traditional assumptions of grief and bereavement.

An Expanded Model of Caregiver Grief

Although the literature points to caregiver grief as a factor that influences the well-being of caregivers, a testable model of caregiver grief has yet to be clearly articulated. Meuser et al proposed a descriptive model of how issues of grief and loss interact with symptoms of stress, burden, and depression. According to the authors, grief occurs in response to a personal loss, and the way in which that grief will be expressed (ie, symptoms of depression, burden, stress) varies according to individual, situational, and cultural factors of each caregiver.¹² However, the model has not been elaborated and does not clearly explain the complicated processes connecting caregiver grief and health outcomes.

Building from the extant literature described previously, it is possible to construct a conceptual model that can be modified as empirical evidence emerges, linking the grief process to health consequences in caregiving. The proposed grief-stress model of caregiving depicted in Figure 2 integrates existing ideas into a framework that lends itself to predicting health outcomes. Similar to stress-process model by Pearlin et al,⁶ this adapted grief-stress model of caregiving can be divided into 3 domains: (1) background and context; (2) primary stressors; and (3) outcomes associated with loss. The first component of the model, the context, is the same as in the Pearlin stress-process model. However, the primary stressors focus on 2 different types of losses: (1) ambiguous loss, as described earlier, which includes when the caregiver and care recipient no longer communicate or are intimate in the ways they once were or where the caregiver no longer feels supported by the care recipient and (2) role overload which is a product of the care provision process. In role overload, the caregiver may experience diminished personal freedom, loss of engagement in personally fulfilling activities, or a loss of occupation as more time is spent in the provision of care. Distinguishing these different categories of loss serve to clarify the varied experiences that caregivers face when caring for a

loved one who is substantially cognitively impaired due to dementia. The third component of the model describes how these losses affect the caregiver and could be construed under a diagnostic label of depression or anxiety; however, the qualitative nature is much more varied than the symptoms of these psychiatric conditions.

As in the stress-process model, the grief-stress model of caregiving assumes that the caregiver will make a specific set of appraisals around loss, and depending on the type and the significance of those losses, as well as the caregiver's perceived coping resources, one of several outcomes could be anticipated. Those who experience relationship loss are more likely to experience grief (which may manifest as symptoms of loneliness, regret, confusion, or agitation) than those who primarily experience caregiving losses. Conversely, caregiving losses are more likely to produce feelings of stress (which may manifest itself as burden, a sense of constriction in one's social or work life and/or role captivity).

Most of the caregiver stress literature has focused on those factors grouped under the "caregiving losses" while issues of grief have been largely ignored. The grief-stress model elevates and makes more visible the consequences of relationship losses. Even though these issues have received less attention in the scientific and clinical literature, there is evidence that suggests that these factors also exert a driving force in caregiver behaviors, moods, and well-being.^{20,29-31}

Grief-Stress Model of Caregiving: Areas for Future Research

The grief-stress model of caregiving described above represents a first step in articulating a framework that could guide future efforts at intervention and assessment. Although it is primarily descriptive, the goal is to better understand grief processes in dementia caregivers through a schematic that engages multiple variables in a process paradigm. Several testable research questions emerge from this model:

- Are there different classes of grief response? And, if so, is a type of grief associated with a specific caregiving situation?
- To what extent does the functional and cognitive status of the care recipient precipitate a grief response in the caregiver?
- Is the caregiver grief response unidimensional or does it alter the phenomenon of caregiving in multiple ways?

- What is the relationship between caregiver stress and caregiver grief?
- In what ways do issues of loss and grief interfere with a caregiver's ability to cope with the stressors of caregiving?
- How do specific grief interventions affect caregiver stress and depression?

Based on these questions it may be possible to formulate additional intervention schemes by using the grief-stress model of caregiving as a guide. The domains measured by the MM-CGI may fit within this framework; however, regardless of the kind of assessment tools that are used, the existing literature documents that issues of loss and grief are important aspects of the caregiving experience. Caregivers would therefore benefit from increased efforts on the part of health care professionals to better understand, assess, and treat grief and its consequences. This may produce a greater array of effective intervention strategies to address the issues underlying the challenges of caregiving.

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