January 2012

Bereavement Outcomes among Spousal Hospice Caregivers: The Role of Rumination, Feelings of Relief, and Perceived Suffering

Jessica Y. Allen
University of South Florida, jessica.y.allen@gmail.com

Scholar Commons Citation
Allen, Jessica Y., "Bereavement Outcomes among Spousal Hospice Caregivers: The Role of Rumination, Feelings of Relief, and Perceived Suffering" (2012). *USF Tampa Graduate Theses and Dissertations.*
https://digitalcommons.usf.edu/etd/4276

Bereavement Outcomes among Spousal Hospice Caregivers: The Role of Rumination, Feelings of Relief, and Perceived Suffering

by

Jessica Y. Allen

A dissertation submitted in partial fulfillment
of the requirements for the degree of Doctor of Philosophy
School of Aging Studies
College of Behavioral and Community Sciences
University of South Florida

Major Professor: William E. Haley, Ph.D.
Susan C. McMillan, Ph.D.
Victor Molinari, Ph.D.
Ron S. Schonwetter, M.D.
Brent J. Small, Ph.D.

Date of Approval: 8/21/2012

Keywords: Older Adults, End-of-Life, Grief, Complicated Grief, Depression

Dedication

I dedicate this dissertation to Dr. Rebecca S. Allen who introduced me to the world of aging and mental health and to my husband Justin Allen who provided unconditional love, support, motivation, dinner, and coffee as I completed the dissertation. I also dedicate this dissertation to my parents and sisters for their support and encouragement and to my “best” cousin William Bashlor who lived fiercely, loved intensely, and whose death in April, 2012 brought new meaning to the project. Finally, I would like to dedicate this dissertation to all of the “Supermen,” “Superwomen” and their spouses. Thank you for sharing your story with me.

Acknowledgements

I would like to acknowledge and thank the staff at LifePath Hospice and Chapters Health System. Thank you to the volunteers who made hundreds of phone calls, the Bereavement Department staff for aiding in identifying possible participants, and the Research Department staff for their integral role in facilitating the data collection efforts. I would also like to acknowledge undergraduate research assistants Ms. Alexis Bautz, Ms. Falon Blessing, and Ms. BrettAshley Tambaco for their dedication and efforts on the project. Thank you to Aging Studies graduate student Chantelle Sharpe for her assistance and “ride-alongs.” In addition, I thank the University of South Florida School of Aging Studies classmates and faculty, with a special “thank you” to fellow students Jessica Krok and Elizabeth Hahn for their friendship, support, encouragement, and lunches! “Thank you” also to Dr. Brianne Stanback for reading multiple drafts of my writing, for encouraging me to define and go for my goals, and for being a wonderful friend and source of support. Finally, “thank you” to dissertation committee members Drs. William Haley, Susan McMillan, Victor Molinari, Ron Schonwetter, and Brent Small and Department Chair Dr. Cathy McEvoy for all of their encouragement, feedback, and guidance throughout the dissertation process.

Table of Contents

List of Tables

List of Figures

Abstract

Background: The death of a spouse is among the most distressing life events faced by older adults and frequently follows long periods of providing extensive care and support. Although many spouses are resilient following loss, a number of bereaved spousal caregivers have poor psychological well-being and may benefit from clinical services. However, it can be difficult to determine who may most benefit from bereavement services and why some individuals are at greater risk for poor bereavement; thus, there is a need for greater understanding of the process of bereavement. Therefore, the purpose of this dissertation was to investigate a number of theoretically relevant factors within the context of bereavement after caregiving as possible predictors of psychological well-being following loss. Specifically, former caregivers' perceptions of loved ones' end-of-life suffering, rumination, and feelings of relief were investigated as possible predictors of caregivers symptoms of depression, grief, and complicated grief following loss.

Method: Participants included 61 former spousal caregivers of hospice patients 50 years of age or older who lost a spouse in the last 6-18 months. Individuals completed an interview that included retrospective recall of perceptions of loved ones' physical, emotional, and existential suffering, current frequency of thoughts about loved ones' suffering, stress-reactive rumination, and feelings of relief following the death. Participants also completed measures assessing current symptoms of depression, present feelings of grief, and complicated grief. Descriptive information about care recipients was obtained via retrospective review of hospice electronic medical records following participant interview. Several regression analyses were conducted to investigate the relationship of possible predictor variables to bereavement outcomes and interactions among predictor variables.

Results: Findings revealed important relationships between rumination, feelings of relief, and former caregivers' psychological well-being follow loss. Higher rumination and less feelings of relief were associated with worse bereavement outcomes. In addition, interaction analyses revealed that rumination and feelings of relief moderated the relationship between participants' perceptions of their spouses' emotional end-of-life suffering and psychological distress. Other descriptive predictors of depression, grief, and complicated grief were identified.

Discussion: Participants were highly distressed former caregivers who were highly engaged in caregiving duties prior to loss. About 40% reported no feelings of relief following the loss, and over one-fourth of participants still had frequent ruminations about their loved ones' suffering. High stress-reactive rumination was an important predictor of bereaved spouses' psychological distress. Clinical interventions, such as cognitive behavioral therapy, could focus on identifying, redirecting, and reducing distressing thoughts or the negative feelings associated with them, such as ruminations associated with loved ones' end-of-life suffering. Future longitudinal research should examine the relationships between rumination, feelings of relief, perceived suffering, and bereavement outcomes in order to identify patterns that may inform clinical interventions.

Chapter One: Introduction

Overview

This dissertation examined relationships among several interpersonal and coping factors within the context of bereavement after caregiving. Chapter One provides an introduction to the dissertation and review of the literature on bereavement following caregiving. Next, a review of the literature on the following interpersonal and coping factors is presented: caregiver rumination in response to loss, feelings of relief after bereavement, and caregiver perceptions of loved ones' suffering. Each topic is reviewed individually, and relationships between them are considered. A description of the study aims and hypotheses conclude Chapter One. The chapters that follow describe the dissertation method and include details about the study sample, procedures, measures, and statistical analyses. The final chapters present the study results and conclusions drawn from study findings.

Introduction

The death of a spouse is recognized as one of the most significant and stressful life events faced by older adults. For many, this loss follows long periods of caregiving for partners with chronic illness during which time caregivers may experience declines in physical and mental health (Boerner & Schulz, 2009; Lavela & Ather, 2010; Xu, Kochanek, Murphy, & Tejada-Vera, 2010). Despite facing potentially distressing circumstances prior to loss, most spouses show resiliency and generally positive outcomes during bereavement (Bonanno, Wortman, et al., 2002; Schulz, Hebert, & Boerner, 2008). However, a minority of spousal caregivers experience poor and potentially clinically significant bereavement outcomes, and identifying individuals who would most benefit from clinical interventions can be difficult. Research efforts that aim to understand risk factors for difficult bereavement among former spousal caregivers can assist providers seeking to target intervention services. This is a clinically relevant objective as early psychosocial intervention can improve caregiver outcomes during bereavement (Haley, et al., 2008). Further, targeting services can benefit programs that have heavy contact with bereaved caregivers but have limited resources for provision of bereavement services (e.g. hospice and palliative care programs).

A number of factors influence the degree to which individuals experience poor well-being during bereavement. Previous research has emphasized interpersonal and situational risk and protective factors such as anticipated or unanticipated loss, type of loss such as spousal or child, sociodemographic factors, and social support received (Stroebe, Schut, & Stroebe, 2007). However, other interpersonal factors and underlying cognitive and coping processes may also be important in affecting psychological well-being during bereavement. One important area of study is how rumination may affect bereavement outcomes. Although not widely studied, there is reason to think that caregivers who are preoccupied with their past caregiving experiences and dwell heavily on related negative feelings may have difficulties during bereavement. Second, previous research has shown that some caregivers report relief after the death of a loved one, but the relationship of caregiver feelings of relief to distress during bereavement have not been widely addressed. Third, while previous work has investigated perceptions of care recipient suffering as stressors during caregiving, these perceptions may also have important implications for bereavement as perceptions of suffering, feelings of relief, and rumination may be closely related to one another. Therefore, the purpose of this dissertation was to expand upon prior research by investigating caregiver rumination, feelings of relief, and perceptions of spousal suffering as possible predictors of well-being following loss. Specifically, it is important that researchers consider multiple assessments of bereavement outcomes, as indicators of psychological well-being such as depression, grief, and complicated grief are related, yet distinct constructs (Bui, Nadal-Vicens, & Simon, 2012; Prigerson, et al., 2009).

Literature Review

Bereavement Following Caregiving

For many caregivers, bereavement follows long periods of providing intensive care and support to loved ones with extensive physical and mental health illness. In 2009, approximately 65.7 million Americans spent at least some time within the last year providing physical, emotional, and financial caregiving support to loved ones (National Alliance for Caregiving, 2009). Sixty-nine percent of caregivers reported providing care to recipients with long-standing physical conditions and approximately 32% provided care to individuals with emotional or mental health conditions. Individuals over the age of 65 were more likely than younger caregivers to be the sole primary caregiver and approximately 19% of older adults were spousal caregivers (National Alliance for Caregiving, 2009). Prior research has shown that spousal caregivers are particularly common among hospice and palliative care populations and a report based on the 2000 National Health Care Survey found that 92% of hospice discharges (86% of whom the reason for discharge was death) had a primary caregiver and 42% of caregivers were spousal (Haupt, 2003).

Although spousal caregivers face distressing challenges throughout the caregiving experience, Hebert and Schulz (2006) suggest that the end-stages of caregiving are among the most difficult because approaching the end of life requires confronting unique challenges such as making end-of-life treatment decisions and witnessing loved ones' suffering and pain. For some caregivers, this distressing time has negative consequences for adjustment after a partner's death. Studies report that 10-40% of bereaved caregivers experience poor psychological well-being including clinical depression and complicated grief 6-months to 1-year following loss (Boerner & Schulz, 2009; Chiu, et al., 2009; Guldin, Vedsted, Zachariae, Olesen, & Jensen, 2011; Hensley, 2006; H. G. Prigerson, et al., 1995; Schulz, Boerner, Shear, Zhang, & Gitlin, 2006). Complicated grief can lead to poor mental and physical health morbities including heightened risk of cancer, cardiac events, and suicidal ideation (Lobb, et al., 2010). Such negative outcomes may be even more common among spousal populations, as research shows spousal loss often follows difficult periods of caregiving for chronic illness (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Xu, et al., 2010). Therefore, researchers should investigate pre-loss spousal caregiving experiences, as these experiences may have important effects on caregiver well-being following spousal loss.

Theoretical Framework

Understanding how pre-loss caregiving experiences affect bereavement outcomes is an important, yet underdeveloped area of research. Two major hypotheses consider individual caregiving experiences and subsequent responses to loss: (1) the hypotheses of wear and tear (i.e. stress accumulation); and (2) the relief hypothesis (i.e. stress reduction) (Boerner & Schulz, 2009; Keene & Prokos, 2008). According to the wear and tear hypothesis, the cumulative stress associated with caregiving depletes coping resources, which leads to poor bereavement outcomes. Conversely, the relief hypothesis posits that caregivers experience a reduction in stress following care recipients' death, which leads to feelings of relief and thus more positive or normal bereavement outcomes. Within the context of these two approaches to understanding how caregiving may affect the experience of bereavement, several important topics deserve further attention. Therefore, this dissertation considered how a number of pre-loss factors (caregiver perceptions of care-recipient suffering at the end of life), one coping response (rumination), and feelings of relief following loss affect bereavement outcomes.

Rumination

Definition

Rumination is described as attentive and repetitive thoughts about oneself and ones' world (Segerstrom, Stanton, Alden, & Shortridge, 2003). Ruminations are commonly conceptualized as negative and distressing in nature, are associated with depression, anxiety, and angry moods, and are typically past-oriented in focus (Nolen-Hoeksema, 1991; Nolen-Hoeksema, Parker, & Larson, 1994; Nolen-Hoeksema, Wisco, & Lyubomirsky, 2008). Although there are many theories of rumination, the most common conceptualizations suggest that rumination on one's negative affect (Conway, Csank, Holm, & Blake, 2000; Nolen-Hoeksema, et al., 2008) and rumination following stressful events (Papageorgiou & Wells, 2004; Robinson & Alloy, 2003) heighten and maintain feelings of sadness and other negative affect.

One of the most commonly cited theories of rumination is the Response Styles Theory (RST) by Nolen-Hoeksema (1991). According to RST, ruminations involve repetitive and passive focus on negative emotions and the causes and consequences of these emotions (Nolen-Hoeksema, 1991; Nolen-Hoeksema, et al., 2008). Further, within the context of RST, rumination is conceptualized as a negative cognitive style that is relatively stable and is correlated with other maladaptive cognitive styles (Nolen-Hoeksema, 1991; Nolen-Hoeksema et al., 2008). Stress-reactive Rumination (SRR) is an extension of RST and suggests that ruminations on negative, event-related inferences occur after experiencing a stressful event (Alloy et al., 2000). Further, Alloy and colleagues suggest that individuals who typically make negative inferences and are likely to ruminate on negative inferences can be at risk for developing depression (Alloy et al., 2000; Robinson & Alloy, 2003). Therefore, whereas RST suggests that ruminations are in response to depressed mood, SRR proposes that ruminations are of thoughts related to a stressor (Smith & Alloy, 2009).

Nolen-Hoeksema and colleagues (1991; 2008) propose that rumination may intensify and even lengthen distress through three main mechanisms: activation of negative thoughts, lack of utilization of problem-solving strategies, and inhibition of adaptive behaviors. Specifically, ruminative coping increases the likelihood that negative thoughts and memories will be activated by individuals' distressed state (e.g. depression) as an attempt to understand their present state. Secondly, rumination impedes employment of problem solving, which is described as a beneficial form of coping. Finally, rumination inhibits instrumental or adaptive behaviors. It is possible that bereaved individuals with high levels of rumination are particularly vulnerable to poor outcomes, as stressors associated with the end of life may become the focus of ruminative thoughts during bereavement. Therefore, Stress-reactive Rumination Theory provides an intriguing premise for studying rumination in response to factors associated with spousal loss, as the death of a spouse is described as one of the most stressful forms of loss.

Rumination and Grief

Several prior studies have identified an important relationship between rumination and depression during bereavement. In one of the first studies to link rumination and bereavement, investigators assessed whether bereaved individuals with a ruminative coping style had exacerbated and prolonged depressed mood in contrast to bereaved individuals who did not have a ruminative coping style (Nolen-Hoeksema, et al., 1994). Results showed that individuals with a more ruminative coping style were more depressed than individuals with less ruminative coping styles at 6-months following loss. In a similar study, bereaved male partners who engaged in high ruminative thought had greater psychological distress and smaller improvements in morale over 12 months than males who engaged in less rumination (Nolen-Hoeksema, McBride, & Larson, 1997). Finally, in a longitudinal study of depression among a diverse sample of bereaved dementia caregivers, Bodnar and Kiecolt-Glaser (1994) found that caregivers with greater levels of rumination about caregiving experiences also reported higher rates of depression, perceived stress, and social isolation.

These studies indicate that rumination in response to loss can have negative effects on psychological well-being during bereavement. However, many previous studies only consider depression, which is a related, but distinct construct from grief. Further, only the study by Bodnar and Kiecolt-Glasser (1994) assessed current rumination about former caregiving experiences within a bereaved sample whereas the other studies examined ruminative response styles. Research that investigates the effects of rumination on multiple constructs of psychological well-being following loss could provide important clinical implications for mental health providers. However, in reviewing the literature, only one identified study specifically utilized a validated measure of complicated grief to investigate rumination as a predictor of bereavement outcomes other than depression. Hardison and colleagues (2005) investigated sleep patterns among bereaved college students and reported that ruminating and dreaming about their loved one were important predictors of higher complicated grief. It is important to note that this study did not include a standardized measure of rumination and only assessed sleep-related ruminations (i.e. how often the participant had trouble falling asleep because they were thinking about their loved one and how often they dreamed about their loved one).

Researchers have frequently conceptualized engaging in rumination as a normal part of the grieving process. For example, Stroebe and colleagues (2007) describe elevated levels of ruminative activity, such as yearning, longing, and being preoccupied with thoughts of the deceased, as common responses to early bereavement. In addition, many grief therapies encourage thinking about one's loss as a confrontational, adaptive process (i.e. grief work) that can lead to positive well-being (Stroebe, Boelen, et al., 2007). Specifically, the process of working through grief requires actively confronting and recurrently which can include focusing on memories of events and feelings before, during, and after the death (Stroebe, 1992; Stroebe & Schut, 1999). Other classic theories of working through grief, such as Worden's "tasks of mourning" (Stroebe & Schut, 1999; Worden, 1991) and Rando's "Six R's" (Rando, 1993), suggest that bereaved individuals must move through a number of phases or tasks following the loss. Two of these tasks have similar conceptualizations to that of rumination. Namely, Worden's second task of mourning requires bereaved individuals "work through" physical and emotional/behavioral pain of grief (Worden, 1991) and Rando's third "R" includes recalling and re-experiencing the memories of the loved one and related feelings (Rando, 1993).

Although conceptually similar, there are a number of proposed differences between rumination and working through grief. Stroebe and colleagues (2007) highlight that many definitions of rumination propose passively focusing on restricted content (e.g. negative grief-related emotions) whereas grief work is typically confrontational and considers a breadth of concerns surrounding the loss. In an intriguing conceptualization of "grief work as rumination," Bonanno and colleagues (2005) propose that grief processing is not required in order to adjust to a loss, as suggested by classic theories of working through grief. In contrast, extreme or extensive grief processing is described as a form of rumination that may exacerbate distressing symptoms (Bonanno, Keltner, Holen, & Horowitz, 1995; Bonanno, Papa, Lalande, Zhang, & Noll, 2005; Bonanno, Papa, & O'Neill, 2002; Bonanno, Wortman, et al., 2002). For example, Bonanno found individuals who were not depressed prior to loss but had a chronic grief pattern during the first 1.5 years following loss also reported frequently thinking about their spouse 6 months following death (Bonanno, Wortman, & Neese, 2004). Therefore, in line with SRR, ruminations focused on stressful aspects surrounding a loss may become the focus of negative ruminations and subsequently greater distress.

Shear has suggested that circumstances and consequences of a death can become the focus of ruminations and increase the risk for complicated grief (Shear, 2012). In consideration of the Stress-reactive Rumination Theory, witnessing care recipients' distressing symptoms associated with suffering at the end of life (e.g. pain, constipation, anxiety, and feelings of lack of purpose) may become the focus of ruminative thought. Further, these ruminations may interact with perceptions of loved ones' suffering at the end of life to predict psychological well-being during bereavement. Therefore, a primary aim of this dissertation was to investigate rumination as both a predictor and moderator variable of bereavement outcomes (i.e. depression, grief, and complicated grief).

Feelings of Relief

A second important area of study involves caregiver feelings of relief following the loss of a loved one. Extensive research has demonstrated that caregivers experience high levels of stress, burden, and depression during caregiving (e.g. Schulz & Beach, 1999; Schulz, Mendelsohn, et al., 2003). While the loss of a loved one can be an emotionally distressing time for caregivers, the loss may also evoke feelings of relief from the heavy physical and emotional demands of caregiving. As described previously, the wear and tear and relief hypotheses have been suggested as conceptual frameworks for studying how caregiving experiences may affect bereavement outcomes. Specifically, researchers have hypothesized that caregivers experience either feelings of relief (i.e. stress reduction) or higher levels of distress (cumulative stress perspective) following loss (Schulz, Boerner, & Hebert, 2008).

Two lines of evidence support the hypothesis that bereaved caregivers frequently experience feelings of relief following the death of a loved one. One line of studies shows that higher pre-loss caregiver strain is associated with better bereavement outcomes such as lower depression, fewer feelings of overload, and heightened sense of mastery (Aneshensel, Botticello, & Yamamoto-Mitani, 2004; Li, 2005; Mullan, 1992). Similarly, a longitudinal study by Bonanno and colleagues (2002) found bereaved spouses with high pre-loss depression had improved functioning following loss (i.e. “depressed-improved”). The authors proposed that the “depressed-improved” group might have disproportionally consisted of caregivers compared to groups that showed less improvement. However, other research that assessed patterns of well-being among bereaved dementia caregivers did not uniformly report reduced distress, but rather found that some caregivers experience increased distress during bereavement (Aneshensel, et al., 2004). Notably, these studies do not directly assess feelings of relief but consider a reduction in pre-loss symptoms as indicators of relief or stress-reduction.

The second line of evidence to support the relief hypothesis involves research that directly assessed feelings of relief, although there is limited work on this topic and only two studies were identified. Using data from a large, multisite intervention project, Schulz and colleagues (2003) reported that over 70% of caregivers felt “somewhat” to “very relieved” in response to care recipients’ death. The second identified study, conducted by Haley and colleagues (2001), reported that the degree to which dementia caregivers reported feelings of relief differed significantly by race/ethnic group. Specifically, African Americans reported less feelings of relief than that of White caregivers, indicating that feelings of relief after caregiving may vary across caregiver populations. It is important to note that both the study by Schulz (2003) and Haley (2001) focus on dementia caregivers. However, because end-stage dementia leads to a poor quality of life, requires high caregiver involvement, and the inevitability of death becomes readily evident in many cases, it is not clear whether such feelings of relief occur similarly in non-dementia caregivers. Based on the limited evidence for feelings of relief after the death of a care recipient, there is a need for research that considers how feelings of relief, or lack thereof, may affect psychological well-being following loss in other samples of former caregivers.

Finally, in reviewing the literature for this dissertation, no empirical studies were identified that examined whether the extent of relief (i.e. high vs. low) is associated with outcomes in bereavement. Further, given that risk factors may interact in complex ways by involving internal perceptions and personal coping methods (e.g. Stroebe, Schut, et al., 2007), research on interactions among interpersonal and intrapersonal factors could further guide coping interventions. For example, stressors (such as care recipient physical and emotional distress) may be related to feelings of relief (high or low) and therefore influence bereavement outcomes (normal or complicated). In response to this prospect, an aim of the current study was to investigate feelings of relief as a moderator of caregiver stressors relevant to the pre-loss caregiving experience (i.e. care recipient suffering at end-of-life) and subsequent bereavement outcomes.

Perceived Suffering

A third important interpersonal area of study within the context of bereavement after caregiving is perceptions of spouses' suffering as they approached the end of life. While much of the literature on pre-loss caregiver strain has focused on stressful aspects of specific caregiving tasks (e.g. managing activities of daily living or behavioral problems), recent work suggests exposure to loved ones' suffering, and perceptions of suffering by the caregiver, could be particularly distressing and have important mental health implications (Monin & Schulz, 2009; Monin, et al., 2010; Schulz, et al., 2009; Schulz, et al., 2007; Schulz, McGinnis, et al., 2008; Schulz, et al., 2010). Broadly, suffering includes threats to personhood that may encompass pain, injury, anxiety, depression, feelings of loss, discomfort, loss of control, helplessness, and inability to cope (Ferrell & Coyle, 2008; Monin & Schulz, 2009). At the end of life, suffering can involve exacerbated physical, mental, and spiritual distress for both the person facing death and loved ones who witness end-of-life suffering in a severely ill relative. In support of this claim, Schulz and colleagues have reported higher perceptions of dementia patients' current emotional and existential suffering were associated with increased depression among family caregivers 6 months after baseline interviews (Schulz, McGinnis, et al., 2008). In another study of older couples, Schulz and colleagues (2009) found that husbands' concurrent and future risk of clinical depression was associated with high levels of wives' self-reported suffering. Overall, these findings suggest suffering, particularly high levels of suffering, may be a caregiving-related stressor that has lasting negative effects on caregiver well-being.

In reviewing the literature, only one identified study investigated retrospective perceptions of suffering and psychological well-being outcomes within a sample of bereaved adults. Barry and colleagues (2002) evaluated perceptions of suffering and complicated grief, major depressive disorder, and post-traumatic stress disorder among a community sample comprised primarily of bereaved spouses. Approximately half of the sample (48%) reported the perceived suffering as minimal and there were no significant associations between perceptions of suffering and subsequent mental health outcomes during bereavement. However, given that this study utilized only a single-item assessment of suffering (i.e. “To what extent do you think your loved one suffered in dying?”) with limited response items (i.e. “minimally”, “moderately”, and “extremely”) (Barry, et al., 2002, p. 449), research that utilizes a more inclusive representation of domains of suffering may yield different results. For example, recent work by Monin and Schulz (2009) suggests that suffering is a holistic concept that includes domains of psychological distress, physical symptoms, and spiritual or existential distress. However, in reviewing the literature, no studies were identified that investigated multiple domains of suffering and caregivers’ psychological well-being following the death of a spouse.

Taken together, research on perceptions of care recipients’ suffering and caregivers’ well-being outcomes suggest promising, yet under-researched, implications for bereavement. Further, the feelings of relief hypothesis may have important interactions with perceptions of suffering. Volicer (2004) suggested that feelings of relief, such as those reported in Schulz’s study (2003), may be related to the caregiver’s perception that their loved one had a poor quality-of-life, or experienced suffering. Because some spousal caregivers are already taxed at their partners’ end-of-life and observe their partners’ distressing symptoms (e.g. pain, vomiting, severe dry mouth, heighted anxiety, agitation, and depression), they may have feelings of relief that their loved one is no longer in a distressed state, which may lead to better bereavement outcomes. However, very little research has been conducted in this area. Therefore, a primary aim of this dissertation is to examine spousal caregiver perceptions of loved ones' physical, psychological, and existential suffering on subsequent symptoms of depression, present feelings of grief, and complicated grief.

Study Aims and Hypotheses

Aim 1: Rumination

The first aim of this dissertation was to investigate the relationship between rumination and spousal caregiver psychological distress during bereavement. In addition, descriptive information was gathered regarding the frequency of caregivers' ruminations about care recipients' physical, emotional, and existential suffering. It was hypothesized that high levels of stress-reactive rumination would be associated with worse caregiver psychological distress (i.e. depression, grief, and complicated grief). However, given that this is the first identified study to investigate ruminative thought about perceived suffering, no a priori predictions were made regarding the frequency of different types of caregiver ruminations.

Aim 2: Feelings of Relief

The second aim of this dissertation was to explore whether feelings of relief were associated with spousal caregiver psychological distress during bereavement. It was predicted that greater feelings of relief would be associated with better bereavement outcomes (i.e. less psychological distress).

Aim 3: Perceived Suffering

A third aim was to explore the relationship between spousal caregiver perceptions of care recipients' physical, psychological, and existential suffering and caregiver psychological distress during bereavement. Too little research has been conducted in this area to offer directional hypotheses.

Aim 4: Interactions

The final aim of this dissertation was to investigate interactions among key study variables (i.e. rumination, relief, and suffering). Specifically, it was hypothesized that: 1) spousal caregivers who report high perceptions of suffering and low feelings of relief would have worse psychological distress during bereavement; and 2) spousal caregivers who reported high levels of rumination with high perceptions of suffering would have worse psychological distress.

.

Chapter Two: Method

Overview

Chapter Two describes the design of the dissertation study. The chapter begins with a description of the sample and eligibility criteria, recruitment efforts, procedures for data collection, and measures utilized during the data collection process. A description of planned analyses to address research Aims 1-3 to investigate key predictor variables (stress-reactive rumination, frequency of thoughts about patients' end-of-life suffering, feelings of relief, and perceptions of suffering) and bereavement well-being outcomes is provided. In addition, planned analyses to investigate interactions among key predictor variables (Aim 4) are described. A description of planned analyses to investigate statistical power concludes the chapter.

Study Sample

Participants included 61 bereaved spousal hospice caregivers of patients admitted to hospice care in one of two large, not-for-profit hospice programs in West Central Florida. Individuals were eligible to participate in the study if they were: (1) 50 years of age or older, (2) cognitively able to participate, (3) English-speaking, (4) identified by the hospice staff/volunteer or researcher as the patient's primary caregiver, and (5) experienced the death of a spouse in the last 6 to 18 months. A minimum of 6 months was utilized in this study, as early grief reactions are not prognostic of lasting clinical distress, and 6-months is a diagnostic criterion for complicated grief (Prigerson, et al., 1996; Prigerson, et al., 1997; Prigerson, et al., 2009). Primary caregiver was defined as a spouse who identified himself or herself as the main person responsible for decision-making.

Recruitment

Participants were recruited in collaboration with Chapters Health System in Tampa, Florida. The hospice programs involved in the Chapters Health System include LifePath Hospice, which covers Hillsborough County and Good Shepherd Hospice, which covers Highlands, Hardee, and Polk counties in Florida. LifePath bereavement and research department staff aided in identifying prospective spousal caregiver participants and provided lists of individuals from both hospice programs. The lists included individuals described as spousal, primary caregivers of patients who lost a loved one over the age of 50 in the last 6-18 months. Individuals who had previously requested to discontinue further mail or telephone contact with hospice were excluded from the lists.

LifePath volunteers who met the following criteria were approved to telephone prospective participants and request former caregivers' consent to be contacted by the research team: (1) 18 years of age or older, (2) completed LifePath patient-family or office training, (3) participated in a 1-hour study training provided by Jessica Allen, and (4) completed a 1-hour specialty bereavement training provided by the LifePath Hospice bereavement coordinator. Upon gaining consent to contact prospective participants, a member of the research team then telephoned individuals to briefly describe the study and evaluate potential interest in the study. Individuals who expressed interest participated in a 5-minute screening to determine study eligibility.

As shown in Figure 2.1, trained hospice volunteers attempted to make contact with 462 possible participants. Volunteers were not able to make contact with 268 individuals due to insufficient contact information or no answer/lack of response to voicemail messages after a maximum of five calls. Among the individuals who volunteers were able to contact, 30 did not meet the study eligibility criteria, and 59 were not willing to receive contact from the research team. One hundred and five individuals consented to receiving a telephone call from a research assistant to hear more about the study.

Researchers made up to five attempts to contact all possible participants. Of the 105 names provided by hospice volunteers, 12 individuals could not be contacted and/or did not return our calls and 7 did not meet the study inclusion criteria. Ten individuals who agreed to a telephone interview did not return a signed copy of the informed consent document and did not answer/return calls from the research team. Fifteen individuals who initially expressed willingness to participate in the study canceled or changed their mind prior to the study interview. Individuals who provided reasons for not consenting to hear more about the study or not completing the study protocol stated a lack of interest, lack of time, worry that talking about bereavement would be upsetting, poor physical health, difficulty hearing, recommendations from mental health providers and/or family members not to participate, moving out of the area (e.g. Snow Birds), a negative experience with hospice, and death. Of 105 possible participants who consented to hearing more about the study, 61 actually completed the study protocol, resulting in a participation rate of 58%. Eighteen individuals (i.e. 14 who were contacted but did not participate in the study and 4 who did participate in the study) requested that our team submit a referral for services to the bereavement department on their behalf. Due to University of South Florida Institutional Review Board regulations, it was not possible to obtain descriptive information about non-participants or determine how non-participants may have differed from individuals who agreed to participate in the study.

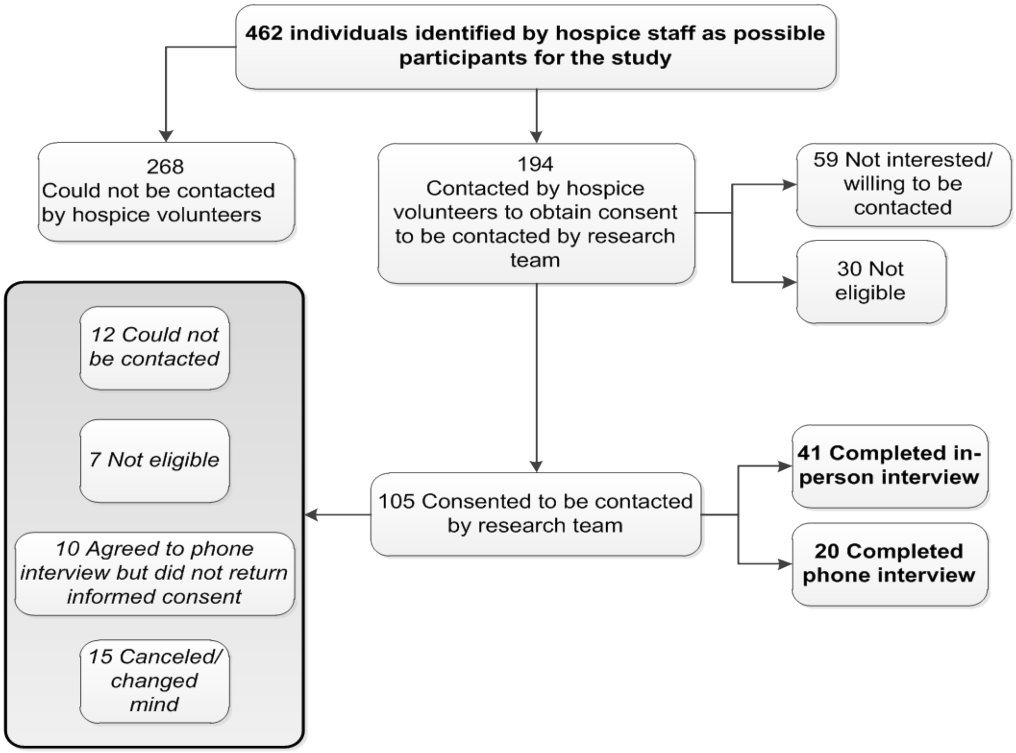

Figure 2.1 Recruitment and study sample (N = 61)

Measures

Demographics

Appendices A and B contain the study measures. Participant and patient socio-demographic information were obtained through self-report and data abstracted from retrospective review of patient electronic medical records. Patient data included gender, age, primary race/ethnicity, education level, and hospice length of stay. Participant data included gender, age, primary race/ethnicity, education level, employment status, living arrangement, and income adequacy. Income adequacy was assessed with a single item that asked participants how difficult it is for them to pay for basics such as food, housing, medical care, and heating (Allen, Allen, Hilgeman, & DeCoster, 2008). Possible responses ranged from 1 (*very difficult*) to 4 (*not at all difficult).* For the purposes of this study, the items were coded so that higher scores indicated greater difficulty paying for basics (i.e. *1 = not at all difficult* and *4 = very difficult*).

Participant Health

A checklist modified from the Chronic Conditions Checklist of the National Comorbidity Survey Replication (NCS-R; Kessler & Merikangas, 2004) ascertained descriptive information about the participant's chronic medical conditions. The NCS-R is a national, community based survey, and the conditions checklist is included in the National Health Interview Survey (NHIS; National Center for Health Statistics, 2011). Previous work has reported acceptable concordance between conditions checklists similar to the NCS-R and medical records (e.g. National Center for Health Statistics, 1994). Participants were asked to provide a "*yes*" or "*no*" response to indicate if they had ever been told by a doctor or a nurse that they had any of 20 possible health conditions (e.g. heart disease, diabetes, stroke within the past year, any mental health diagnoses such as depression or anxiety). Participants who endorsed cancer as a health condition were asked to provide what type of cancer and participants who endorsed mental health conditions were asked if they were currently taking any medications. Endorsed conditions were summed to create a total score.

Patient Health

Patient health information was abstracted retrospectively from hospice electronic medical records to understand the context of patient illness at time of admission to hospice care. Variables included primary diagnoses, activities of daily living (ADLs; Katz, Ford, Moskowitz, Jackson, & Jaffee, 1963) and Palliative Performance Scale scores (PPS; Anderson, Downing, Hill, Casorso, & Lerch, 1996). The PPS is an indicator of patient prognosis that evaluates patient mobility, intake of food and fluids, and level of consciousness. Scores range from 0-100 with 100 indicating full capacity in all domains and 0 representing death. Acceptable test-retest reliability and content validity have been reported (Ho, Downing, & Lesperance, 2008). Concurrent validity has also been supported by research that compared the instrument score with length of survival (Mortia, Tsunoda, Inoue, & Chihara, 1999). To assess patient impairment with ADLs, electronic charts were reviewed to determine if patients required assistance with any of 7 possible ADLs at admission to hospice care.

Caregiving Experience

Descriptive information about the caregiving experience was ascertained via self-report and included the following: length of time caregiving in number of months and years, approximate number of hours per week spent caregiving during the last month of life, a "*yes*" or *"no*" response to the availability of other caregivers to regularly assist the participant, number of available caregivers, and how many hours per week they assisted with care. Participants were also asked to report if they regularly assisted with their spouses' activities of daily living (ADLs; Katz, et al., 1963) during the month prior to beginning hospice care. Specifically, participants were asked to provide a "*yes"* or "*no"* response to regularly assisting with 7 possible ADLs during the month prior to beginning hospice care. A Cronbach's alpha of .80 was achieved in the current sample. Prior research reported satisfactory external and construct validity in a sample of older adults (for review, see Wallace & Shelkey, 2008).

Main Predictor Variables of Interest

Rumination

Stress-Reactive Rumination Scale. The first measure of rumination was the Negative Inferential Style Subscale of the Stress-Reactive Rumination Scale, which assesses negative ruminations in response to a stressful event (SRRS; Alloy, et al., 2000). Participants indicated on a scale of 0 (*Do not focus on this at all)* to 100 (*Focus* *on this a great extent*) how frequently they would think and do each item. The instructions were modified for the current study so that questions reflected how frequently participants currently thought and did each item. Example items include, "*How often or to what extent do you think about how the stressful event is all your fault"* and *"How often or to what extent do you think about the causes of the stressor?"* For the purposes of this dissertation, the stressful life event was described as the "spouses' suffering during the last month of life." Previous internal consistency of .89 and test-retest reliability of .71 have been reported (Alloy, et al., 2000; Robinson & Alloy, 2003). A Cronbach's alpha of .82 was achieved in the current sample.

Frequency of Thoughts about Suffering. The second measure of rumination included a series of questions developed by the author to assess the participants' frequency of thoughts about their spouses' end-of-life suffering. Specifically, four questions were developed to assess thoughts about each domain of care recipient suffering and participants were asked how often they thought about the physical suffering that their loved one experienced during the last 30 days of life, how much the physical suffering might have bothered their loved one, how often they thought about their loved ones' emotional suffering, and how often they thought about the existential suffering. Scores were rated on a 0 to 3 summated rating scale with 0 indicating "*never*" and 3 indicating "*always*." In the current sample, a Cronbach's alpha of .77 was achieved.

Relief

Participant feelings of relief in response to loss were assessed utilizing a single-item abstracted from the Resources for Enhancing Alzheimer's Caregiver Health (REACH; Schulz, Belle, et al., 2003; Schulz, Mendelsohn, et al., 2003) project and reads as follows: "*To what extent was the care recipient's death a relief to you?"* Possible responses range from 1 (*Not at all*) to 3 (*Very Much*). No studies were identified that report on convergent or predictive validity of this single item.

Perceived Suffering

Participant perceptions of patient suffering were assessed using Schulz and colleagues' (2010) Experience of Suffering Scales, which are comprised of three measures that evaluate perception of physical, emotional, and existential/spiritual suffering. The measures have been proposed for use both in self (personal ratings of the experience of suffering) and in others (perceptions of others' suffering) (Schulz, et al., 2010). Whereas the original scales ask perceptions of suffering during the last 7 days, the scale was modified for the current study to ask participants to reflect on the last 30 days prior to patient death. High levels of convergent and discriminant validity have been reported when assessed with multiple measures of quality of life, general health, functional status, pain, depression, and burden (Schulz et al., 2010). Further, Schulz and colleagues (2010) reported that relationships between the suffering scales and other assessments of health, quality of life, depression, and burden were in expected directions. In the present study, the corrected item-total correlation scores for the subscales were all above 0.30 and ranged from 0.43-0.73.

Physical Suffering Subscale. The physical suffering scale is comprised of 9 items that reflect symptoms experienced in the last 30 days of life. Responses range from 0 (*Not at all*) to 3 (*Very often/everyday*). For each endorsed symptom, participants were asked how much the symptom bothered or distressed the patient with possible responses ranging from 0 (*Not at all*) to 3 (*Very much*). The items were dichotomized such that distress ratings of "*quite a bit*" or "*very often*" were coded as 1 and ratings of "*not at all*" and "*a little*" were coded as 0. An index score was then created by summing the distress ratings. Psychometric analyses from a recent study of three caregiver samples, (i.e. two of caregivers of individuals with Alzheimer's disease, and one of older married couples of recipients with osteoarthritis), achieved Cronbach's alpha scores of .49, .72, and .64 for the physical suffering scale (Schulz, et al., 2010). The authors suggest that differences in reported physical alphas may result from differences in number of physical symptoms reported between samples. A Cronbach's alpha of .73 was achieved in the current sample.

Emotional Suffering Subscale. The emotional suffering scale includes 15 items that ask participants how often patients experienced symptoms within the last 30 days of life. Possible responses are on a summated rating scale and range from 0 (*Not at all*) to 3 (*Very often/everyday*). Positive items are reverse coded. In the study by Schulz and colleagues (2010), Cronbach's alpha scores of .87, .90, and .89 were achieved in three samples of caregivers. An alpha of .82 was achieved in the current sample.

Existential Suffering Subscale. Finally, the existential suffering scale asks participants to indicate how frequently patients experienced or felt 9 existential symptom statements during the last 30 days of life. Possible responses range from 0 (*Not at* all) to 4 (*Very much*). Psychometric analyses from the study by Schulz and colleagues (2010) reported Cronbach's alpha scores of .86, .88, and .83 for the existential suffering scale. A Cronbach's alpha of .74 was achieved in the current sample.

Bereavement Outcomes

Depression. Frequency of depressive symptoms within the past week was assessed using the 20-item Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977). Possible scores range from 0 to 60 with higher scores indicating more symptoms of depression and a score of 16 or greater indicating clinical significance (Radloff, 1977). A Cronbach's alpha of 0.86 was achieved in the current sample. Acceptable construct, concurrent, and discriminant validity have been reported in clinical and general populations (Radloff, 1977). In addition, the CES-D has been reported to have better predictive validity than other assessments of depression frequently utilized in an older sample, such as the Geriatric Depression Scale (Baker, Velli, Freidman, & Wiley, 1995).

Grief. Current feelings of grief were assessed using the 13-item Present Feelings Index of the Texas Revised Inventory of Grief (TRIG; Faschingbauer, Zisook, & DeVaul, 1987). Responses are on a summated rating scale and range from 1 (*completely true*) to 5 (*completely false*). For the present study, responses were recoded so that high scores indicated high (i.e. worse) grief. Previously reported alpha coefficients for this index range from .69 to .93 (Neimeyer, Hogan, & Laurie, 2008). A Cronbach's alpha of .78 was achieved in the current sample. A recent study examined factorial validity of the Present Feelings Index within two samples of bereaved, community-dwelling older adults (Futterman, Brown, Holland, Thompson, & Gallagher-Thompson, 2010). Results indicated a 3-factor model with clusters of Emotional Response, Thoughts, and Non-acceptance. Analyses examining convergent validity considered 14 predictors for which correlations were consistent with prior research and internal consistency scores ranged from .75 to .87 (Futterman, et al., 2010).

Complicated Grief. Presence of complicated grief was measured with the 12-item Inventory of Complicated Grief Revised (ICG-R; Jacobsen, Zhang, Block, Maciejewski, & Prigerson, 2010; Prigerson, Vanderwerker, & Maciejewski, 2008). The 12-item version was chosen over the frequently utilized 25-item scale as recent work using Item Response Theory indicated a more appropriate 12-item version that loaded on a single Patient Grief factor; the remaining items were considered biased as they loaded onto a single factor of Major Depressive Disorder (Prigerson, et al., 2009). Respondents rated the presence of symptoms in the past month on a 5-point scale ranging from 0 (*never*) to 4 (*always*). The 12-item version was recently utilized to generate a diagnostic algorithm for Prolonged Grief Disorder (PGD) by Prigerson and colleagues (2009), which has been proposed for inclusion in the DSM-V and ICD-11. The initial inventory has been reported to have convergent and criterion validity as well as high internal consistency with reported Cronbach's alphas of .92-.94 (Prigerson, et al., 1995). Similarly, the 25-item revised inventory has good evidence of criterion validity and high reliability (Cronbach's alphas of .82 and .86 have been reported for the 12-item scale (Jacobsen, et al., 2010; Prigerson, et al., 2009). A Cronbach's alpha of .87 was achieved in the current sample.

Study Design and Procedures

The Chapters Research Review Panel and the University of South Florida Institutional Review Board (IRB) approved the study protocol. All participants completed an IRB approved informed consent and a one-time 60-90 minute interview to complete the study protocol. Participants were given the opportunity to complete the interview in-person or by telephone. Individuals who elected an in-person interview completed the informed consent at the beginning of the interview and participants who elected a telephone interview received the informed consent document by mail. The researcher contacted the potential participant a few days after mailing the informed consent to verbally review the document and answer any questions. Telephone interviews were scheduled upon researcher's receipt of the informed consent with participants' original signature. All participants retained a second copy for their records.

Following completion of the informed consent, interviews began with an assessment of sociodemographic information followed by assessment of participant health and the caregiving experience. Next, the researcher conducted survey measures of rumination, relief, and perceptions of loved one's suffering at the end of life. Finally, the researcher conducted survey measures of depression, present feelings of grief, and complicated grief. At the completion of each recruitment call and interview, individuals were asked if they would like to have a member of the bereavement department contact them regarding available bereavement services. If yes, a referral was made to the LifePath bereavement department for follow-up. Following participant interview, patient demographic and health-related data were abstracted via retrospective chart review at a LifePath Hospice resource center. All participants were eligible to win one of two $50 gift certificates to a local grocery store chosen randomly at the completion of data collection.

Analyses

All analyses were conducted using SPSS v. 20.0 computer software. Statistical significance was determined with the probability of a Type I error, $p < 0.05$. First, study variables were examined for accuracy of data entry, missing values, and normality of distribution of the outcome and predictor variables of interest. Skewness and kurtosis indicators revealed that no transformations were needed. Missing values were handled on a case-by-case basis. Four individuals refused to answer items on the CES-D and one PPS score was not available in the patient electronic medical record. Missing items on the CES-D were imputed at the item level and the sample mean PPS score was imputed for the single missing value. In addition, responses of "*don't know*" on the suffering survey measures were interpreted to indicate that the participant did not perceive any suffering in relation to the corresponding symptom. Therefore, "*don't know"* responses were coded as "*not at all*."

There was substantial missing data on a number of items in the electronic medical records. Patient ADLs and education had inconsistent or incomplete documentation. Therefore, these variables were excluded from analyses. In addition, there was missing data from several caregivers regarding the number of additional caregivers and how many hours per week additional caregivers helped with caregiving in the month prior to loss. These variables were also excluded from analyses.

Descriptive Analyses

Basic descriptive and frequency analyses assessed participant and patient demographic and health characteristics, caregiving experience, rumination, feelings of relief, and perceptions of suffering, as well as the bereavement outcomes. Independent-samples t-tests and chi-square tests were conducted to detect any group (telephone vs. in-person) differences on study variables.

Correlation Analyses

Next, bivariate analyses were conducted to examine Pearson Product Moment correlations between the independent variables and the outcome measures to identify necessary covariates for regression analyses. In order to trim the number of variables for best power with the small sample size and large number of predictors, only those independent variables that were significantly correlated with the bereavement outcome variables were selected for the regression analyses. In addition, the pattern of the correlations among study variables were used to consider the concurrent and discriminant validity of the measures that were modified for the purposes of this study or that have not previously been reported in a sample of older adults (e.g. SRRS).

Regression Analyses

Following correlation analyses, hierarchical multiple regression analyses were conducted to address study Aims 1, 2, and 3. The same order of entry was used in each regression. First, participant variables (i.e. education level, retirement status, ability to pay for basics, total number of chronic health conditions, total number of hours spent caregiving per week, number of days since spousal death) were entered into the regression model. Second, patient variables were entered into the model (i.e. patient age), followed by the main predictor variable of interest (i.e. rumination, relief, perceptions of suffering). A separate hierarchical regression was conducted for each outcome measure (i.e. depression, grief, complicated grief). Collinearity statistics were examined to ensure that Variance Inflation Factor (VIF) scores remained around1 and that no VIF scores were above 10 (Bowerman & O'Connell, 1990; Myers, 1990).

Interaction Analyses

To address study Aim 4, several linear regression analyses were performed separately for each of the bereavement outcomes. Possible interactions among the main study predictor variables (i.e. frequency of thoughts about rumination, stress-reactive rumination, feelings of relief, and perceptions of physical, emotional, and existential suffering) were explored using linear regression analyses as described by Cohen, Cohen, West, and Aiken (2003). A centered variable was created by subtracting the mean from each predictor variable and an interaction term was computed by multiplying the centered focal predictor variables and the moderator variable.

Several ordinary least squares (OLS) regression models were estimated with each of the measures of bereavement as outcome variables, perceptions of suffering as the focal predictor (*F*), rumination and feelings of relief indicators as the moderator (*M*), and the interaction (*F x M*). The same covariates entered into the hierarchical regression analyses to investigate Aims 1-3 were also entered in the models exploring interactions. Participant and patient independent variables, the focal variable (e.g. emotional suffering), and the moderator variable (e.g. stress-reactive rumination) were entered first. The interaction term was entered into the regression models last in order to determine if interactions predicted bereavement outcomes while controlling for covariates. Computational procedures for probing single-degree-of-freedom interactions were conducted using the MODPROBE macro provided by Hayes and Matthes (2009). Estimated values of the outcome from the model were utilized to generate visual plots of the interaction one standard deviation above the mean, at the mean, and one standard deviation below the mean using the following equation: ($\hat{Y} = (\beta_1 + \beta_3 z)x + (\beta_o + \beta_2 z)$).

Power Analyses

Post-hoc power analyses were conducted using the G*Power 3 software package (Faul, Erdfelder, Lang, & Buchner, 2007) to determine the sample size necessary to detect medium correlation effects of .30 at a p-value of .05 (Cohen, 1992) among non-significant key predictor variables of interest. In addition, post-hoc power analyses were conducted for the sample size (N = 61) for Aims 1-4 to calculate the statistical power of the regression analyses. Acceptable power was determined as being greater than or equal to .80 (Cohen, 1988, 1992).

Chapter Three: Results

Overview

Chapter Three provides a summary of the study findings. First, descriptions of both the participant and patient samples are provided followed by the findings from analyses conducted to explore group differences among participants who completed the study protocol over the telephone vs. in-person. Possible predictors identified by correlation analyses are presented and evidence for content validity is described. Next, findings from hierarchical regression analyses (Aims 1-3) that investigated key predictor variables of interest (rumination, relief, and perceptions of suffering) as predictors of bereavement outcomes are presented. Finally, findings from exploratory moderation analyses (Aim 4) conclude the chapter.

Descriptive Information

Participant characteristics

Table 3.1 describes the study sample. Interviews were conducted an average of 11 months following patient death. A minority of participants were living with a child (11.5%) or partner (1.6%) and a small proportion were employed either full (14.8%) or part- time (8.2). A majority of participants reported that it was either "*not at all difficult*" (42.6%) or "*not very difficult*" (36.1%) to pay for basics. Few participants had attained an education level of less than a high school diploma (6.6%) and over half of participants had received post-baccalaureate education (62.4%) with nearly 15% completing a Masters, Doctoral, or other professional degree. Participants reported being a primary caregiver for a range of 2 weeks to more than 20 years. The mean number of years as a primary caregiver was nearly 3.5 years.

The most commonly reported participant health conditions were arthritis (54.1%), high blood pressure (44.3%) and chronic back or neck problems (42.6%). Among participants who endorsed a diagnosis of cancer (i.e.18%), 36.4% reported cancer of the skin, 27.3% reported breast cancer, 18.2% reported cancer of the kidney, and 18.2% reported cancer of the ovaries/uterus. Six participants (13%) reported being diagnosed with a mental health condition such as depression or anxiety, and among these individuals, 7 (11.5%) reported that they were currently taking medication.
Descriptive information about participants' psychological well-being during bereavement is shown in Table 3.2. Nearly half of participants (n = 29) scored a 16 or higher on the CES-D, indicating clinically relevant symptoms of depression.

Descriptive information about main predictor variables to address study Aims 1, 2, and 3 are presented in Table 3.3. Over one-fourth (32.8%) of the sample reported that they think about their loved one's physical suffering either "*often*" or *"always*". Similarly, 36% reported currently thinking about how much the physical suffering might have bothered their loved one "*often*" or *"always*" and 32.8% reported currently thinking about their loved ones' emotional suffering "*often*" or *"always*." A majority of participants reported currently thinking about their spouses' existential or spiritual suffering "*never*" (60.7%) or "*sometimes*" (21.3%). Approximately 26% of participants reported that the death was "*not at all*" a relief and 34% reported the death was "*very much*" a relief.

Patient characteristics

As shown in Table 3.1, hospice patient length of stay varied greatly with some patients having very short lengths of stay and others having lengths of stay of over 2 years. However, a majority of patients were enrolled in hospice care for less than 6 months (93.4%) and the median length of stay was 24 days. Patients were slightly younger than participants and just over half of the patients had a non-cancer primary diagnosis at hospice admission with 23% having a primary diagnosis of cardiovascular /heart disease, and 8% having a primary diagnosis of dementia.

Table 3.1

Means, standard deviations, ranges, and correlations of descriptive independent variables and main outcome measures of depression, grief, and complicated grief (N = 61)

Independent variable	M	SD	Range	Correlations		
				Depression	Grief	Complicated Grief
Participant Demographics						
Gender (% Female)	0.82 (82%)	0.39	0-1	-0.021	-0.042	-0.197
Age	69.52	9.81	50-89	-0.220	-0.191	-0.199
Race/ethnicity (% White)	0.16 (95%)	0.82	0-1	0.070	-0.055	0.147
Education (% ≥ High School)	2.00 (93.5%)	1.16	0-1	0.031	-0.253	-0.136
Retired (%)	0.59 (59%)	0.50	0-1	-0.389**	-0.339**	-0.366**
Living arrangement (% Alone)	0.61 (80.3%)	1.38	0-1	0.021	-0.044	0.202
Ability to pay for basics	1.85	0.91	1-4	0.283*	0.015	0.100
Participant Health						
Number of health conditions	3.33	2.29	0-11	0.287*	-0.016	0.178
Caregiving Experience						
Number of days since death	338.79	121.31	200-548	-0.206	-0.264*	-0.294*
Length of time CG (months)	41.75	66.19	0.25-312	-0.092	-0.133	-0.138
Time spent CG (hours/week)	113.70	67.63	0-168	0.215	0.146	0.296*
Other caregivers (% Yes)	0.56 (55.7%)	0.51	0-1	-0.105	-0.036	-0.001
ADL assistance	3.62	2.34	0-7	0.047	0.122	0.179
Patient Demographics						
Gender (% Female)	0.18 (18%)	10.63	0-1	0.021	0.042	0.197
Age	73.13	10.63	48-92	-0.186	-0.299*	-0.302*
Race/ethnicity (% White)	0.15 (95%)	0.72	0-1	0.083	-0.203	-0.020
Patient Health						
Hospice length of stay (Days)	60.67	116.31	2-812	-0.158	-0.054	-0.133
Primary diagnosis (% Cancer)	1.08 (45.9%)	1.25	0-1	-0.171	-0.223	-0.144
Palliative Performance Scale	34.56	12.58	10-60	0.168	0.158	0.093

Note. * p<.05, **p<.01. M= mean, SD= standard deviation, CG = caregiver, ADL = activities of daily living.

Table 3.2

Means and standard deviations for outcome measures (N = 61)

Outcome measure	M	SD	Range	Range of Instrument
Depression	16.30	9.81	0-39	0-60
Grief	41.08	8.22	23-61	13-65
Complicated Grief	13.91	9.37	0-43	0-48

Note*.* * p<.05, **p<.01. M= mean, SD= standard deviation. Higher numbers indicate more symptoms of depression, worse grief, and worse complicated grief.

Table 3.3

Means, standard deviations, ranges, and correlations of main predictor variables and main outcome measures of depression, grief, and complicated grief (N = 61)

Independent variable	M	SD	Range	Correlations		
				Depression	Grief	Complicated Grief
Rumination						
Stress-Reactive Rumination	202.89	158.45	0-570	0.484***	0.354**	0.497***
Frequency of Thoughts	4.26	2.65	0-12	0.200	0.389**	0.338**
Relief						
Feelings of Relief	2.08	0.78	1-3	-0.286*	-0.284*	-0.450***
Participant perceptions of patient suffering						
Physical Suffering	4.00	2.40	0-9	0.124	0.127	0.196
Emotional Suffering	16.43	7.92	0-35	0.260*	0.106	0.118
Existential Suffering	11.78	7.00	0-35	-0.051	-0.025	-0.100

Note. * p<.05, **p<.01. M= mean, SD= standard deviation

Descriptive Group Differences by Interview Type

A majority of participants completed the study interview in-person (67%). Independent samples t-tests and chi-square analyses revealed no significant group differences among participants who completed the interview in-person compared to participants who completed the interview by telephone on any of the main predictor variables of rumination, feelings of relief, or perceptions of suffering. There were also no significant group differences for any of the outcome variables. There was a significant group difference on the days since death descriptive variable such that participants who completed a telephone interview had significantly fewer days since patient death at time of interview than participants who completed the interview in person [t (59), = -2.87, $p <$ .01]. However, given that only 1 of 29 possible variables differed by group, data were pooled for the purposes of the present study.

Correlation Analyses

Bivariate correlations among demographic, health, and caregiving experience variables and the outcome measures of depression, grief, and complicated grief are displayed in Table 3.1. All variables significantly correlated with any of the bereavement outcomes were entered into each regression model. Displayed in Table 3.3 are correlations among study Aims 1, 2, and 3 predictor variables (i.e. rumination, relief, and perceptions of suffering) and bereavement outcomes. The outcome variables of depression, grief, and complicated grief were highly correlated with one another such that grief and complicated grief were highly correlated with depression (r (59) = .572, p <.001; r (59) = .744, p <.001, respectively) and grief and complicated grief were highly correlated with one another (r (59) =.749, p <.001).

Identified Covariates

As shown in Table 3.1, participant education level, retirement status, perceived ability to pay for basics, number of days since patient death, number of hours per week spent caregiving one month prior to beginning hospice services, and patient age were significantly associated with bereavement outcomes. Specifically, lower education attainment was significantly associated with worse grief. Greater perceived difficulty in ability to pay for basics and a greater number of participant health conditions were significantly associated with more symptoms of depression. A higher number of hours spent caregiving per week was significantly correlated with worse complicated grief. Being retired was significantly correlated with fewer symptoms of depression, grief, and complicated grief. Finally, fewer number of days since loss and younger patient age were significantly correlated with worse grief and complicated grief.

Primary Predictor Variables

As shown in Table 3.3, only the emotional subscale of the perceptions of suffering measures was significantly correlated with any of the outcome measures. Specifically, higher perceived emotional suffering was correlated with greater symptoms of depression. Stress-reactive rumination and feelings of relief were significantly associated with depression, grief, and complicated grief such that higher stress-reactive rumination and less reported feelings of relief were associated with greater symptoms of depression and worse grief and complicated grief. Finally, greater frequency of thoughts about loved ones' suffering was significantly associated with worse grief and complicated grief.

Validity of Measures Developed

Correlation analyses were examined to review evidence for convergent and discriminant validity for measures of rumination and perceptions of suffering, because these measures were modified from original versions that had previously been validated. The correlations discussed above and shown in Table 3.3 between rumination, relief, and the outcome measures provide preliminary evidence consistent with the construct validity of these scales, since they were associated in the predicted direction. As shown in Table 3.4, the measures of rumination (i.e. stress-reactive rumination and frequency of thoughts) were also significantly positively correlated with one another, indicating that both measures were measuring similar constructs. In addition, stress-reactive rumination and frequency of thoughts were significantly positively correlated with emotional and existential suffering. Given that participants were asked to indicate the level of stress-reactive rumination in response to perceptions of suffering, the positive relationship between these two measures indicate evidence of convergent validity. The finding that the measures of existential and emotional suffering were associated positively with each other was further evidence for construct validity, and the finding that physical suffering was not significantly associated with the other two suffering measures suggests divergent validity.

Table 3.4

Correlations to assess convergent and discriminant validity of main predictor variable measures

	SRRS	Frequency	Physical	Emotional	Existential
Participant Age	-0.051	-0.041	-0.195	-0.224	0.051
CG Gender	-0.122	-0.116	0.036	0.079	0.016
Basics	0.231	0.037	0.015	0.336**	-0.01
CG Health	0.198	0.093	0.276*	0.194	0.098
Days since death	-0.132	-0.164	-0.193	-0.047	-0.096
ADL assistance	0.301*	0.127	0.062	0.239	0.292*
PT Age	-0.041	-0.101	-0.204	-0.109	0.077
PT Gender	0.122	0.116	-0.036	-0.079	-0.016
Hospice LOS	-0.201	0.005	-0.009	-0.083	0.061
PPS	-0.146	-0.087	-0.206	-0.119	-0.136
SRRS	--	0.522***	0.179	0.399**	0.118
Freq. thoughts		--	0.312*	0.338**	0.280*
Physical Suffering			--	0.227	0.066
Emotional Suffering				--	0.652**
Existential Suffering					--

Note. * p<.05, **p<.01, ***p<.001. CG = Caregiver, ADL = activities of daily living, PT = patient, LOS = length of stay, Freq. thoughts = frequency of thoughts, PPS = Palliative Performance Scale, SRRS = Stress-reactive Rumination Scale.

Regression Analyses

Aim 1: Investigating Rumination as a Predictor of Well-being Following Loss

Stress-Reactive Rumination

Hierarchical regression models predicting depression, grief, and complicated grief with stress-reactive rumination as the main predictor variable of interest are shown in Table 3.5. For depression, the regression model accounted for 41% of the total variance and participant descriptive covariates predicted significant variance in the model with a non-retirement status and more caregiving hours per week predicting greater symptoms of depression. Patient characteristics did not predict significant variance in the model. Stress-reactive rumination predicted significant additional variance (10%), with high levels of rumination associated with more symptoms of depression. Similarly, for grief, the regression model accounted for 41% of the variance explained with a non-retirement status, and more caregiving hours per week predicting worse grief. Stress-reactive rumination again predicted significant additional variance (8%), with higher rumination associated with worse grief. Finally, for complicated grief, the regression model accounted for 51% of the variance explained and lower education attainment and not being retired predicted worse complicated grief. Again, patient characteristics did not account for any additional variance explained. Stress-reactive rumination added significant variance (14%) with higher rumination associated with worse complicated grief.

Frequency of Thoughts about Suffering

Table 3.6 shows the hierarchical regression models predicting bereavement outcomes with frequency of participant thoughts about loved ones' suffering as the main predictor variable of interest. The model predicting symptoms of depression accountedfor 33% of the variance and the models for grief and complicated grief accounted for 40% and 41% of the variance, respectively. Participant descriptive covariates that were significant in the previous regression models were again significant in the current model with not being retired and a greater number of hours spent caregiving per week being associated with more symptoms of depression and worse complicated grief. Lower education attainment and not being retired were also associated with worse grief. Frequency of thoughts about loved ones' suffering only added significant variance in the regression predicting grief, with greater frequency of thoughts associated with worse complicated grief.

Table 3.5

Hierarchical regression analyses investigating stress-reactive rumination as a predictor of depression, grief, and complicated grief (N = 61)

Variables	Depression			Grief			Complicated Grief		
	β	R^2	Δ R^2	*β*	R^2	Δ R^2	*β*	R^2	Δ R^2
Model 1: *Participant*		0.32**	0.32**		0.30**	0.30**		0.34**	0.34**
Education level	0.02			-0.33**			-0.18		
Retired	-0.32*			-0.41**			-0.39**		
Ability to pay basics	0.21			0.02			0.04		
Health conditions	0.15			-0.13			0.07		
Time caregiving/week	0.24*			0.18			0.33**		
Days since death	-0.19			-0.18			-0.20		
Model 2: *Patient*		0.32**	0.00		0.33**	0.03		0.38**	0.04
Age at admission	-0.05			-0.20			-0.21		
Model 3: *Rumination*		0.41**	0.10*		0.41***	0.08*		0.51***	0.14***
Stress-reactive	0.33**			0.30*			0.40***		

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

Table 3.6

Hierarchical regression analyses investigating frequency of thoughts about perceived suffering as a predictor of depression, grief, and complicated grief (N = 61)

Variables	Depression			Grief			Complicated Grief		
	β	R^2	Δ R^2	*β*	R^2	Δ R^2	*β*	R^2	Δ R^2
Model 1: *Participant*		0.32**	0.32**		0.30**	0.30**		0.34**	0.34**
Education level	0.02			-0.33**			-0.18		
Retired	-0.32*			-0.41**			-0.39**		
Ability to pay basics	0.21			0.02			0.04		
Health conditions	0.15			-0.13			0.07		
Time caregiving/week	0.24*			0.18			0.33**		
Days since death	-0.19			-0.18			-0.20		
Model 2: *Patient*		0.32**	0.00		0.33**	0.03		0.38**	0.04
Age at admission	-0.05			-0.20			-0.21		
Model 3: *Rumination*		0.33**	0.01		0.40**	0.07*		0.41***	0.03
Frequency of thoughts	0.08			0.28*			0.19		

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

Aim 2: Investigating Feelings of Relief as a Predictor of Well-being Following Loss

In the regression models to predict well-being outcomes with feelings of relief as the main predictor of interest (see Table 3.7), 37% of the variance was explained in the model predicting depression, 38% in the model predicting grief, and 52% in the model predicting complicated grief. The participant descriptive covariates significant in the previous regression models were again significant in the current model and followed the same direction. In the hierarchical regression models to predict depression and complicated grief, feelings of relief added significant variance (i.e. 5% and 15%, respectively) with less feelings of relief predicting more symptoms of depression and worse grief.

Table 3.7

Hierarchical regression analyses investigating feelings of relief following loss as a predictor of depression, grief, and complicated grief (N = 61)

Variables	Depression			Grief			Complicated Grief		
	β	R^2	ΔR^2	*B*	R^2	ΔR^2	*β*	R^2	ΔR^2
Model 1: *Participant*		0.32**	0.32**		0.30**	0.30**		0.34**	0.34**
Education level	0.02			-0.33**			-0.18		
Retired	-0.32*			-0.41**			-0.39**		
Ability to pay basics	0.21			0.02			0.04		
Health conditions	0.15			-0.13			0.07		
Time caregiving/week	0.24*			0.18			0.33**		
Days since death	-0.19			-0.18			-0.20		
Model 2: *Patient*		0.32**	0.00		0.33**	0.03		0.38**	0.04
Age at admission	-0.05			-0.20			-0.21		
Model 3: *Relief*		0.37**	0.05*		0.38**	0.05		0.52***	0.15***
Feelings of relief	-0.24*			-0.23			-0.41***		

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

Aim 3: Investigating Perceptions of Suffering as Predictors of Well-being Following Loss

Given that only the subscale assessing perceptions of emotional suffering was significantly correlated with any of the bereavement outcomes, regression analyses were not conducted to test perceptions of physical suffering and existential suffering as possible predictors. Hierarchical regression analyses revealed that perceptions of emotional suffering did not predict significant variance in the models for depression, grief, or complicated grief (see Table 3.8). As described above, not being retired and spending a greater number of hours per week caregiving were significant predictors of greater symptoms of depression and worse complicated grief. Lower education attainment and a non-retirement status were significant predictors of worse grief.

Table 3.8

Hierarchical regression analyses investigating perceptions of emotional suffering as a predictor of depression, grief, and complicated grief (N = 61)

Variables	Depression			Grief			Complicated Grief		
	β	R^2	Δ R^2	*β*	R^2	Δ R^2	*β*	R^2	Δ R^2
Model 1: *Participant*		0.32**	0.32**		0.30**	0.30**		0.34**	0.34**
Education level	0.02			-0.33**			-0.18		
Retired	-0.32*			-0.41**			-0.39**		
Ability to pay basics	0.21			0.02			0.04		
Health conditions	0.15			-0.13			0.07		
Time caregiving/week	0.24*			0.18			0.33**		
Days since death	-0.19			-0.18			-0.20		
Model 2: *Patient*		0.32**	0.00		0.33**	0.03		0.38**	0.04
Age at admission	-0.05			-0.20			-0.21		
Model 3: *Suffering*		0.32**	0.00		0.33**	0.00		0.38**	0.00
Emotional suffering	0.03			0.05			-0.05		

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

Aim 4: Exploring Interactions among Predictor Variables and Well-being Following Loss

Stress-Reactive Rumination

As shown in Table 3.9, results revealed that the combined effect of emotional suffering and stress-reactive rumination on grief and complicated grief was significant when controlling for other covariates. As shown in Figures 3.1 and 3.2, when perceptions of suffering were low, there was little difference in grief and complicated grief between participants high or low in rumination. However, when perceptions of suffering were high, as predicted, those high in rumination had high grief and complicated grief scores. Conversely, when perceptions of suffering were high, participants low in rumination showed lower levels of grief and complicated grief. There was not a significant emotional suffering-by-stress-reactive rumination effect on the outcome of depression.

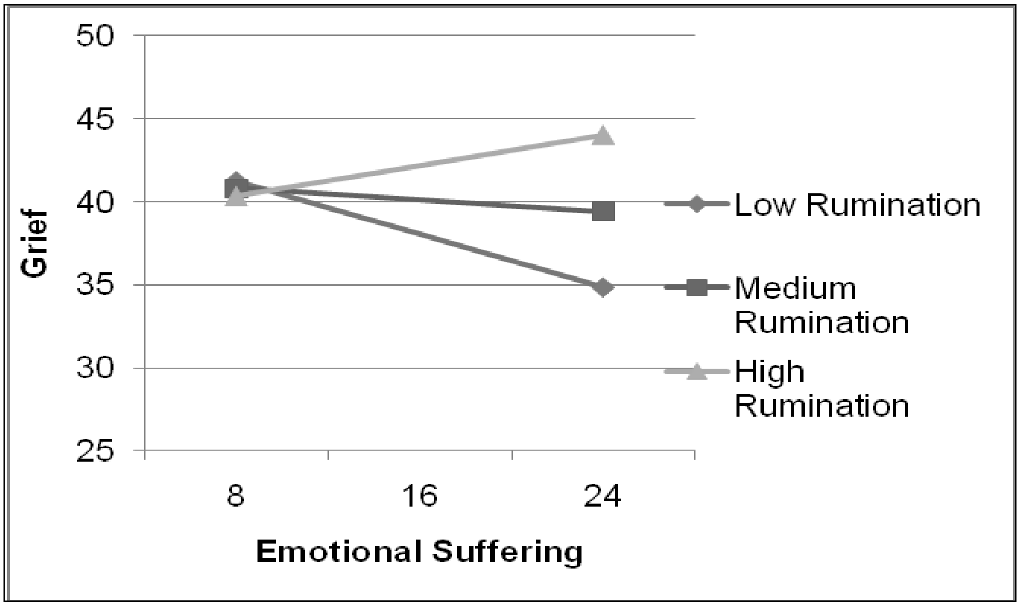

Figure 3.1
Interaction of the moderating effect of rumination on the relationship between emotional suffering and grief (*N* = 61).

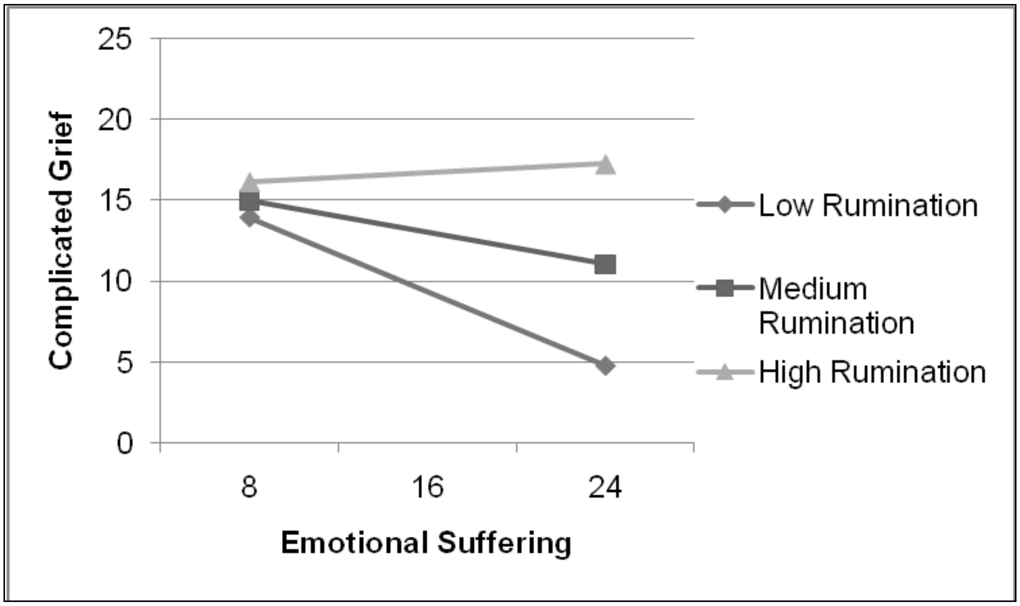

Figure 3.2
Interaction of the moderating effect of rumination on the relationship between emotional suffering and complicated grief (*N* = 61).

Table 3.10 shows a significant existential suffering-by-stress-reactive rumination interaction effect on present feelings of grief scores. As shown in Figure 3.3, when perceptions of existential suffering were low, there was little difference in grief and complicated grief between participants high or low in rumination. However, when perceptions of existential suffering were high, individuals high in rumination had high grief and complicated grief, as predicted. Conversely, when perceptions of existential suffering were high, participants low in rumination showed lower levels of grief and complicated grief. Finally, no significant existential suffering-by-stress-reactive rumination effects were found when depression was investigated as an outcome variable.

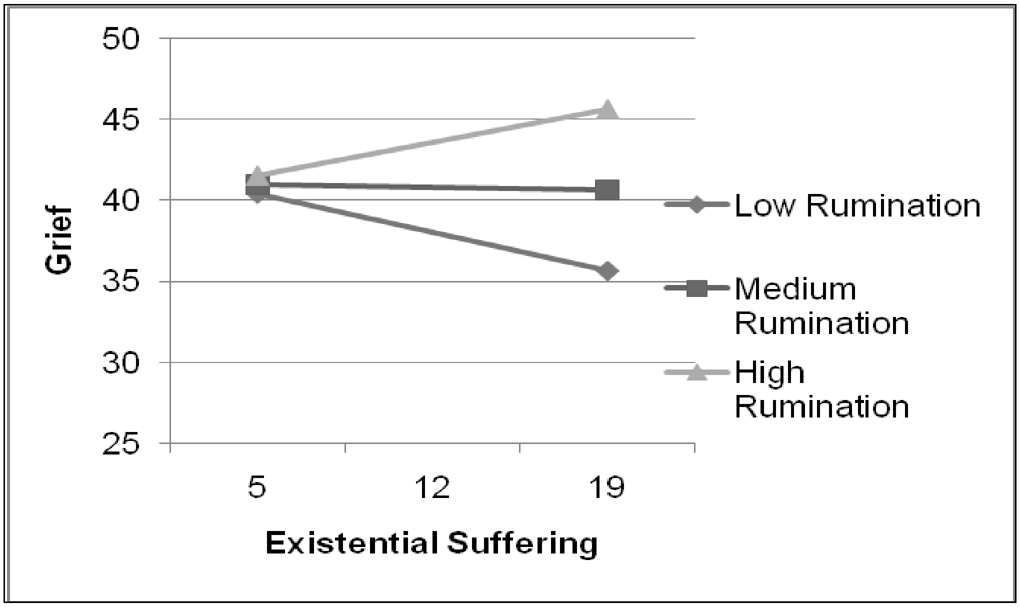

Figure 3.3
Interaction of the moderating effect of rumination on the relationship between existential suffering and grief (*N* = 61).

Table 3.9

Regression analyses investigating emotional suffering-by-stress-reaction rumination interaction as a predictor of grief and complicated grief (N = 61)

Variables	Grief			Complicated Grief		
	β	R^2	ΔR^2	β	R^2	ΔR^2
Model 1: *Covariates*		0.40**	0.40**		0.53***	0.53***
Education level	-0.34**			-0.17		
Retired	-0.31*			-0.30*		
Ability to pay basics	-0.09			-0.07		
Health conditions	-0.09			0.11		
Time caregiving/week	0.14			0.28**		
Days since death	-0.09			-0.11		
Age at admission	-0.22			-0.23*		
Emotional suffering	-0.05			-0.18		
Stress-reactive rumination	0.32*			0.45***		
Model 2: *Interaction Term*		0.48***	0.07*		0.59***	0.06*
Emotional suffering X Stress-reactive rumination	0.29*			0.25*		

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

Table 3.10

Regression analysis investigating existential suffering-by-stress-reaction rumination interaction as a predictor of grief (N = 61)

Variables	Grief		
	β	R^2	ΔR^2
Model 1: *Covariates*		0.41**	0.41**
Education level	-0.35**		
Retired	-0.30*		
Ability to pay basics	-0.11		
Health conditions	-0.09		
Time caregiving/week	0.14		
Days since death	-0.09		
Age at admission	-0.22		
Existential suffering	-0.01		
Stress-reactive rumination	0.31*		
Model 2: *Interaction Term*		0.47***	0.06*
Existential suffering X Stress-reactive rumination	0.25*		

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

Feelings of Relief

Table 3.11 shows that the combined effect of emotional suffering and feelings of relief on grief and complicated grief was significant. Figures 3.4 and 3.5 visually describe the interaction effect among those participants who reported low, moderate, and high feelings of relief following loss. Specifically, the figures show when perceptions of emotional suffering were low, there was little difference in grief and complicated grief between participants high and low in feelings of relief. However, when perceptions of emotional suffering were high, as predicted, those high in relief had lower grief and complicated grief scores, indicating better bereavement. Conversely, when perceptions of emotional suffering were high, individuals with low relief showed higher levels of grief and complicated grief. Similar to the findings regarding stress-reactive rumination, there was not a significant interaction effect on depression.

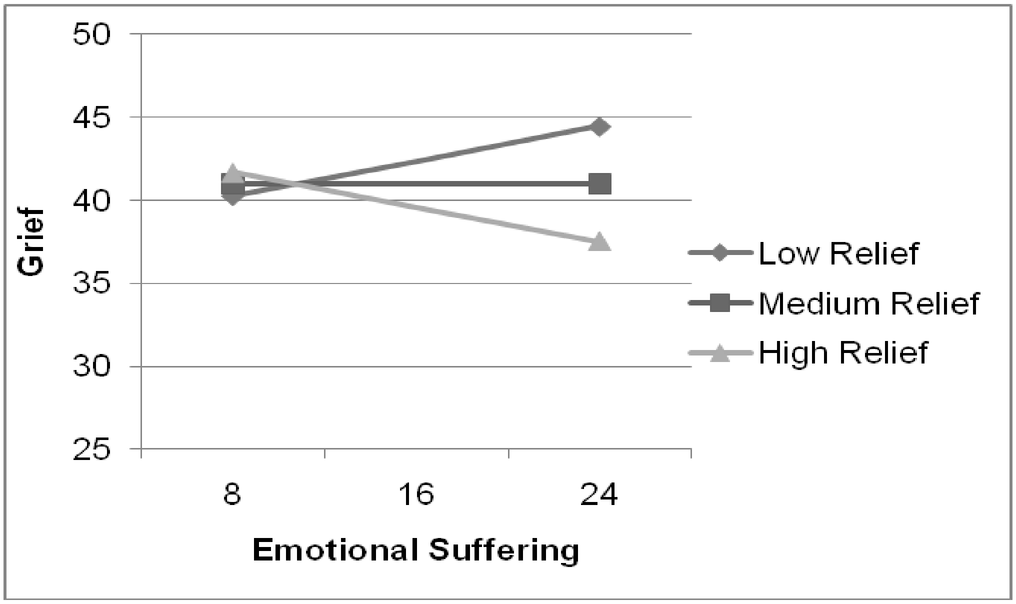

Figure 3.4
Interaction of the moderating effect of relief on the relationship between emotional suffering and grief (*N* = 61).

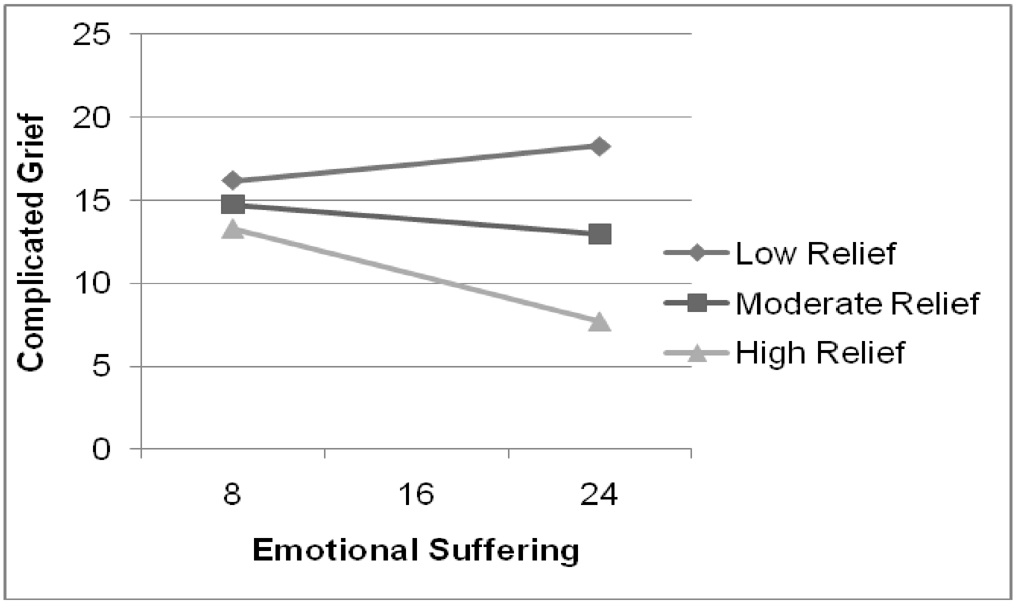

Figure 3.5
Interaction of the moderating effect of relief on the relationship between emotional suffering and complicated grief (*N* = 61).

Table 3.11

Regression analyses investigating emotional suffering-by-stress-reaction rumination interaction as a predictor of grief and complicated grief (N = 61)

Variables	Grief			Complicated Grief		
	β	R^2	ΔR^2	*B*	R^2	ΔR^2
Model 1: *Covariates*		0.38**	0.38**		0.52***	0.52***
Education level	-0.33**			-0.14		
Retired	-0.32*			-0.31*		
Ability to pay basics	-0.01			0.07		
Health conditions	-0.14			0.02		
Time caregiving/week	0.20			0.38***		
Days since death	-0.12			-0.15		
Age at admission	-0.17			-0.16		
Emotional suffering	0.04			-0.06		
Relief	-0.23			-0.41***		
Model 2: *Interaction Term*		0.44**	0.07*		0.57***	0.04*
Emotional suffering X Relief	-0.27*			-0.22*		

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

Power Analyses

Given that frequency of thoughts about perceptions of suffering was significantly correlated with grief and complicated grief but not depression, G*power analyses to determine the necessary sample size to detect a significant effect were conducted. Results showed that a sample size of 193 would be necessary to detect a medium effect with 80% power at the $p<.05$ level. In addition, larger sample sizes would be needed to detect an effect of physical suffering on any of the bereavement outcomes (ranging from 202-508) and emotional suffering on the grief or complicated grief bereavement outcomes (ranging from 561-696). The necessary sample size for appropriate power to detect a medium effect of existential suffering on any of the bereavement outcomes was very large and ranged from 782-12556 participants. Analyses investigating the power achieved in the linear regression models (Study Aims 1-3) revealed acceptable power with a sample size of 61 and 8 predictors in regression model, with the lowest power observed being 73% for the regression investigating emotional suffering as a predictor. Analyses investigating the power achieved in the interaction models (Study Aim 4) revealed acceptable power of above 90% for each regression with a sample size of 61 and 10 predictors in regression model.

Chapter Four: Discussion

Overview

The purpose of this dissertation was to investigate the association of rumination, feelings of relief, and perceptions of suffering with psychological well-being at 6-18 months after bereavement and caregiving for a spouse. In addition, the study explored other potential predictors including caregivers' and patients' demographic and descriptive characteristics, factors associated with the caregiving experience, and patient health. Chapter Four provides a discussion of the study findings and supported hypotheses. The chapter begins with a discussion of descriptive information about rumination, relief, perceived suffering, and bereavement outcomes among study participants. Next, a discussion addresses study Aims 1-3, which investigated rumination, feelings of relief, and former caregivers' perceptions of physical, emotional, and existential suffering as possible predictors of psychological well-being following loss. The sections that follow discuss study findings from Aim 4, which explored interactions among the main predictor variables of interest and discuss additional findings, which were not part of the hypotheses, identifying participant and patient descriptive predictors of depression, grief, and complicated grief. A discussion of the study limitations, possible implications, and proposed areas of future research conclude the chapter.

Study Findings

Descriptive Characteristics

Participants in the current sample represent a group of highly distressed former caregiving spouses who were highly engaged in caregiving activities for lengthy periods prior to loss. Many participants provided care to patients 24 hours per day during the month prior to hospice admission and less than half of the caregivers reported receiving any caregiving assistance from others. Further, caregivers provided care to individuals with very poor health and functioning. Participants had very low PPS scores on admission to hospice care, with the average score indicating patients were totally bedbound, unable to do any activity, had extensive disease, required total self-care, had reduced food and liquid intake, and did not consistently have full consciousness.

Former caregivers in the present study were highly emotionally distressed and participants reported poor psychological well-being, even at an average of 11 months following patient death. For example, nearly half of the sample was above the cut-off for clinically relevant symptoms of depression, despite having access to hospice bereavement services. Further, participants reported that they still frequently thought about their loved ones' physical and emotional suffering at the end of life. Specifically, more than one-fourth of participants reported thinking about loved ones' physical and emotional suffering "often" or "always." Although a majority of the sample reported never thinking about their loved ones' existential or spiritual suffering, participants did perceive their loved ones to have moderate amounts of physical and emotional suffering. Finally, we found that 60% of caregivers felt the death to be "somewhat" or "very much" a relief, which has previously only been reported by Schulz (2003) who found 72% of caregivers felt the death to be "somewhat" or "very much" a relief. Therefore, this dissertation provides a unique sample of highly distressed, highly engaged former spousal caregivers from which to draw important theoretical and practice implications regarding study findings.

Aim 1: Investigating Rumination as a Predictor of Well-being Following Loss

Frequency of Thoughts

A primary aim of the dissertation was to investigate the relationship between rumination and caregiver psychological distress during bereavement. First, assessing the frequency of thoughts about spouses' suffering was an important step in the present study. If participants reported that they did not think about loved ones' suffering, it would not be reasonable to conceptualize patient suffering as the "stressful event" for the purposes of measuring stress-reactive rumination. However, we found that participants frequently thought about their loved ones' physical and emotional suffering and total frequency of thoughts about spouses' suffering was a significant independent predictor of participants' present feelings of grief. Specifically, greater frequency of thoughts about emotional suffering was associated with worse present feelings of grief. Notably, this is the first known study to investigate if frequency of caregivers' thoughts about a loved one's end-of-life experience are associated with psychological well-being following loss.

Stress-Reactive Rumination

A second purpose of Aim 1 was to investigate the association of stress-reactive rumination with multiple caregiver bereavement outcomes. Findings supported our hypothesis and showed that higher stress-reactive rumination was a significant predictor of more symptoms of depression, greater present feelings of grief, and worse complicated grief. While a review of the literature suggests that this dissertation may be the first study to investigate stress-reactive rumination during bereavement, our findings that higher rumination is associated with more symptoms of depression following loss is similar to prior, related research investigating rumination as a response style (e.g. RST; Nolen-Hoeksema, et al., 1997; Nolen-Hoeksema, et al., 1994). However, it is important to highlight that while RST considers ruminations in response to depressed mood, stress-reactive rumination considers ruminations in response to stressful life events that may act as a precursor to depressed mood. Therefore, it is possible that ascertaining stress-reactive rumination in response to caregiving-related stressors early during the bereavement process could be indicative of risk for long-term outcomes, although it was not possible to test this hypothesis in the current, cross-sectional study.

Finally, the findings that high ruminators have poorer bereavement outcomes may provide support for the grief work as rumination hypothesis; which states that grief work is a form of rumination that can lead to poorer outcomes (Bonanno, et al., 2005). However, pre-loss levels of distress were not assessed in the current study and future work should evaluate the SRRS within the context of the grief work as rumination hypothesis. It will also be important for future work to investigate if the findings regarding stress-reactive rumination hold true in other bereaved populations including cross-cultural populations, especially given that the "grief work hypothesis" has not been found to hold across non-Western cultures (Bonanno, et al., 2005).

Aim 2: Investigating Feelings of Relief as Predictor of Well-being Following Loss

The second aim was to investigate the extent to which caregivers' feelings of relief in response to the death of a spouse predicted bereavement outcomes. Our second hypothesis was supported and individuals who reported greater feelings of relief had better bereavement outcomes. Importantly, less relief was a predictor of more symptoms of depression and worse complicated grief following loss. These findings may provide support for the relief hypothesis (Schulz, Boerner, et al., 2008) as caregivers with higher feelings of relief had better bereavement outcomes. However, an important tenet of the relief hypothesis is that caregivers experience distress prior to loss as result of burdens associated with caregiving. Further, the relief hypothesis posits that with death, as specific caregiving-related stressors are eliminated, caregivers experience more positive psychological well-being. However, the present study did not include measures of caregivers' pre-loss burden and it is not possible to determine if certain stressors that were present prior to loss were eliminated following loss and thus directly influenced caregivers' feelings of relief during bereavement.

Finally, although many caregivers in the present study expressed that they "somewhat" or "very much" felt relief following loss, it is possible that our findings are understated. Specifically, some participants may have felt guilty or ashamed for feeling relief after the death of a spouse and thus minimized their response. Anecdotally, we observed some participants made comments during interviews that they did not want to say they "very much" felt a relief because doing so would "sound like I was glad (s)he was gone". It is possible that feeling "relieved" from the responsibilities of caregiving duties or even the emotional strain of supporting a spouse who is approaching the end of life would lead to feelings of guilt. It would be interesting for future work to include follow-up questions that asked caregivers the extent to which they felt guilty for feeling relief.

Aim 3: Investigating Perceptions of Suffering as Predictors of Psychological Well-Being Following Loss

The third primary aim of this dissertation was to investigate former spousal caregivers' perceptions of loved ones' suffering as they approached the end of life as possible predictors of bereavement outcomes. Specifically, the study considered perceptions of physical, emotional, and existential/spiritual suffering during the last month of hospice care prior to patient death. In contrast to findings by Schulz and colleagues (2009), who investigated caregivers' concurrent perceptions of loved ones' suffering and symptoms of depression while caregiving, our findings revealed that on bivariate analyses, only perceptions of emotional suffering were associated with bereavement outcomes. Further, perceptions of emotional suffering were only significantly associated with depression at the bivariate level, and were not significant multivariate predictors of well-being following loss. However, our findings may suggest that witnessing a loved one's emotional distress has a greater impact on caregivers well-being following loss than witnessing physical distress. For example, we observed that several caregivers stated feeling distressed that their spouse was "anxious" or "worried about me and worried if I was going to be okay." In addition, several participants stated that while they felt that their loved one may have experienced physical suffering (e.g. pain), they also felt patients hid or downplayed symptoms in an effort to refrain from upsetting the caregiver or "let [them] know how bad it really was." Finally, study findings may provide support for the wear and tear hypothesis as exposure and perceptions of loved ones' suffering over time could be stressors that deplete caregivers' coping resources, and lead to poorer mental health during bereavement. However, it is important to reiterate that despite these observations, we did not find a significant effect of emotional suffering on bereavement outcomes when examined as an independent predictor.

Aim 4: Exploring Interaction Effects of Rumination, Relief, and Suffering on Well-Being Following Loss

Stress-Reactive Rumination

The final aim of the dissertation was to explore interactions among rumination, feelings of relief, and participants' perceptions of suffering on psychological well-being following loss. Our findings partially supported the hypothesis that individuals who reported high perceptions of suffering and low feelings of relief would have poorer bereavement outcomes. First, results showed that there was an important combined effect of stress-reactive rumination and perceptions of loved ones' emotional suffering on grief and complicated grief scores. Although perceptions of emotional suffering was not an independent predictor of grief and complicated grief, results revealed that former caregivers who had high perceptions of loved ones' suffering and engaged in high levels of rumination about negative inferences associated with suffering, had poorer bereavement outcomes. Notably, a significant interaction effect was not found for depression, which may provide additional support for Prigerson and colleagues (2009) who strongly argue that bereavement-related depression and grief are distinct constructs that require unique clinical interventions.

Second, existential suffering and stress-reactive rumination had a significant combined effect on present feelings of grief. Similar to the findings on emotional suffering, results showed that caregivers who perceived that patients had high levels of existential suffering and reported high levels or stress-reactive rumination had worse symptoms of grief. Therefore, while perceptions of existential suffering did not have a significant association to bereavement outcomes on their own, these perceptions do appear to have an important effect on psychological well-being for individuals who engage in high levels of rumination. Further, findings from interaction analyses that rumination and perceptions of emotional and existential suffering work together in predicting bereavement outcomes may align with Shear's proposal that rumination on circumstances surrounding the death can increase an individuals' risk for developing complicated grief (Shear, 2012). Therefore, our study findings may have important clinical implications for mental health providers seeking to tailor intervention services to highly distressed individuals.

Feelings of Relief

Finally, the hypothesis that feelings of relief and perceptions of spouses' suffering would interact to predict psychological well-being was partially supported. Specifically, former caregivers who reported high perceptions of loved ones' emotional suffering and low feelings of relief had worse grief and complicated grief. Findings that feelings of relief and perceptions of suffering work together to predict caregiver bereavement outcomes may provide support for the proposal that caregivers' feelings of relief are related to perceptions that their loved one had a poor quality-of-life as they approached death (Volicer, 2004). For example, some caregivers may have felt relieved that their loved one was no longer "suffering" or "in pain." During study interviews, we observed several individuals stated that their spouse being "gone" was "not a relief" but the thought that patients were "not suffering or in pain" was a "relief." Further, perceptions of loved ones' suffering appear to have an important negative effect on bereavement when caregivers are both high in rumination and experience low relief. Whereas there was not sufficient power in the present study to investigate three-way interaction effects, it would be interesting for future work to consider how rumination, feelings of relief, and perceptions of suffering work together to affect grief and complicated grief.

Descriptive Predictors of Depression, Grief, and Complicated Grief

Results revealed a number of descriptive characteristics as factors associated with caregiver bereavement outcomes. Consistent with previous literature, lower education attainment was a significant predictor of higher levels of bereaved spousal caregivers' grief (Schulz, McGinnis, et al., 2008). In addition, the finding that retirement status was associated with better bereavement outcomes aligns with other work that being employed was associated with poorer bereavement outcomes. In the study by Aneshensel and colleagues (2004), which utilized longitudinal data to cluster bereaved caregivers according to trajectories of depressive symptoms, being employed was associated the “repeatedly distressed” group. It is possible that employed caregivers face unique stressors that contribute to their level of distress compared to individuals who are not working. However, some researchers have argued, in line with the “relief” hypothesis, that the death of a care recipient allows bereaved caregivers to reestablish roles such as employment (Bernard & Guarnaccia, 2003), and thus a more positive adjustment to loss. Given that a majority of participants in the current study were retired rather than unemployed, the inclusion of questions that investigated if participants returned to other pre-loss activities or responsibilities that were suspended during the caregiving process may have added support to the relief hypothesis.

Finally, more time spent caregiving each week was a significant predictor of worse depression and complicated grief. These findings may provide support for the “wear and tear” hypothesis, suggesting that individuals who have a more demanding caregiving experience a “depletion” of coping resources and thus poorer well-being after the death of their spouse. It is important to note that the number of reported hours spent caregiving may be relatively high in the current sample. For example, Haley and colleagues (2001) reported caregivers of hospice patients with lung cancer and dementia provided care than 100 hours per week, on average. However, many of the dementia caregivers in the sample had relatives who resided in nursing homes. The sample of caregivers of patients with lung cancer provided a mean of 116 hours per week, which is similar to findings in the current study. It is possible the high number of reported hours spent caregiving in the current sample is a result of the way in which the item was presented to respondents. Several caregivers in the present sample reported caregiving “24/7” each week during the month before hospice care. However, Schulz and colleagues (2003) reported 59% that of dementia caregivers reported being “on-duty" 24 hours per day, a response option that was not available in the present study. Further, in Schulz's study, actual time spent performing caregiving tasks were measured by hours assisting activities and instrumental activities of daily living. Therefore, the extent to which caregivers reported that they were "caregiving" in the present study may reflect feelings of being "on-duty." These findings may suggest that feelings of "duty" to a loved one, rather than actually performing tasks have important effects on bereavement outcomes, even 6-18 months following loss.

Less perceived ability to pay for basics and caregiver health were not significant predictors of subsequent bereavement outcomes. The finding that lower perceived ability to pay for basics was not associated with bereavement is in contrast to findings by other researchers who report higher income is associated with better bereavement. For example, longitudinal findings by Li (2005) showed symptoms of depression among bereaved caregivers were more likely to decrease over time when compared to caregivers who reported lower incomes. In addition, the finding that caregiver health was not associated with bereavement outcomes is a bit surprising, as prior research has frequently shown a relationship between health and bereavement and that better caregiver health is associated with more positive bereavement outcomes (e.g. Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Stroebe, Schut, & Stroebe, 2007). Recent research on former spousal caregivers found self-reported physical health was a significant predictor of risk for complicated grief and major depressive disorder (Utz, Caserta, & Lund, 2012). However, all participants in the current sample were community-dwelling and over 80% resided alone. Therefore, participants in our study may have been relatively high functioning in comparison to other study samples. In addition, findings from the current study may contrast with prior studies because this study focuses only on a group of spousal caregivers, whereas other studies have included mixed groups of caregivers. Finally, it was not possible to determine the state of caregivers' health prior to loss and if they experienced changes in health during bereavement.

Perhaps surprisingly, length of time since patient death was not a significant predictor of bereavement outcomes, although a fewer number of days since death was associated with worse grief and complicated grief in the correlation analyses. Prior research suggests that greater length of time since loss is a significant predictor of better bereavement outcomes. For example, Boerner and colleagues (2004) reported fewer days since death are a significant predictor of caregiver symptoms of depression during bereavement. However, in the study by Boerner (2004), the mean number of days since death at time of study interview was 3 months or less. Therefore, it is possible that a significant effect was not found in the present study because number of days since death ranged from 6-18 months. Alternatively, it is possible that individuals in the present study experienced either stability or increases in poor bereavement outcomes that were not detected because of the cross-sectional design of the present study. Bonanno and colleagues (2002) reported that while the most common response to loss is a "low depression" or "resilient" pattern, a sizable minority of individuals experience chronic grief. Among chronic grievers, symptoms of depression are relatively low prior to loss but are elevated at 6 months and a minority reported having enduring, chronic depression. It is important to note that the findings by Bonanno and colleagues (2002) did not provide clear support for a delayed grief reaction and it is unlikely that participants in the current study were experiencing "delayed grief."

Study Limitations and Strengths

Limitations

There are important study limitations that should be noted. First, because of the cross-sectional design of the study, data are aggregated across participants and it was not possible to consider different trajectories of adjustment over time. Bonanno and colleagues (2002) highlight cross-sectional design as an important limitation in bereavement research because predictor variables can be confounded with changes in perception and functioning. However, given that previous literature shows many bereaved individuals are resilient or experience a decline in distress over time (Bonanno, Wortman, et al., 2002; Ringdal, Jordhoy, Ringdal, & Kaasa, 2001) and that participant interviews for the current study took place an average of 11 months following loss, it is possible participants in the current study have long-standing emotional distress, similar to “common” or “chronic grievers” (Bonanno, Wortman, et al., 2002). It is important to note that work by Aneshensel and colleagues (2004) that extended Bonanno’s research, found that depressive symptoms were highest during the first year of bereavement, and dropped substantially during the second year. Therefore, follow-up interviews later into bereavement may have allowed us to see declines in participants’ distress.

Second, the relatively small sample size limited the statistical power of analyses and the population of study may not reflect a typical hospice sample, which may limit the generalizabilty of findings. For example, participants in the current study were highly educated, were providing care for long periods prior to loss, and may be a highly grieving sample. However, significant predictor variables in the current study were consistent across multiple models such that rumination was a consistent predictor of 3 out of 3 possible bereavement outcomes, feelings of relief predicted 2 out of 3 possible bereavement outcomes, and interactions investigating feeling of relief, rumination, and emotional suffering were significant in 4 out of 6 models. Therefore, identified predictor variables seem to be common and important to highly distressed former spousal caregivers of hospice patients and are worthy of further research in a prospective, longitudinal study.

A third limitation is the use of some retrospective measures. Although a majority of bereavement studies utilize retrospective recall, subjective assessments of patient end-of-life symptoms can be affected by bereavement and memory. Some researchers propose individuals modify subjective assessments in retrospective appraisals to reflect their new bereaved status (Hinton, 1996; Stroebe, Stroebe, & Schut, 2003). For example, in a review of the literature on after-death surveys, Addington-Hall and McPherson (2001) identified that relatives' retrospective appraisals of patients' end-of-life symptoms had little correspondence with patients' pre-loss reports. However, prospective studies that attempt to follow patient symptoms at the end of life and subsequent bereavement outcomes require multiple interviews of soon-to-be bereaved during loved ones' terminal decline, which is a sensitive time that is of ethical concern in end-of-life research (Addington-Hall & McPherson, 2001; Teno, 2005). It is important to note that a major aim of this dissertation was to investigate recollections or feelings, rather than accurate portrayals of past events as these recollections and feelings are often an important focus of grief therapy and are worthy of study. Further, factors identified during retrospective research can be tested by prospective research.

Finally, limited research has provided evidence for the validity of the suffering measures. To our knowledge, the current study is among the first to utilize the Experience of Suffering Scales published by Schulz and colleagues (2010) within a bereaved sample of caregivers. While it is possible perceptions of loved ones' overall suffering do not affect psychological well-being following loss, as suggested by our findings and those by Barry and colleagues (2002), it is also possible that a different measure or slightly modified measure should be considered. Although Cassell (1999), a leader in the conceptualization of suffering, proposed that even single item assessments can be informative, literature by Schulz and colleagues (2010) proposes inclusion of a more holistic and psychometrically sound approach can yield results that are more informative. While the measure is still relatively new, the initial validity analyses reported by Schulz and colleagues (2010) showed low internal consistency for the physical suffering index. Further, while Schulz and colleagues (2010) reported a confirmatory factor analysis revealed a 3-factor model (i.e. physical, psychological, and existential); the authors acknowledge cross-loading by one of the physical suffering scale items (i.e. "confusion and difficulty concentrating") on all three factors. The authors suggest that it would not be appropriate to eliminate this item because it is theoretically relevant to the construct of physical suffering. Although there was not enough power in the current sample to conduct factor analyses, future work should examine the suffering subscales, with particular focus on the physical suffering subscale.

Strengths

This dissertation has a number of important strengths that should be noted. Despite the relatively small sample size, important effects that are not previously documented in bereavement literature were consistently detected in the present study. For example, this dissertation may be the first study to investigate the relationship of stress-reactive rumination to bereavement outcomes and is believed to be among the first to consider how frequency of caregivers' thoughts about a spouse's end-of-life experience are associated with psychological well-being following loss. Whereas previous research has primarily considered rumination and bereavement-related depression, the current findings suggest that ruminations could have long-term negative effects on multiple bereavement outcomes, including complicated grief.

Second, there are strengths associated with the homogenous group of participants in the study sample. Spousal caregivers are among the most common types of caregivers and spousal loss is recognized as one of the most distressing forms of loss (Burton, Haley, & Small, 2006; Haupt, 2003; National Alliance for Caregiving, 2009; Stroebe, Schut, et al., 2007). Therefore, focusing research on former spousal caregivers allows researchers to identify risk factors for poor bereavement among a common and highly distressed group of bereaved individuals. Further, factors identified in this sample can be tested in other caregiving populations, which allow researchers to identify common maladaptive patterns of distress to assist in targeting bereavement services and clue the focus of clinical interventions such as cognitive behavioral therapy (CBT). In addition, this study only included former caregivers of hospice patients, who represent a group of caregivers that provided extensive support to loved ones with chronic terminal disease. Therefore, the findings of this study not only provide a snapshot of distressing cognitions and emotions of associated with the end of life among a common group of caregivers, but also provide important information for hospice and palliative care bereavement departments to the needs of highly distressed caregivers who could benefit from the Medicare-mandated bereavement services.

A third important strength is that while many previous studies on bereavement focused only on depression the present study included multiple assessments of caregivers' psychological well-being following loss. Previous research has shown that depression, grief, and complicated grief are related indicators of well-being after bereavement, but each includes distinct elements. For example, antidepressant medications improve symptoms of bereavement-related depression but are ineffective to modestly effective in reducing the intensity of grief (Pasternak, et al., 1993; Pasternak, et al., 1991; Zisook, Shucter, Pedrelli, Sable, & Deaciuc, 2001). Similarly, individuals with complicated grief have symptoms that are distinct from present feelings of grief such as difficulty returning to pre-bereavement levels of functioning, increased morbidity, intense yearning and searching, preoccupations, and feelings of disbelief for an extended period of time (i.e. six months or greater) (Boelen & van den Bout, 2005; Newson, Boelen, Hek, Hofman, & Tiemeier, 2011; Prigerson & Maciejewski, 2005; Prigerson, et al., 1995). Finally, Prigerson and colleagues (1995) reported only small overlap between individuals with complicated grief and bereavement-related depression. Taken together, these findings suggest that, when used alone, individual assessments of psychological well-being during bereavement do not create a comprehensive picture of bereaved individuals' response to loss. However, inclusion of multiple bereavement-related outcomes allow for a clearer and more clinically relevant assessment of caregiver adjustment to spousal loss.

Study Implications and Future Research

Findings from this dissertation provide an exciting platform from which to develop clinical and theoretical implications and opportunities for future research. Study findings have particularly important theoretical and practice implications related to the concept of "working through" grief. The dual process model of coping with bereavement proposes two major orientations of focus in response to the loss of a loved one: loss-oriented and restoration-oriented (Stroebe & Schut, 1999). Specifically, Stroebe and Schut (1999) suggest bereavement is an adaptive process during which time individuals "oscillate" between loss and restorative forms of coping. Loss-oriented coping is conceptualized as a "dealing with" or "processing" aspects of the loss, which aligns with traditional grief work theories (Stroebe & Schut, 1999). The authors suggest that loss-oriented coping frequently involves ruminations about the person who died as well as circumstances and events surrounding the loss and ruminations have been conceptualized as part of the "grief work" associated with loss-oriented coping (Stroebe, Boelen, et al., 2007; Stroebe & Schut, 1999, 2010). We found that ruminations associated with loved ones' suffering were associated with negative bereavement outcomes, even after 6-18 months. Therefore, it is possible that high ruminators were more likely to engage in loss-oriented coping than restoration-oriented coping.

One way that clinicians may assist bereaved spouses to move away from ruminative thoughts that led to more loss-oriented coping is Cognitive Behavioral Therapy. Cognitive behavioral therapy is aimed at identifying troubling cognitions and can be useful to help bereaved individuals identify ways to alter or redirect distressing thoughts (Boelen, de Keijser, van den Hout, & van den Bout, 2007). For example, clients may learn to redirect their thoughts away from focusing on why the person got cancer or the pain or anxiety that their loved one endured, to focusing on positive memories of the good things that they enjoyed with their spouse during their life together. One approach proposed by Kavanagh (1990) is "controlled exposure," which assists bereaved individuals in recognizing thoughts associated with severe emotional distress and encourages clients to identify and, in light of gathered evidence, dispel negative thoughts, (Kavanagh, 1990; Matthews & Marwit, 2004). Similarly, revisiting the death is useful component of exposure therapy that has been identified as an effective treatment of complicated grief in a randomized controlled trial (Shear, Frank, Houck, & Reynolds, 2005).

Using work by Kavanagh (1990) as a springboard, Stroebe and colleagues (2007; 1999) propose that interventions for individuals who engage in extreme rumination that involve exposure to grief cues may be detrimental and that focus on avoidance or restoration-orientated tasks may be more productive. Therefore, an important question for researchers to consider is if therapies that encourage focusing on “re-experiencing” or “re-telling the story” of the death, as some grief work therapies suggest (e.g. Shear, et al., 2005), would be clinically helpful to high ruminators who report poor psychological well-being. Emerging literature by Larson and Hoyt (2007) suggests that there is a lack of empirical or statistical foundation for claims, such as those put forth by Neimeyer (2000), that bereavement counseling is ineffective or harmful to clients, although further work examining rumination-related grief counseling protocols is needed.

Findings from this dissertation study also provide a foundation for future longitudinal research. Prospective, longitudinal studies suggest that bereaved individuals experience unique trajectories during bereavement including common grief, chronic grief, improvement during bereavement, and resilience (Bonanno, Papa, et al., 2002; Bonanno, Wortman, et al., 2002). Future longitudinal research should consider if stress-reactive rumination, feelings of relief, and perceptions of suffering change over time and if these thoughts and feelings are associated with particular bereavement patterns. For example, it would be interesting for researchers to consider if “chronic grievers” are more likely than individuals who experience “common grief” to engage in stress-reactive rumination. Further, it would be interesting to investigate if there is a particular time point (e.g. 6 months or a year) at which mental health providers should recommend intervention services. It is important to note that in light of the findings by Robinson and Alloy (2003) that stress-reactive rumination can predict the duration of depressive episodes, it would be interesting to conduct a longitudinal study that investigates if individuals who report high stress-reactive rumination are more likely to have lasting depression and grief compared to individuals reporting lower stress-reactive rumination.

In addition, findings from the present study indicate a number of additional predictors that should be considered in future research. For example, our findings suggest that a lack of feelings of relief has a negative effect on bereavement outcomes, especially when coupled with high perceptions of emotional suffering. It is possible that specific factors are associated with the extent to which caregivers feel relief following loss. Given that the current study did not assess pre-loss caregiver burden, future work that includes pre-loss measures of caregiver burden and direct post-loss measures of sources of relief could provide important theoretical implications for the wear and tear and relief hypotheses. Further, researchers should consider if feelings of relief-related guilt are associated with poor bereavement outcomes, as mental health providers could focus on feelings of guilt in clinical interventions.

Finally, findings from the present study provide useful practice implications for hospice bereavement departments seeking to target interventions services to patient family members at high risk for difficult bereavement. For example, the ‘frequency of thoughts’ questions and the single item assessing feelings of relief can be completed relatively quickly and seem to be useful in identifying individuals who are highly distressed even after extended periods following loss and could be utilized by hospice bereavement departments as a quick screening tool. When working with volunteers in recruitment efforts for the present study, we noticed that some office volunteers offer to make calls for an hour or two after their usual office staff duties. Further, in our request for volunteers we immediately received multiple offers from individuals to assist with making calls to bereaved caregivers, suggesting that bereavement departments could utilize trained hospice volunteers in screening for poor bereavement. In addition, it is important to highlight that although measures of depression, grief, and complicated grief were highly correlated with one another, predictors of each outcome varied slightly with analyses investigating predictors of depression and complicated grief producing the most similar results. Hospice and palliative care programs should consider inclusion of multiple bereavement-related outcomes to provide a more clinically relevant assessment of caregiver adjustment to loss.

Conclusion

This dissertation investigated several nuanced interpersonal and coping factors relevant to the caregiving-bereavement continuum and found that stress-reactive rumination in response to a loved one's end-of-life suffering and feelings of relief following the death were important predictors of bereaved spouses' psychological well-being. In addition, results showed that feelings of relief and rumination moderate the relationship of perceptions of emotional suffering on bereavement outcomes such that when perceptions of emotional suffering are high, high rumination and low feelings of relief are associated with worse grief and complicated grief. Further, when perceptions of existential suffering are high and individuals are high ruminators, caregivers report higher present feelings of grief. The study findings provide important implications for clinical practice, and suggest that thoughts about negative inferences associated with perceptions of suffering, may be important thoughts of focus during cognitive behavioral therapy. The study findings also provide a springboard for future longitudinal work that could further inform theoretical and clinical approaches for rumination and bereavement within the context of caregiving.

References

Addington-Hall, J., & McPherson, C. (2001). After-death interviews with surrogates/bereaved family members: Some issues of validity. *Journal of Pain and Symptom Management, 22*(3), 784-790. doi: 10.1016/S0885-3924(01)00330-X

Allen, R. S., Allen, J. Y., Hilgeman, M. M., & DeCoster, J. (2008). End-of-life decision-making, decisional conflict, and enhanced information: Race effects. *Journal of the American Geriatrics Society, 56*, 1904-1909. doi: 10.1111/j.1532-5415.2008.01929.x

Alloy, L. B., Abramson, L. Y., Hogan, M. E., Whitehouse, W. G., Rose, D. T., Robinson, J., et al. (2000). The Temple-Wisconsin Cognitive Vulnerability to Depression Project: Lifetime history of axis I psychopathology in individuals at high and low cognitive risk for depression. *Journal of Abnormal Psychology, 109*(3), 403-418. doi: 10.1037/0021-843X.109.3.403

Anderson, F., Downing, G. M., Hill, J., Casorso, L., & Lerch, N. (1996). Palliative Performance Scale (PPS): A new tool. *Journal of Palliative Care, 12*(1), 5-11.

Aneshensel, C. S., Botticello, A. L., & Yamamoto-Mitani, N. (2004). When caregiving ends: The course of depressive symptoms after bereavement. *Journal of Health and Social Behavior, 45*, 422-440.

Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. J. (1995). *Profiles in caregiving: The unexpected career*. San Diego: Academic Press.

Baker, F. M., Velli, S. A., Freidman, J., & Wiley, C. (1995). Screening tests for depression in older Black vs. White patients. *The American Journal of Geriatric Psychiatry, 3*(1), 45-31. doi: 1995-23706-001

Barry, L. C., Kasl, S. V., & Prigerson, H. G. (2002). Psychiatric disorders among bereaved persons. *American Journal of Geriatric Psychiatry, 10*(4), 447-457. Retrieved from http://ovidsp.tx.ovid.com/sp-3.2.1/ovidweb.cgi?T=JS&PAGE=fulltext&D=ovft&AN=00019442-200207000-00011&NEWS=N&CSC=Y&CHANNEL=PubMed

Bernard, L. L., & Guarnaccia, C. A. (2003). Two models of caregiver strain and bereavement adjustment: A comparison of husband and daughter caregivers of breast cancer hospice patients. *The Gerontologist, 43*(6), 808-816. doi: 10.1093/geront/43.6.808

Bodnar, J. C., & Kiecolt-Glaser, J. K. (1994). Caregiver depression after bereavement: Chronic stress isn't over when it's over. *Psychology and Aging, 9*(3), 372-380. doi: 10.1037/0882-7974.9.3.372

Boelen, P. A., de Keijser, J., van den Hout, M. A., & van den Bout, J. (2007). Treatment of complicated grief: A comparison between cognitive behavioral therapy and supportive counseling. *Journal of Consulting and Clinical Psychology, 72*(2), 277-284. doi: 10.1037/0022-006X.75.2.277

Boelen, P. A., & van den Bout, J. (2005). Complicated grief, anxiety, and depression as postloss syndromes: A confirmatory factor analysis study. *American Journal of Psychiatry, 162*, 2175-2177. doi: 10.1176/appi.ajp.162.11.2175

Boerner, K., & Schulz, R. (2009). Caregiving, bereavement and complicated grief. *Bereavement Care, 28*(3), 10-13. doi: 10.1080/02682620903355382

Boerner, K., Schulz, R., & Horowitz, A. (2004). Positive aspects of caregiving and adaptation to bereavement. *Psychology and Aging, 19*(4), 668-678. doi: 0.1037/0882-7974.19.4.668

Bonanno, G. A., Keltner, D., Holen, A., & Horowitz, M. J. (1995). When avoiding unpleasant emotions might not be such a bad thing: Verbal-automatic response of dissociation and midlife conjugal bereavement. doi: 10.1037/0022-3514.69.5.975

Bonanno, G. A., Papa, A., Lalande, K., Zhang, N., & Noll, J. G. (2005). Grief processing and deliberate grief avoidance: A prospective comparison of bereaved spouses and parents in the United States and the People's Republic of China. *Journal of Consulting and Clinical Psychology, 73*(1), 86-98. doi: 10.1037/0022-006X.73.1.86

Bonanno, G. A., Papa, A., & O'Neill, K. (2002). Loss and human resilience. *Applied and Preventive Psychology, 10*(3), 193-206. doi: 10.1016/S0962-1849(01)80014-7

Bonanno, G. A., Wortman, C. B., Lehman, D. R., Tweed, R. G., Haring, M., Sonnega, J., Carr, D., …Neese, R.M. (2002). Resilience to loss and chronic grief: A prospective study from preloss to 18-months postloss. *Journal of Personality and Social Psychology, 83*(5), 1150-1164. doi: 10.1037//0022-3514.83.5.1150

Bonanno, G.A., Wortman, C.B., & Neese, R.M. (2004). Prospective patterns of resilience and maladjustment during widowhood. *Psychology and Aging, 19*, 260-271. doi: 10.1037/0882-7974.19.2.260

Bowerman, B. L., & O'Connell, R. T. (1990). *Linear statistical models: An applied approach* (2nd ed.). Belmont, CA: Duxbury.

Bui, E., Nadal-Vicens, M., & Simon, N. M. (2012). Pharmacological approaches to the treatment of complicated grief: Rationale and a brief review of the literature. *Dialogues in Clinical Neuroscience, 14*(2), 149-157. Retrieved from http://www.dialogues-cns.com/wp-content/uploads/2012/06 /DialoguesClinNeurosci-14-149.pdf

Burton, A. M., Haley, W. E., & Small, B. J. (2006). Bereavement after caregiving or unexpected death: Effects on elderly spouses. *Aging & Mental Health, 10*(3), 319-326. doi: 10.1080/13607860500410045

Cassell, E. J. (1999). Diagnosing suffering: A perspective. *Annals of Internal Medicine, 131*, 531-534. Retrieved from http://www.annals.org/content/131/7/531.full. pdf+html

Chiu, Y.-W., Huang, C.-T., Yin, S.-M., Huang, Y.-C., Chien, C.-h., & Chuang, H.-Y. (2009). Determinants of complicated grief in caregivers who cared for terminal cancer patients. *Supportive Care in Cancer*. Retrieved from http://www.springerlink.com/content/t558h3r7747778l8/fulltext.pdf doi:10.1007/s00520-009-0756-6

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd Ed.). New York: Academic Press.

Cohen, J. (1992). A power primer. *Psychological Bulletin, 112*(1), 155-159. doi: 10.1037/0033-2909.112.1.155

Cohen, J., Cohen, P., West, S. G., & Aiken, L. S. (2003). *Applied multiple regression/correlation analyses for the behavioral sciences* (3rd ed.). Mahway, NJ: Lawrence Erlbaum Associates, Inc.

Conway, M., Csank, P. A. R., Holm, S. L., & Blake, C. K. (2000). On assessing individual differences in rumination on sadness. *Journal of Personality Assessment, 75*(3), 404-425. doi: 10.1207/S15327752JPA7503_04

Faschingbauer, T., Zisook, S., & DeVaul, R. (1987). The Texas Revised Inventory of Grief. In S. Zisook (Ed.), *Biospychosocial aspects of bereavement* (pp. 111-124). Washington DC: American Psychiatric Press.

Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39*, 175-191. doi: 10.3758/BF03193146

Ferrell, B., & Coyle, N. (2008). *The nature of suffering and the goals of nursing*. New York: Oxford University Press.

Futterman, A., Brown, P. J., Holland, J. M., Thompson, L. W., & Gallagher-Thompson, D. (2010). Factorial validity of the Texas Revised Inventory of Grief Present Scale among bereaved older adults. *Psychological Assessment, 22*(3), 675-687. doi: 10.1037/a0019914

Guldin, M.-B., Vedsted, P., Zachariae, R., Olesen, F., & Jensen, A. (2011). Complicated grief and need for professional support in family caregivers of cancer patients in palliative care: A longitudinal cohort study. *Supportive Care in Cancer*, 1-7. doi: 10.1007/s00520-011-1260-3

Haley, W. E., Bergman, E. J., Roth, D. L., McVie, T., Gaugler, J. E., & Mittelman, M. S. (2008). Long-term effects of bereavement and caregiver intervention on dementia caregiver depressive symptoms. *The Gerontologist, 48*, 732-740. doi: 10.1093/geront/48.6.732

Haley, W. E., LaMonde, L. A., Han, B., Burton, A. M., & Schonwetter, R. (2003). Predictors of depression and life satisfaction among spousal caregivers in hospice: Application of a stress process model. *Journal of Palliative Medicine, 6*, 215-224. doi: 10.1089/109662103764978461

Haley, W. E., LaMonde, L. A., Han, B., Narramore, S., & Schonwetter, R. (2001). Family caregiving in hospice: Effects on psychological and health functioning in spousal caregivers for patients with lung cancer or dementia. *The Hospice Journal, 15*, 1-18. doi: 10.1300/J011v15n04_01

Hardison, H. G., Neimeyer, R. A., & Lichstein, K. L. (2005). Insomnia and complicated grief symptoms in bereaved college students. *Behavioral Sleep Medicine, 3*(2), 99-111. doi: 10.1207/s15402010bsm0302_4

Haupt, B. J. (2003). Characteristics of hospice care discharges and their length of service: United States, 2000. *Vital and Health Statistics. Series 13: Data from the National Health Survey, 154*. Retrieved from: http://www.cdc.gov/nchs/data /series/sr_13/sr13_154.pdf

Hayes, A. F., & Matthes, J. (2009). Computational procedures for probing interactions in OLS and logistic regression: SPSS and SAS implementation. *Behavior Research Methods, 42*, 924-936. doi: 10.3758/BRM.41.3.924

Hebert, R. S., & Schulz, R. (2006). Caregiving at the end of life. *Journal of Palliative Medicine, 9*(5), 1174-1187. doi: 10.1089/jpm.2006.9.1174

Hensley, P. L. (2006). Treatment of bereavement-related depression and traumatic grief. *Journal of Affective Disorders, 92*(1), 117-127. doi: 10.1016/j.jad.2005.12.041

Hinton, J. (1996). How reliable are relatives' retrospective reports of terminal illness? Patients' and relatives' accounts compared. *Social Science and Medicine, 43*(8), 1229-1236. doi: 10.1016/0277-9536(95)00437-8

Ho, F., Downing, M. G., & Lesperance, M. (2008). A reliability and validity study of the Palliative Performance Scale. *BMC Palliative Care, 7*, 1-10. doi: 10.1186/1472-684X-7-10

Holtslander, L. F., & McMillan, S. C. (2011). Depressive symptoms, grief, and complicated grief among family caregivers of patients with advanced cancer three months into bereavement. *Oncology Nursing Forum, 38*(1), 60-65. doi: 10.1188/11.ONF.60-65

Jacobsen, J. C., Zhang, B., Block, S. D., Maciejewski, P. K., & Prigerson, H. G. (2010). Distinguishing symptoms of grief and depression in a cohort of advanced cancer patients. *Death Studies, 34*(3), 257-273. doi: 10.1080/07481180903559303

Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., & Jaffee, M. W. (1963). Studies of illness in the aged: The index of ADL, a standardized measure of biological and psychological function. *JAMA, 185*, 914-919. doi: 10.1001/jama. 1963.03060120024016

Kavanagh, D. J. (1990). Towards a cogntive-behavioural intervention for adult grief reactions. *British Journal of Psychiatry, 157*, 373-383.

Keene, J. R., & Prokos, A. H. (2008). Widowhood and the end of spousal care-giving: Relief or wear and tear? *Ageing & Society, 28*, 551-570. doi: 10.1017/S0144686X07006654

Kessler, R. C., & Merikangas, K. R. (2004). The National Comorbidity Survey Replication (NCS-R): Background and aims. *International Journal of Methods in Psychiatric Research, 13*(2), 60-68. doi: 10.1002/mpr.166

Larson, D. G., & Hoyt, W. T. (2007). What has become of grief counseling? An evaluation of the empirical foundations of the new pessimism. *Professional Psychology: Research and Practice, 38*(4), 347-355. doi: 10.1037/0735-7028.38.4.347

Lavela, S. L., & Ather, N. (2010). Psychological health in older adult spousal caregivers of older adults. *Chronic Illness, 6*, 67-80. doi: 10.1177/1742395309356943

Li, L. W. (2005). From caregiving to bereavement: Trajectories of depressive symptoms among wife and daughter caregivers. *Journal of Gerontology: Psychological Sciences, 60B*(4), P190-P198. doi: doi:10.1093/geronb/60.4.P190

Lobb, E. A., Kristjanson, L. J., Aoun, S. R., Monterosso, L., Halkett, G. K. B., & Davies, A. (2010). Predictors of complicated grief: A systematic review of empirical studies. *Death Studies, 34*(8), 673-698. doi: doi: 10.1080/07481187.2010.496686

Matthews, L. T., & Marwit, S. J. (2004). Complicated grief and the trend toward cognitive-behavioral therapy. *Death Studies, 28*(9), 849-863. doi: 10.1080/07481180490490924

Monin, J. K., & Schulz, R. (2009). Interpersonal effects of suffering in older adult caregiving relationships. *Psychology and Aging, 24*(3), 681-695. doi: 10.1037/a0016355

Monin, J. K., Schulz, R., Martire, L. M., Jennings, J. R., Lingler, J. H., & Greenberg, M. S. (2010). Spouses' cardiovascular reactivity to their partners' suffering. *Journal of Gerontology: Psychological Sciences, 65B*(2), 195-201. doi: 10.1093/geronb/gbp133

Mortia, T., Tsunoda, J., Inoue, S., & Chihara, S. (1999). Validity of the Palliative Performance Scale from a survival perspective [letters]. *Journal of Pain and Symptom Management, 18*(1), 2-3. doi: 10.1016/S0885-3924(99)00040-8

Mullan, J. T. (1992). The bereaved caregiver: A prospective study of changes in wellbeing. *The Gerontologist, 32*(5), 673-683. doi: 10.1093/geront/32.5.673

Myers, R. (1990). *Classical and modern regression with applications* (2nd ed.). Boston, MA: Dubxury.

National Alliance for Caregiving. (2009). *Caregiving in the U.S.*: Retrieved from http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf.

National Center for Health Statistics, Centers for Disease Control and Prevention National Center for Health Statistics. (1994). *Evaluation of National Health Interview Survey Diagnostic Reporting* Retrieved from http://www.cdc.gov/nchs/data/series/sr_02/sr02_120.pdf.

National Center for Health Statistics, Centers for Disease Control and Prevention. (2011). *National Health Interview Survey (NHIS) Public Use Data Release: NHIS Survey Description*. Hyattsville, MD: Retrieved from http://www.cdc.gov/nchs/data/nhis/srvydesc.pdf.

Neimeyer, R. A. (2000). Searching for the meaning of meaning: Grief therapy and the process of reconstruction. *Death Studies, 24*, 541-558. doi: 10.1080/07481180050121480

Neimeyer, R. A., Hogan, N. S., & Laurie, A. (2008). The measurement of grief: Psychometric considerations in the assessment of reactions to bereavement. In M. S. Stroebe, R. O. Hansson, W. Stroebe & H. Schut (Eds.), *Handbook of bereavement research and practice: Advances in theory and intervention*. Washington DC: American Psychological Association.

Newson, R. S., Boelen, P. A., Hek, K., Hofman, A., & Tiemeier, H. (2011). The prevalence and characteristics of complicated grief in older adults. *Journal of Affective Disorders, 132*, 231-238. doi: doi:10.1016/j.jad.2011.02.021

Nolen-Hoeksema, S. (1991). Responses to depression and their effects on the duration of depressive episodes. *Journal of Abnormal Psychology, 100*(4), 569-582. doi: 10.1037/0021-843X.100.4.569

Nolen-Hoeksema, S., McBride, A., & Larson, J. (1997). Rumination and psychological distress among bereaved partners. *Journal of Personality and Social Psychology, 72*(4), 855-862. doi: 10.1037//0022-3514.72.4.855

Nolen-Hoeksema, S., Parker, L. E., & Larson, J. (1994). Ruminative coping with depressed mood following loss. *Journal of Personality and Social Psychology, 67*(1), 92-104. doi: 10.1037//0022-3514.67.1.92

Nolen-Hoeksema, S., Wisco, B. E., & Lyubomirsky, S. (2008). Rethinking rumination. *Perspectives on Psychological Sciences, 3*(5), 400-424. doi: 10.1111/j.1745-6924.2008.00088.x

Papageorgiou, C., & Wells, A. (2004). Nature, functions, and beliefs about depressive rumination. In C. Papageorgiou & A. Wells (Eds.), *Depressive Rumination: Nature, Theory, and Treatment*. Chichester: John Wiley & Sons

Pasternak, R. E., Reynolds, C. F., Frank, E., Miller, M., Houck, P. R., Schlernitauer, M., Prigerson, H.G., …Kupfer, D.J. (1993). The temporal course of depressive symptoms and grief intensity in late-life spousal bereavement. *Depression, 1*, 45-49. doi: 10.1002/depr.3050010109

Pasternak, R. E., Reynolds, C. F., Schlernitzauer, M., Houch, c. C., Buysse, D. J., Houck, P. R., Perel, J.M. (1991). Acute open-trial nortriptyline therapy of bereavement-related depression in late life. *Journal of Clinical Psychiatry, 52*(7), 307-310.

Prigerson, H. G., Bierhals, A. J., Kasl, S. V., Reynolds, C. F., Shear, K., Newsom, J. T., Jacobs, S. (1996). Complicated grief as a disorder distinct from bereavement-related depression and anxiety: A replication study. *American Journal of Psychiatry, 153*, 1484-1486. Retrieved from: http://ajp.psychiatryonline.org/ article.aspx?volume=153&page=1484

Prigerson, H. G., Bierhals, A. J., Kasl, S. V., Reynolds, C. F., Shear, M. K., Day, N., Berry, L.C., …Jacobs, S. (1997). Traumatic grief as a risk factor for mental and physical morbidity. *American Journal of Psychiatry, 154*(5), 616-623. Retrieved from: http://ajp.psychiatryonline.org/article.aspx?volume=154&page=616

Prigerson, H. G., Horowitz, M. J., Jacobs, S., Parkes, C. M., Aslan, M., Goodkin, K., Raphael, B., …Maciejewski, P.K. (2009). Prolonged grief disorder: Psychometric validation of criteria proposed for DSM-V and ICD-11. *Public Library of Science Medicine, 6*(8), 1-12. doi: 10.1371/journal.pmed.1000121

Prigerson, H. G., & Maciejewski, P. K. (2005). A call for sound empirical testing and evaluation of criteria for complicated grief proposed for DSM-V. *Omega 52*, 9-19. doi: 10.2190/ANKH-BB2H-D52N-X99Y

Prigerson, H. G., Maciejewski, P. K., Reynolds, C. F., Bierhals, A. J., Newsom, J. T., Fasiczka, A., Frank, E., …Miller, M. (1995). Inventory of complicated grief: A scale to measure maladaptive symptoms of loss. *Psychiatry Research, 59*, 65-79. doi: 10.1016/0165-1781(95)02757-2

Prigerson, H. G., Vanderwerker, L. C., & Maciejewski, P. K. (2008). A case for inclusion of prolonged grief disorder in *DSM-V*. In M. S. Stroebe, R. O. Hansson, W. Stroebe & H. Schut (Eds.), *Handbook fo bereavement research and practice: Advances in theory and intervention* (pp. 165-186). Washington DC: American Psychological Association.

Radloff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385-401. doi: 10.1177/014662167700100306

Rando, T. (1993). *Treatment of complicated mourning*. Champaign, IL: Research Press.

Ringdal, G. I., Jordhoy, M. S., Ringdal, K., & Kaasa, S. (2001). Factors affecting grief reactions in close family members to individuals who have died of cancer. *Journal of Pain and Symptom Management, 22*(6), 1016-1026. doi: 10.1191/026921601674021869

Robinson, M. S., & Alloy, L. B. (2003). Negative cognitive styles and stress-reactive rumination interact to predict depression: A prospective study. *Cognitive Therapy and Research, 27*(3), 25-292. doi: doi: 10.1023/A:1023914416469

Schulz, R. & Beach, S.R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *JAMA, 282*, 2215-2219. doi: 10.1001/jama.282.23.2215

Schulz, R., Beach, S. R., Hebert, R. S., Martire, L. M., Monin, J. K., Tompkins, C. A., Albert, S.M. (2009). Spousal suffering and partner's depression and cardiovascular disease: The Cardiovascular Health Study. *American Journal of Geriatric Psychiatry, 17*(3), 246-254. doi: 10.1097/JGP.0b013e318198775b

Schulz, R., Belle, S. H., Czaja, S. J., Gitlin, L., Wisniewski, S., & Ory, M. G. (2003). Introduction to the special section on Resources for Enhancing Alzheimer's Caregiver Health (REACH). *Psychology and Aging, 18*(3), 357-360. doi: 10.1037/0882-7974.18.3.357

Schulz, R., Boerner, K., & Hebert, R. S. (2008). Caregiving and bereavement. In M. S. Stroebe, R. O. Hansson, W. Stroebe & H. Schut (Eds.), *Handbook of bereavement research and practice: Advances in theory and intervention* (pp. 262-286). Washington DC: American Psychological Association.

Schulz, R., Boerner, K., Shear, K., Zhang, S., & Gitlin, L. N. (2006). Predictors of complicated grief among dementia caregivers: A prospective study of bereavement. *American Journal of Geriatric Psychiatry, 14*(8), 650-658. doi: 10.1097/01.JGP.0000203178.44894.db

Schulz, R., Hebert, R., & Boerner, K. (2008). Bereavement after caregiving. *Geriatrics, 63*(1), 20-22. Retrieved from: http://www.ncbi.nlm.nih.gov/pmc/articles /PMC2790185/?tool=pubmed

Schulz, R., Hebert, R. S., Dew, M. A., Brown, S. L., Scheier, M. F., Beach, S. R., Czaja, S.J., …Nichols, L. (2007). Patient suffering and caregiver compassion: New opportunities for research, practice, and policy. *The Gerontologist, 47*(1), 4-13. doi: 10.1093/geront/47.1.4

Schulz, R., McGinnis, K. A., Zhang, S., Martire, L. M., Hebert, R., Beach, S. R., Zdaniuk, B., …Belle, S.H. (2008). Dementia patient suffering and caregiver depression. *Alzheimer Disease and Associated Disorders, 22*(2), 107-176. doi: 10.1097/WAD.0b013e31816653cc

Schulz, R., Mendelsohn, A. B., Haley, W. E., Mahoney, D., Allen, R. S., Zhang, S., Thompson, L., …Belle, S.H. (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *New England Journal of Medicine, 349*, 1936-1942. doi: 10.1056/NEJMsa035373

Schulz, R., Monin, J. K., Czaja, S. J., Lingler, J. H., Beach, S. R., Martire, L. M., Dodds, A.,…Cook, T.B. (2010). Measuring the experience and perception of suffering. *The Gerontologist*, *50*(6), 774-748. doi: 10.1093/geront/gnq033

Segerstrom, S. C., Stanton, A. L., Alden, L. E., & Shortridge, C. E. (2003). A multidimensional structure for repetitive thought: What's on your mind, and how, and how much? *Journal of Personality and Social Psychology, 85*(5), 909-921. doi: 10.1037/0022-3514.85.5.909

Shear, K. (2012). Grief and mourning gone awry: Pathway and course of complicated grief. *Dialogues in Clinical Neuroscience, 14*(2), 119-128. Retrieved from : http://www.dialogues-cns.com/publication/grief-and-mourning-gone-awry-pathway-and-course-of-complicated-grief/

Shear, K., Frank, E., Houck, P. R., & Reynolds, C. F. (2005). Treatment of complicated grief: A randomized controlled trial. *JAMA, 293*(21), 2601-2608. doi: 10.1001/jama.293.21.2601

Stroebe, M. (1992). Coping with bereavement: A review of the grief work hypothesis. *Omega, 26*(1), 19-42. doi: 10.2190/TB6U-4QQC-HR3M-V9FT

Stroebe, M., Boelen, P. A., van den Hout, M., Stroebe, W., Salemink, E., & van den Bout, J. (2007). Ruminative coping as avoidance: A reinterpretation of its function in adjustment to bereavement. *European Archives of Psychiatry and Clinical Neuroscience, 257*, 462-472. doi: 10.1007/s00406-007-0746-y

Stroebe, M., & Schut, H. (1999). The dual process model of coping with bereavement: Rationale and description. *Death Studies, 23*(3), 197-224. doi: 10.1080/074811899201046

Stroebe, M., & Schut, H. (2010). The dual process model of coping with bereavement: A decade on. *Omega, 61*(4), 273-289. doi: 10.2190/OM.61.4.b

Stroebe, M., Schut, H., & Stroebe, W. (2007). Health outcomes of bereavement. *The Lancet, 370*, 1960-1973. doi: 10.1016/S0140-6736(07)61816-9

Stroebe, M., Stroebe, W., & Schut, H. (2003). Bereavement research: Methodological issues and ethical concerns. *Palliative Medicine, 17*, 235-240. doi: 10.1191/0269216303pm768rr

Teno, J. M. (2005). Measuring end-of-life care outcomes retrospectively. *Journal of Palliative Care, 8*(S1), S42-S49. doi: 10.1089/jpm.2005.8.s-42

Utz, R.L., Caserta, M., & Lund, D. (2012). Grief, depressive symptoms, and physical health among recently bereaved spouses. *The Gerontologist, 52*(4), 460-471. doi: 10.1093/geron/gnr10

Volicer, L. (2004). End-of-life care and bereavement: Effect on family carers. *The Lancet Neurology, 3*(3), 144. doi: 10.1016/S1474-4422(04)00677-5

Wallace, M., & Shelkey, M. (2008). Monitoring functional status in hospitalized older adults. *American Journal of Nursing, 108*(4), 64-71. doi: 10.1097/01.NAJ.0000314811.46029.3d

Worden, J. W. (1991). *Grief counseling and grief therapy: A handbook for the mental health practitioner*. New York: Springer.

Xu, J., Kochanek, K. D., Murphy, S. L., & Tejada-Vera, B. (2010). *Deaths: Final data for 2007*. Hyattsville, MD: National Center for Health Statistics.

Zisook, S., Shucter, S. R., Pedrelli, P., Sable, J., & Deaciuc, S. C. (2001). Bupropion sustained release for bereavement: results of an open trial. *Journal of Clinical Psychiatry, 62*(4), 227-230. doi: 10.4088/JCP.v62n0403

Appendices

Appendix A: Participant Interview Protocol

Participant ID#______________ RA Initials:_______

Caregiver Interview

<u>BEFORE BEGINNING</u>

1. THANK the participant for speaking with you.
2. Ask if they have any questions before you begin.

Date of interview:___________________________ **RA Initials:**_____________

Telephone or in-person?____________________

Date entered into SPSS:______________________ **RA Initials:**_______________

Caregiver Demographics

1. In what year were your born?

☐ ☐ ☐ ☐

2. How old are you now?

☐ ☐

3. What is your sex or gender?

M ☐

F ☐

4. How would you describe your primary racial or ethnic group?

- ☐ White, Caucasian
- ☐ Black, African American
- ☐ Native American, Eskimo, or Aleut
- ☐ Asian or Pacific Islander
- ☐ Hispanic, Latino
- ☐ No primary group or Mixed
- ☐ Other: _______________

5. How many years of education have you completed?

☐ ☐ ☐

6. What is your current living arrangement?

☐ Living alone
☐ Living with a spouse or partner
☐ Living with children
☐ Living with children and a spouse or partner
☐ Living with roommates of no relation
☐ Other: ______________________

7. Do you live in a private home or in a facility?

☐ Home ☐ Facility

⇩

☐ Nursing Home ☐ Assisted Living Facility

☐ Hospital

☐ Other: _________________

8. Which of the following best describes your current employment situation?

☐ Working full time
☐ Working part time
☐ On leave with pay
☐ On leave without pay
☐ Not employed

⇩

☐ Disabled ☐ Retired ☐ Seeking Work ☐ Supported by others

9. How hard is it for you to pay for the very basics like food, housing, medical care, and heating?

☐ Very difficult
☐ Difficult
☐ Not very difficult
☐ Not at all difficult

Caregiving Experience

10. In the month prior to when your spouse was admitted to hospice care, how many **hours per week**, would you say that you provided care to your spouse, on average?

☐☐☐ hours/ week

11. Were there other caregivers who routinely helped you to provide care?

☐ No ☐ Yes

⇩

11a. How many? ☐☐

11b. How many hours per week did they assist you with care?

☐☐☐ hours/ week

12. Did you regularly assist your spouse with any of the following activities?

12a. Bathing	☐ Yes	☐ No
12b. Dressing	☐ Yes	☐ No
12c. Toileting	☐ Yes	☐ No
12d. Transferring	☐ Yes	☐ No
12e. Bowel Continence	☐ Yes	☐ No
12f. Bladder Continence	☐ Yes	☐ No
12g. Feeding	☐ Yes	☐ No

13. For how many months/years were you the primary caregiver (i.e. the main person responsible for decision-making) for your spouse?

Months	**Years**
☐☐	☐☐

Caregiver Health

14. Has a doctor or a nurse told you that you have:

Condition	Yes	No	Comments
Arthritis or rheumatism			
Chronic back or neck problems			
Frequent or severe headaches			
Any other chronic pain			
Seasonal allergies like hay fever			
Stroke within past year			
Heart attach within past year			
Heart Disease			
High blood pressure			
Asthma			
Tuberculosis			
Any other chronic lung disease			e.g. COPD or emphysema
Diabetes or high blood sugar			
An ulcer in your stomach or intestine			
HIV infection or AIDS			
Epilepsy or seizures			
Cancer			Type:
Alzheimer’s disease or dementia			
Mental Health condition			Any medications?
Other:			

SRRS

Negative Inferential Style Subscale

People think and do many different things when they experience stressful events. Please read each of the items below and indicate how frequently you think or do each item in response to the suffering your spouse experienced at the end-of-life. A 100 indicates that you would focus on this to a great extent in response to the your loved ones' suffering. Please indicate what you do, and not what you think you should do.

|______|______|______|______|______|______|______|______|______|______|
0 10 20 30 40 50 60 70 80 90 100
Not focus Focus on Focus on
on this at all this somewhat this to a great
extent

15a. Think about how the stressful event is all your fault.	
15b. Think about how the negative event will negatively affect your future.	
15c. Think about what the occurrence of the event means about you.	
15d. Think that the cause of the event will lead to additional stressful events in your life	
15e. Think about the causes of the stressor.	
15f. Ruminate about how the stressor will affect other areas of your life.	
15g. Think about how important the stressful event is to you.	
15h. Think about how things like this always happen to you.	
15i. Think that the event means that you will be unable to cope with events in the future.	

Rumination on Suffering

Please tell me if you never, sometimes, often, or always think about the following:

16a. Think about physical suffering (such as pain, nausea, constipation, dry mouth, etc…) that your loved one experienced during the last month of life?

Never ***Sometimes*** ***Often*** ***Always***

16b. Think about how much this bothered your loved one?

Never ***Sometimes*** ***Often*** ***Always***

16c. Think about psychological or emotional suffering (e.g. depression, anxiety, being a burden, etc…) experienced during the last month of life?

Never ***Sometimes*** ***Often*** ***Always***

16d. Think about existential or spiritual suffering (e.g. if life had meaning, feeling peaceful, feeling a sense of purpose) experienced during the last month of life?

Never ***Sometimes*** ***Often*** ***Always***

Feelings of Relief

17. To what extent was the care recipient’s death a relief to you?

Not at all ***Somewhat*** ***Very much***

Perceived Experience of Suffering

Part I: Physical Symptoms

18. How often did your spouse experience the following symptom during the last month of life?

Symptom	Not at all	A little (a few days	Quite a bit (most days)	Very often	Refused	Don't know
a. Lack of energy/fatigue	0	1	2	3	-1	-2
b. Lack of appetite	0	1	2	3	-1	-2
c. Pain	0	1	2	3	-1	-2
d. Dry mouth	0	1	2	3	-1	-2
e. Shortness of breath	0	1	2	3	-1	-2
f. Nausea	0	1	2	3	-1	-2
g. Difficulty sleeping	0	1	2	3	-1	-2
h.Constipation/diarrhea	0	1	2	3	-1	-2
i. Confusion/difficulty concentrating	0	1	2	3	-1	-2

19. How much did it bother him/ her?

Symptom	Not at all	A little (a few days	Quite a bit (most days)	Very often	Refused	Don't know
a. Lack of energy/fatigue	0	1	2	3	-1	-2
b. Lack of appetite	0	1	2	3	-1	-2
c. Pain	0	1	2	3	-1	-2
d. Dry mouth	0	1	2	3	-1	-2
e. Shortness of breath	0	1	2	3	-1	-2
f. Nausea	0	1	2	3	-1	-2
g. Difficulty sleeping	0	1	2	3	-1	-2
h.Constipation/diarrhea	0	1	2	3	-1	-2
i. Confusion/difficulty concentrating	0	1	2	3	-1	-2

P*art 2: Psychological Symptoms*

20. How often did (s)he experience the following emotions?

	Not at all	A little (a few days)	Quite a bit (most days)	Very often (everyday)	Refused	Don't Know
a. Afraid	0	1	2	3	-1	-2
b. Confident	3	2	1	0	-1	-2
c. Worried or anxious	0	1	2	3	-1	-2
d. Irritable	0	1	2	3	-1	-2
e. Depressed	0	1	2	3	-1	-2
f. Cheerful	3	2	1	0	-1	-2
g. Hopeless	0	1	2	3	-1	-2
h. Sad, blue	0	1	2	3	-1	-2
i. Burden to others	0	1	2	3	-1	-2
j. Angry	0	1	2	3	-1	-2
k. Lonely	0	1	2	3	-1	-2
l. Embarrassed about themselves	0	1	2	3	-1	-2
m. Guilty	0	1	2	3	-1	-2
n. Abandoned	0	1	2	3	-1	-2
o. Rejected	0	1	2	3	-1	-2

Part 3: Existential Symptoms

21.Statement	Not at all	A little	Somewhat	Quite a bit	Very much	Refused	Don't Know
a. (S)he felt peaceful	4	3	2	1	0	-1	-2
b. (S)he had a reason for living	4	3	2	1	0	-1	-2
c. His/her life had been a failure	0	1	2	3	4	-1	-2
d. (S)he had trouble feeling peace of mind	0	1	2	3	4	-1	-2
e. (S)he felt a sense of purpose in his/her life	4	3	2	1	0	-1	-2
f. (S)he felt a sense of harmony within him/herself	4	3	2	1	0	-1	-2
g. His/her life lacked meaning and purpose	0	1	2	3	4	-1	-2
h. (S)he knew that whatever happened with his/her illness, things would be ok	4	3	2	1	0	-1	-2
i. Life was not worth living anymore	0	1	2	3	4	-1	-2

	Rarely or none of the time	**Some or a little of the time**	**Occasionally or a moderate amount of the time**	**Most or almost all of the time**
CES-D	**< 1 day**	**1-2 days**	**3-4 days**	**5-7 days**
22a. I was bothered by things that usually don't bother me.				
22b. I didn't feel like eating; appetite was poor.				
22c. I felt that I could not shake off the blues, even with help from my family and friends				
22e. I felt that I was just as good as other people.				
22f. I had trouble keeping my mind on what I was doing.				
22g. I felt depressed.				
22h. I felt that everything I did was an effort.				
22i. I felt hopeful about the future.				
22j. I thought my life had been a failure.				
22k. I felt fearful.				
22l. My sleep was restless.				
22m. I was happy.				
22n. I talked less than usual.				
22o. I felt lonely.				
22p. People were unfriendly.				
22q. I enjoyed life.				
22r. I had crying spells.				
22s. I felt sad.				
22t. I felt that people disliked me.				
22u. I could not get going				

12-item Inventory of Complicated Grief-Revised

Please provide the answer that best describes how you have been feeling over the past month. The blanks refer to the deceased person over whom you are grieving.

Almost never = less than once a month
Rarely= once a month or more, less than once a week
Sometimes= once a week or more, less than once a day
Often = once every day
Always= several times every day

23a. I feel myself longing or yearning for my spouse.

Almost Never, Rarely, Sometimes, Often, Always

23b. I have intense feelings of emotional pain, sorrow, or pangs of grief for the death my spouse

Almost Never, Rarely, Sometimes, Often, Always

23c. I go out of my way to avoid reminders of my spouse.

Almost Never, Rarely, Sometimes, Often, Always

23d. I feel stunned, shocked, or dazed over my spouse's death.

Almost Never, **Rarely, Sometimes, Often, Always**

23e. I feel confused about my role in life or a diminished sense of self (i.e., feeling that a part of me died along with my spouse)?

Almost Never, Rarely, Sometimes, Often, Always

23f. I feel that I have trouble accepting the death?

Almost Never, Rarely, Sometimes, Often, Always

23g. Ever since my spouse died, I have difficulty trusting people.

Almost Never, Rarely, Sometimes, Often, Always

23h. I am bitter over my spouse's death.

Almost Never, Rarely, Sometimes, Often, Always

23i. I feel it is hard to concentrate on anything else.

Almost Never, Rarely, Sometimes, Often, Always

23j. I feel like I have become emotionally numb since the death of my spouse.

Almost Never, Rarely, Sometimes, Often, Always

23k. I feel that life is unfulfilling, empty, or meaningless without my spouse.

Almost Never, Rarely, Sometimes, Often, Always

23l. I believe that my grief has resulted in a significant reduction in my social, occupational or other areas (e.g., domestic responsibilities)?

Almost Never, Rarely, Sometimes, Often, Always

TRIG PRESENT FEELINGS INDEX	Completely False	Mostly False	True and False	Mostly True	Completely True
24a. I still cry when I think of the person who died	0	1	2	3	4
24b. I still get upset when I think about the person who died.	0	1	2	3	4
24c. I cannot accept this person's death.	0	1	2	3	4
24d. Sometimes I very much miss the person who died.	0	1	2	3	4
24e. Even now it's painful to recall memories of the person who died.	0	1	2	3	4
24f. I am preoccupoied with thoughts (often think) about the person who died.	0	1	2	3	4
24g. I hide my tears when I think about the person who died.	0	1	2	3	4
24i. No one will ever take the plance in my life of the person who died.	0	1	2	3	4
24j. I can't avoid thinking about the person who died.	0	1	2	3	4
24k. I feel that it's unfair that this person died.	0	1	2	3	4
24l. Things and people around me still remind me of the person who died.	0	1	2	3	4
24m. I am unable to accept the death of the person who died.	0	1	2	3	4
24n. At times I still feel the need to cry for the person who died.	0	1	2	3	4

BEFORE ENDING/LEAVING:

1. THANK the participant
2. Make sure that you did not accidently miss/skip any pages
3. Ask the participant if they are aware of hospice bereavement services and/or if they would like for someone from bereavement to contact them. If they would like to be contacted by bereavement, please fill out the bereavement referral form.
4. Remind the participant about the $50.00 raffle.
5. Document any final comments/requests:

____

____

____

____

____

____

____

____

6. **THANK the participant AGAIN!!!!!**

Appendix B: Patient Retrospective Chart Review

Patient Demographics

25a. What was the patient’s age at time of hospice admission?

☐☐

25b. At time of death?

☐☐

26. What was the patient’s gender?

☐ Male ☐ Female

27. Which of the following describes the patient’s primary racial or ethnic group?

- ☐ White, Caucasian
- ☐ Black, African American
- ☐ Native American, Eskimo, or Aleut
- ☐ Asian or Pacific Islander
- ☐ Hispanic, Latino
- ☐ No primary group or Mixed
- ☐ Other: _______________

28. How many years of education did the patient complete?

☐☐☐

29. In number of days from the most recent admission prior to death, how long was the patient enrolled in hospice care?

☐☐☐

Patient Health

Palliative Performance Scale (PPS)

30. What was the patient’s PPS score at hospice admission?

%	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
100	Full	Normal Activity No Evidence of Disease	Full	Normal	Full
90	Full	Normal Activity Some Evidence of Disease	Full	Normal	Full
80	Full	Normal Activity with Effort Some Evidence of Disease	Full	Normal or Reduced	Full
70	Reduced	Unable Normal Job / Work Some Evidence of Disease	Full	Normal or Reduced	Full
60	Reduced	Unable Hobby / House Work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
50	Mainly Sit/Lie	Unable to Do Any Work Extensive Disease	Considerable Assistance Necessary	Normal or Reduced	Full or Confusion
40	Mainly in Bed	As Above	Mainly Assistance	Norma or Reduced	Full or Drowsy or Confusion
30	Totally Bed Bound	As Above	Total Care	Reduced	Full or Drowsy or Confusion
20	As Above	As Above	Total Care	Minimal Sips	Full or Drowsy or Confusion
10	As Above	As Above	Total Care	Mouth Care Only	Drowsy or Coma
0	Death	-	-	-	-

31. At hospice admission, was the patient independent in the following symptoms?

a. Bathing	☐ Yes	☐ No
b. Dressing	☐ Yes	☐ No
c. Toileting	☐ Yes	☐ No
d. Transferring	☐ Yes	☐ No
e. Bowel Continence	☐ Yes	☐ No
f. Bladder Continence	☐ Yes	☐ No
g. Feeding	☐ Yes	☐ No

32. At time of hospice admission, what was/were the patient's primary diagnoses?

☐☐☐.☐☐☐ ICD-9 Code

☐☐☐.☐☐☐ ICD-9 Code