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The Relationship between Caregiving and Bereavement: A Series of Three Studies

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The Relationship between Caregiving and Bereavement: A Series of Three Studies

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Aging Studies
College of Arts and Sciences
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Dedication

This dissertation is dedicated to my Granny, Dorothy B. Glover, without whom I could

never have gotten to this point in my life. You have been so many things to me: an

inspiration, a pillar of support (in countless ways), a role model, and a friend (just to

name a few). I have always felt like one of the luckiest women in the world to have you

on my side and cannot thank you enough for all of your love and support. You are an

ever-present guiding spirit in my life. I have always believed that I was more like you

than anyone else I have ever known, and that idea has helped me to be proud of who I

am, to stand up for what I believe in, and to cherish my independence. There were

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priorities were misplaced, and you were always there exactly when I needed you to put

things into perspective and to keep me on the right path. Thank you for always being

there for me and for contributing to my life in countless ways. I love you more than I

could ever express in words and I sincerely hope that you are proud of the woman I have

become because so much of who I am has been shaped by you.

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The Relationship between Caregiving and Bereavement: A Series of Three Studies

Allison M. Burton

ABSTRACT

Spousal bereavement has been consistently demonstrated in the literature to be one of the most highly stressful experiences in an individual's lifetime. In addition many deaths in the United States are preceded by a period of caregiving, which is also believed to be highly stressful and have a profound impact on bereavement. However the literature has been inconsistent as to the exact nature of the relationship between caregiving and bereavement and there has been some debate as to whether or not positive and negative affect variables are mutually exclusive.

This dissertation sought to further address the issue of the relationship between caregiving and the bereavement experience through a series of three studies which utilized information from two datasets. The first was the Changing Lives of Older Couples (CLOC) study, a project that included both pre- and post-loss data. The second was a subset of a dataset that recruited elderly spousal caregivers of terminally ill patients from a large, local non-profit hospice. This dataset included both pre- and post-loss data and included a variety of widely used and validated measures that allowed for the examination of caregiving stressors, appraisals, and social support and their effect on both positive and negative mental health outcomes during bereavement.

The first study examined the impact of caregiving on well-being during bereavement, specifically within the domains of psychological, social, and physical health, utilizing both positive and negative affect measures. The second addressed how varying levels of caregiving experience were related to previously established bereavement trajectories (Boerner, Wortman, & Bonanno, 2005; Bonanno, Wortman, Lehman, Tweed, Haring, et al., 2002), and the last one examined the mechanisms by which caregiving had an effect on bereavement outcomes, specifically focusing on stressors, appraisals, and social support.

This dissertation consists of five chapters. Chapter 1 is an introduction to the caregiving and bereavement literature, Chapters 2-4 describe the series of three studies conducted, and Chapter 5 discusses the overall conclusions as well as future directions for research.

Preface

I want to thank the following people, without whom this dissertation and my professional growth during my years in the Ph.D. in Aging Studies program would not have been possible:

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My Family: Being so far away from you all of the time is harder than I have ever really expressed. I regret missing so many of the family moments over the years, but hope that all of you understand why I have chosen this path in life. I love all of you very much and know beyond a shadow of a doubt that there is no way I could be where I am today without having received so much love, support, and guidance from all of you. I cannot possible acknowledge everyone individually, so please don't take it personally if you are not mentioned by name.

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Chapter One

Overview

Introduction

The loss of spouse is one of the most stressful events that an individual may
encounter over the course of his or her lifetime (Stroebe & Stroebe, 1987). Spousal
bereavement has been demonstrated in previous research to have a profound effect on an
individual's well-being, including increased incidence of depression, decreased life
satisfaction and social activities, and physical health decrements (i.e., Bonanno, Notarius,
Gunzerath, Keltner, & Horowitz, 1998; Carr, House, Wortman, Nesse, & Kessler, 2001;
Davis & Nolen-Hoeksema, 2001; Folkman, 2001; Schulz & Beach, 1999; Stroebe,
Stroebe, Abakoumkin, & Schut, 1996). Little is known about how family caregiving
experiences affect the course of bereavement, although it has been well established that
certain types of deaths, such as suicide or homicide, are particularly stressful and that
unexpected death may be particularly difficult for survivors (Carr et al., 2001).

Extensive and stressful periods of informal caregiving often precede spousal
bereavement for older adults who die after a chronic illness (Aneshensel, Pearlin, Mullan,
Zarit, & Whitlatch, 1995; Minino & Smith, 2001). Caregiving experiences often place
family caregivers, particularly spouses, at risk for a variety of mental and physical health

decrements; some of these documented effects include increased incidence of depression, increased time for wound healing, and increased chance of mortality (i.e., Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1996; Pinquart & Sorensen, 2003; Schulz & Beach, 1999; Schulz, O'Brien, Bookwala, & Fleissner, 1995).

A review article that systematically and comprehensively examined the literature on the effects of bereavement after family caregiving came to the conclusion that caregiving researchers often do not carry out their research long enough after the death of the care recipient to get a clear picture of the role this experience plays in shaping the bereavement experience. In addition many bereavement researchers to date have not obtained enough information about pre-death circumstances to fill in this gap either (Schulz, Newsom, Fleissner, Decamp, & Nieboer, 1997). This review (Schulz et al., 1997) notes that two opposing hypotheses have shaped the research on caregiving and bereavement, the first that the reduction in caregiving burden following the loss of a spouse results in improvements in mental and physical health outcomes, and the second that a depletion of resources results from prolonged exposure to caregiving stressors leaving the surviving spouse more vulnerable to negative outcomes during widowhood. This review paper also identified a variety of methodological weaknesses in prior caregiving and bereavement research. These methodological weaknesses included cross-sectional design, inappropriate comparison groups, small sample sizes, no control group, inconsistency in outcomes measures, and a focus on very specific subsets of the caregiving population (i.e., Bass & Bowman, 1990; Bodnar & Kiecolt-Glaser, 1994; Cleiren, van der Wal, & Deikstra, 1988; George & Gwyther, 1994; McHorney & Mor, 1988; Mullan, 1992; O'Bryant, 1991; Skaff, Pearlin, & Mullan, 1996). In addition

studies addressing this issue which were published subsequent to the Schulz et al. (1997) review paper also possess some of the same methodological issues (Park & Folkman, 1997; Robinson-Whelen, Tada, MacCallum, McGuire, & Kiecolt-Glaser, 2001).

Bereavement researchers who have attempted to examine death context variables have largely utilized two categories: expected and unexpected deaths (i.e., Carr et al., 2001; Hill, Thompson, & Gallagher, 1988; Lundin, 1984; Reed, 1998). Overall results from these studies indicate that individuals who experience the loss of a loved one due to an unexpected death are more likely to experience higher levels of depression and an increased difficulty in adjusting to the death of a loved one than their counterparts. This categorization ignores the great variability among individuals who are included in the expected death group, ranging from no personal experience with providing care to highly stressful, full-time caregiving. In order to address the variability in caregiving, researchers have used a variety of classification methods, specifically breaking down groups using disease type, duration, severity of impairment, extent of caregiving, or level of perceived stressfulness.   A prospective, population-based sample was used in a recent study to examine changes in self-reported and objective mental and physical health outcomes after bereavement among elderly individuals who were involved in varying levels in the caregiving experience (Schulz, Beach, Lind, Martire, Zdaniuk, et al., 2001). This study used three groups, non-caregivers, caregivers reporting no strain, and caregivers reporting strain, to examine changes in depression, antidepressant medication use, health risk behaviors, and weight among for individuals who had been bereaved for varying lengths of time. This study found that depression scores remained high for the strained caregiving group from pre-loss to post-loss; however they increased for the other

two groups. In addition while the non-caregiver and low strain caregiver groups experienced little change in health risk behaviors during the study period, the strained caregiver group experienced significant improvements in this domain following the deaths of their spouses. The researchers came to the overall conclusion that variations in the caregiving experience play a significant role in determining the mental and physical health outcomes of bereaved spouses.

The previous study by Schulz and his colleagues (2001) addressed an important area of the caregiving and bereavement literature that merits further attention: improvement. More specifically, the idea that improvement may occur in certain areas of well-being following the loss of a spouse for highly stressed caregivers. As previously noted, the researchers of this study found that, when compared with behavior while caregiving, individuals demonstrated significant improvements in health risk behaviors following the death. Consistent with these results, declines in depressive symptomatology by three-months post-loss were found in a recent study of dementia caregivers, and by one year post-loss these individuals reached levels lower than those reported while actively caregiving (Schulz, Mendelsohn, Haley, Mahoney, Allen, et al., 2003). In addition, Schulz et al. (2003) reported that 72% of these bereaved dementia caregivers considered the death of their relative to be at least somewhat of a relief.

The current series of studies is designed to further address the issue of the relationship between caregiving and the bereavement experience by using information from two datasets. The first is the Changing Lives of Older Couples (CLOC) study, a project that includes both pre- and post-loss data. The comprehensive nature of the CLOC dataset allows for the examination of a wide variety of variables, including but not

limited to caregiving characteristics, personality traits, bereavement trajectories, social interaction, depression, sociodemographics, self-rated physical health, and positive well-being, and their relationship to involvement in the caregiving experience. The second is a subset of a dataset that recruited elderly spousal caregivers of terminally ill patients from a large, local non-profit hospice. This dataset includes both pre- and post-loss data and includes a variety of widely used and validated measures that allow for the examination of caregiving stressors, appraisals, and social support and their effect on both positive and negative mental health outcomes during bereavement.

The first study examines the impact of caregiving on well-being during bereavement, specifically within the domains of psychological, social, and physical health, utilizing both positive and negative affect measures. The second in this series of three studies addresses how varying levels of caregiving experience are related to previously established bereavement trajectories (Boerner, Wortman, & Bonanno, 2005; Bonanno, Wortman, Lehman, Tweed, Haring, et al., 2002), and the last one examines the mechanisms by which caregiving has an effect on bereavement outcomes, specifically focusing on stressors, appraisals, and social support.

Chapter Two

Bereavement after caregiving or unexpected death: Effects on elderly spouses

Abstract

Responses to bereavement have been shown to vary depending on whether death is expected or unexpected, and on the nature of family caregiving experiences, but no previous research has examined these factors simultaneously. To address these issues, we utilized prospective data on bereavement from 193 participants in the Changing Lives of Older Couples (CLOC) study, who were assessed both before their loss and at 6 and 18 months after the death. Participants who experienced either unexpected loss, or expected loss without caregiving, with low-stress caregiving, or with high-stress caregiving completed measures of psychological, social, and health functioning on each occasion. Using mixed model analyses, the results showed that unexpected death was associated with marked increases in depression, while the nature of caregiving did not affect the trajectory of any of the psychological well-being measures. All groups except highly stressed caregivers showed improvements in social activity and support after bereavement, suggesting that highly stressed caregivers may be at an increased risk for social isolation during bereavement. Thus experiencing an unexpected death may put

bereaved spouses at risk for depression, while high stress caregiving may lead to problems with social isolation.

Introduction

One of the most stressful events that an individual may encounter over the course of his or her lifetime is the death of a spouse (Stroebe & Stroebe, 1987). Previous research has demonstrated that spousal bereavement has a profound effect on an individual's well-being, including increased incidence of depression, decreased life satisfaction and social activities, and physical health decrements (i.e., Bonanno, Notarius, Gunzerath, Keltner, & Horowitz, 1998; Carr, House, Wortman, Nesse, & Kessler, 2001; Davis & Nolen-Hoeksema, 2001; Folkman, 2001; Schulz & Beach, 1999; Stroebe, Stroebe, Abakoumkin, & Schut, 1996). While it has been well established that certain types of deaths, such as suicide or homicide, are particularly stressful and unexpected death may be particularly difficult for survivors (Carr et al., 2001), little is known about how family caregiving experiences affect the course of bereavement.

Spousal bereavement frequently follows extensive and stressful periods of informal caregiving for older adults who die after chronic illness (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Minino & Smith, 2001). Family caregivers, particularly spouses, are at risk for a variety of mental and physical health decrements as a result of their caregiving experience; some of these documented effects include increased incidence of depression, decreased immune system response, and increased chance of

mortality (i.e., Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser,1996; Pinquart & Sorensen, 2003; Schulz & Beach, 1999; Schulz, O'Brien, Bookwala, & Fleissner, 1995).

A review article that systematically and comprehensively examined the literature on the effects of bereavement after family caregiving concluded that caregiving researchers often do not continue their research long enough after the death to get a clear picture of the role this experience plays in shaping the bereavement experience; in addition many bereavement researchers to date have not obtained enough information about pre-death circumstances to fill in this gap (Schulz, Newsom, Fleissner, Decamp, & Nieboer, 1997). This review (Schulz et al., 1997) notes that research on caregiving and bereavement has been based on two opposing hypotheses, the first that a depletion of resources results from prolonged exposure to caregiving stressors leaving the surviving spouse more vulnerable to negative outcomes during widowhood, and the second that the reduction in caregiving burden following the loss of a spouse results in improvements in mental and physical health outcomes. This review paper also identified methodological weaknesses in prior caregiving and bereavement research including cross-sectional design, inappropriate comparison groups, small sample sizes, no control group, inconsistency in outcomes measures, and a focus on very specific subsets of the caregiving population (i.e., Bass & Bowman, 1990; Bodnar & Kiecolt-Glaser, 1994; Cleiren, van der Wal, & Deikstra, 1988; George & Gwyther, 1994; McHorney & Mor, 1988; Mullan, 1992; O'Bryant, 1991; Skaff, Pearlin, & Mullan, 1996). In addition studies addressing this issue which were published subsequent to the Schulz et al. (1997) review paper also possess some of the same methodological issues (Park & Folkman, 1997; Robinson-Whelen, Tada, MacCallum, McGuire, & Kiecolt-Glaser, 2001).

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Bereavement researchers who have attempted to examine death context variables have largely limited these to two categories: expected and unexpected deaths (i.e., Carr et al., 2001; Hill, Thompson, & Gallagher, 1988; Lundin, 1984; Reed, 1998). Taken together, results from these studies indicate that individuals who experience an unexpected death are more likely to experience higher levels of depression and an increased difficulty in adjusting to the death of a loved one than their counterparts. This distinction ignores the great variability among individuals who are categorized into the expected death group, ranging from no personal experience with providing care to highly stressful, full-time caregiving. Caregiving researchers have addressed variability in caregiving in many ways, specifically by breaking down groups using disease type, duration, severity of impairment, extent of caregiving, or level of perceived stressfulness. One recent study utilized a prospective, population-based sample in order to examine changes in self-reported and objective mental and physical health outcomes after bereavement among elderly individuals who were involved in varying levels in the caregiving experience (Schulz, Beach, Lind, Martire, Zdaniuk, et al., 2001). This study examined changes in depression, antidepressant medication use, health risk behaviors, and weight among three groups: noncaregivers, caregivers reporting no strain, and caregivers reporting strain for individuals who had been bereaved for varying lengths of time. The findings from this study indicated that depression scores remained high for the strained caregiving group throughout the study; however they increased for the other two groups. In addition the strained caregiver group experienced significant improvements in health risk behaviors following the death of their spouses, whereas the other two groups experienced little change during the study period. Overall the researchers concluded that

the variations in the caregiving experience play a significant role in determining the mental and physical health outcomes of bereaved spouses.

The previous Schulz et al. (2001) study addressed an additional area of the caregiving and bereavement literature that merits further attention: that improvement may occur in certain areas of well-being following the loss of a spouse for highly stressed caregivers. As previously noted, in this study the researchers found significant improvements in health risk behaviors during bereavement when compared with behavior while caregiving. Consistent with these results, another recent study found that dementia caregivers showed declines in depressive symptomology by three-months post-loss and by one year post-loss they reached levels lower than those reported while actively caregiving (Schulz, Mendelsohn, Haley, Mahoney, Allen, et al., 2003). Schulz et al. (2003) also reported that among these bereaved dementia caregivers, 72% considered the death of their relative to be at least somewhat of a relief.

The current study is designed to further address the issue of the relationship between caregiving and the bereavement experience by using information from the Changing Lives of Older Couples (CLOC) study, a project that includes both pre- and post-loss data. This project will go beyond the examination in previous CLOC analyses (Carr et al., 2001) of expected versus unexpected deaths and utilize four groups: unexpected death, expected death with no caregiving, expected death with low levels of stress associated with the caregiving experience, and expected death with high levels of stress associated with the caregiving experience. The comprehensive nature of the CLOC dataset allows for the examination of a wide variety of variables, including but not limited to social interaction, depression, sociodemographics, self-rated physical health,

and positive well-being, and their relationship to involvement in the caregiving experience. For the current study, this dataset has sufficient sample size and variability to allow for the examination of the impact of caregiving on well-being during bereavement, specifically within the domains of psychological, social, and physical health. In addition this dataset allows for the examination of positive and negative affect measures as separate constructs and they will be analyzed as such. There is some debate in the literature at this time as to whether or not positive and negative affect variables are mutually exclusive and the current study examines this idea within the context of bereavement (Larsen, McGraw, & Cacioppo, 2001; Reich, Zautra, & Davis, 2003; Russell & Carroll, 1999); in addition there are a handful of studies to date that have examined this concept in the caregiving literature, but the findings are not clear (Chappell & Reid, 2002; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991).

Despite the important recent findings in this area, there are several important gaps in the literature on caregiving and bereavement. While a number of studies have contrasted either expected versus unexpected deaths, or low or high stress caregiving, no study to date has included all relevant groups: unexpected death, expected death without caregiving, expected death with low-stress caregiving, and expected death with high-stress caregiving. In addition, studies in this area to date have examined a limited range of potential outcome variables, primarily focusing on depression and physical health. It is particularly important to include not only measures of negative affect, such as depression, but also measures of positive affect and social engagement.

Based on the prior literature, we hypothesized that highly stressed caregivers would show improvements in well-being at the eighteen-month follow-up, particularly

within the domain of negative psychological affect. We also predicted that spouses experiencing unexpected deaths would significantly increase in depression scores at both post-loss time points, while both no caregiving and low stress caregiving groups would show either stability or temporary worsening at the short-term follow-up. For the measures within social engagement, we predicted that highly stressed caregivers would show the lowest levels of social interaction and satisfaction with support when compared with the other three groups, due to previous findings showing that caregiving is associated with decreased social support and engagement (Robinson-Whelen et al., 2001). In addition we expected to see the highest decrements within the domain of physical health, particularly self-rated health, to be for the unexpected death group and the highly stressed caregivers.

Methods

Participants

The current study utilized the data obtained from bereaved individuals who participated in the Changing Lives of Older Couples (CLOC) study, a prospective study of a two-stage area probability sample of 1532 married men and women from the Detroit Standardized Metropolitan Statistical Area. In order to be eligible for the study, individuals had to meet the following criteria: English-speaking, married, residing in a household in which the husband was at least 65 years of age, non-institutionalized, and able to participate in a two hour face-to-face initial interview (University of Michigan,

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n.d.). In addition, the researchers who designed the study oversampled women in order to obtain the highest number of bereaved spouses possible during the study period. Baseline interviews for the CLOC study were conducted between June 1987 and April 1988, and approximately 68% of individuals contacted participated in the initial interview, a response rate that is consistent with other studied conducted in the Detroit area (see the University of Michigan CLOC website for additional details).

Researchers utilized the daily obituaries in the Detroit-area newspapers and monthly death record tapes provided by the state of Michigan in order to identify the initial participants who had experienced the loss of a spouse. The National Death Index (NDI) was used to confirm the deaths and to obtain the causes of death. Of the initial sample, 316 individuals lost their spouse during the study period and were asked to participate in a follow-up interview six months after the loss of their spouse. The final sample for the current study was 193 (61% of the original dataset) with the primary reasons for non-participation being ill health or death and refusal.

The mean age of this sample was 69.48 (s.d.=6.90) at the baseline interview and 88.08% (n=170) were female. In addition, 160 participants identified themselves as Caucasian American (84.22%) and 30 as African American (15.78%) and had on average 11.48 years of education. The four groups did not differ significantly on any of these demographic characteristics, as shown in Table 1. For the purposes of this study, the two cases that reported death as a result of murder, suicide, or homicide have been excluded because of the unique attributes associated with a loss of this nature (Sheskin & Wallace, 1976).

A number of papers have been published utilizing the CLOC dataset (Bonanno, Wortman, Lehman, Tweed, Haring, et al., 2002; Carr, House, Kessler, Nesse, Sonnega, et al., 2000; Carr et al., 2001); however to date we have not able to identify any that examined caregiving characteristics and how they affect the bereavement experience.

Table 1. Demographic Characteristics of the Sample by Caregiving Status

	Unexpected Death	No Caregiving	Low Stress Caregiving	High Stress Caregiving
N	37	65	43	48
Age, mean years (SD)	70.14 (5.79)	70.49 (6.94)	69.74 (5.72)	67.58 (8.39)
% Female	89.20	87.70	83.70	89.60
% White	70.30	90.80	83.70	83.30
Education, mean years (SD)	11.43 (3.03)	11.28 (2.46)	11.40 (2.74)	11.73 (2.44)
Marital Quality, z-score (SD)	-.26 (1.21)	-.34 (1.33)	.02 (0.93)	-.17 (0.91)

Measures

Pre-loss Caregiving Status

The four groups for this study were chosen based upon their response to three questions: the first asking whether the spouse died of either an ongoing serious

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condition, an accident, murder, or suicide, or an unspecified cause indicated as not being an ongoing serious condition, the second asking those whose spouses died of a serious ongoing condition whether or not they provided care for their spouse 6 months prior to death, and the third asking individuals who reported providing care for their spouses how stressful they found the experience to be. For the question regarding stressfulness of the caregiving experience, participants were asked to provide a response based upon a 5-point Likert-type scale with responses ranging very stressful to not at all stressful. Individuals who responded to this question as either very stressful or quite stressful were included in the high stress group and individuals who responded as somewhat stressful, not too stressful, or not at all stressful are included in the low stress group. Participants were divided into the following four categories: individuals whose spouses died unexpectedly (n=37), individuals whose spouses died from a serious ongoing medical condition but did not provide care six months prior to the death (n=65), individuals whose spouses died from a serious ongoing medical condition who did provide care six months prior to the death and reported low levels of stress associated with the caregiving experience (n=43), and individuals whose spouses died from a serious ongoing medical condition who did provide care six months prior to the death and reported high levels of stress associated with the caregiving experience (n=48).

Demographics and Marital Quality

Demographic and descriptive variables, specifically age, gender, race/ethnicity, education, and number of hours per week spent in the caregiving role, were assessed by self-report. Marital quality (alpha=.85) was determined based upon a 4 item composite

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score with higher scores being associated with more positive ratings of the marriage. These four questions were asked during the initial interview and included the following items: 1) How much does your spouse make you feel loved and cared for, 2) How much is your spouse willing to listen when you need to talk about your worries or problems, 3) Thinking about your marriage as a whole, how often do you feel happy about it, and 4) Taking all things together, how satisfied are you with your marriage.

Well-Being Measures

Psychological

Overall psychological well-being was measured using five items from the Bradburn Affect Balance Scale (ABS; Bradburn, 1969) (alpha=.79). Participants responded using a 5-point Likert-type scale ranging from strongly disagree to strongly agree to five questions: 1) I was particularly excited or interested in something, 2) I was pleased about having accomplished something 3) I felt that things were going my way, 4) I felt proud because someone complimented me on something I had done, and 5) I felt on top of the world. This variable (as well as all of the other indices within the CLOC dataset) was converted into z-scores with a mean of 0 and a standard deviation of 1, with higher scores indicating higher levels of overall psychological well-being.

Depression was measured using an eleven item subscale of the Center for Epidemiological Studies-Depression (CES-D; Kohout, Berkman, Evans, & Cornoni-Huntley, 1993; Radloff, 1977) (alpha=.78) coded using a 5-point Likert-type scale with responses ranging from strongly disagree to strongly agree; as with the full CES-D,

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higher values on this scale indicate higher levels of depressive symptomology. The CES-D 11-item scale has been used in other studies, most notably in the Health and Retirement Study (HRS) and the Assets and Health Dynamics of the Oldest-Old (AHEAD) study (HRS/AHEAD Documentation Report, 2000).

Self-esteem was a composite of five items within the dataset (alpha=.72). These items included: 1) On the whole I am satisfied with myself, 2) At times I think I am no good at all, 3) I wish I could have more respect for myself, 4) All in all I feel that I am inclined to be a failure, and 5) All in all, I feel that I am a person of worth, at least equal with others. All of these items utilized a 5-point Likert-type scale with ratings ranging from strongly disagree to strongly agree, with higher numbers indicating higher levels of self-esteem.

Social Engagement

Frequent contact with children and grandchildren (alpha=.70) was a summation of two questions within the dataset that utilized a 5-point Likert-type scale with higher scores indicating more frequent contact. These two items were: 1) In the past 12 months, how often did you have contact with at least one of your children who does not live with you either in person, by phone, or by mail, and 2) How often do you see your grandchildren.

Positive support from all sources (alpha=.66) was a composite variable that included four items with higher scores indicating higher levels of positive support and were rated using a 5-point Likert-type scale. Two questions were asked for two groups of

people: children and friends and relatives. The two questions were: 1) How much do

your _____ make you feel loved and cared for, and 2) How much is he or she willing to

listen to you when you need to talk about your worries or problems.

Physical Health

Satisfaction with good health (alpha=.84) was a combination of three items that

utilized a 5-point Likert-type scale with higher scores indicating higher levels of

satisfaction. The items included in this variable were: 1) In general how satisfied are

you with your health, 2) How would you rate your health at the present time, and 3) How

much are your daily activities limited in any way by your health or health-related

problems.

Difficulty with activities (alpha=.78) utilized four items rated on a 5-point Likert-

type scale with higher numbers indicating a higher degree of difficulty with daily

activities. The questions were: 1) How much difficulty do you have bathing yourself, 2)

How much difficulty do you have climbing a few flights of stairs because of your health,

3) How much difficulty do you have walking several blocks because of your health, and

4) How much trouble would you have doing heavy work around the house such as

shoveling snow or washing walls because of your health.

Statistical Analysis Plan

First measures including race/ethnicity, gender, age, education, and marital

quality were examined in order to determine if any of these differed in our four groups of

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interest. In addition number of hours per week in the caregiving role was examined for the high and low stress caregiver groups in order to determine whether or not there were quantitative differences in their caregiving experiences. In addition to describing the sample and the groups, these analyses allowed us determine if it was necessary to include any covariates in the analyses.

In order to further examine the relationship between caregiving status and the domains of well-being, mixed model designs were used for all seven of our outcome variables. The procedures used for these analyses are detailed in Singer and Willett (2003). Specifically, three random effects models were run for each of our outcome measures. Model one was an unconditional means model. This model examined whether a change or time component needed to be incorporated into the model. Model two was an unconditional growth model that specified changes in each of the outcome variables as a function of linear terms (pre-loss, 6 months post-loss, and 18 months post-loss). This model examined whether a group component needed to be incorporated into the model. Model three was a growth model that examined the effects of group status (unexpected loss, expected loss with no caregiving, expected loss with low stress caregiving, expected loss with high stress caregiving) on each of the outcome variables. This model examined whether an interaction component needed to be incorporated into the model. If a significant interaction was present, separate models were run for each of the groups, examining change over time, to determine the nature of longitudinal changes across the groups.

Results

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Basic Descriptive Analyses

The initial set of analyses determined that there were no significant differences (p>.05) between the four groups of interest on any of the demographic characteristics, specifically age, gender, race/ethnicity, and education, or marital quality (Table 1). The analyses did not include any of the demographic characteristics or marital quality in subsequent analyses as covariates.

In order to gain a better understanding of the differences between the high stress caregiver group and low stress caregiver group, we looked at the mean number of hours per week in the caregiving role these individuals reported during the six months prior to their spouses' deaths. The low stress caregiver group indicated that they spent an average of 55.19 hours per week and the high stress caregiver group indicated that they spent an average of 70.48 hours per week on caregiving-related tasks (t=-2.02, df=85, p=.048). These findings illustrate that both of the caregiving groups dedicated significant amounts of time to the caregiving tasks, but that there were quantitative differences in their caregiving experience.

Mixed Model Analyses

Psychological

Mixed model analyses revealed no significant (p>.05) time, group, or group by time interaction effects for either of the positive affect variables, overall psychological well-being and self-esteem.

For depression we found both a significant time effect and a significant group by time interaction. Table 2 (see page 24) displays the parameters of the random effects models for depression scores as a function of time and caregiving status. In addition Figure 1 (see page 21) shows that depression increased significantly over time for the unexpected death group (estimate=.146, s.e.=.042, p=.001) and remained stable for the high stress (estimate=-.043, s.e.=.035, p=.234), low stress (estimate=.032, s.e.=.041, p=.441), and non-caregiving groups (estimate=-.016, s.e.=.031, p=.620).

Figure 1. Depression change as a function of Time and Caregiving Status
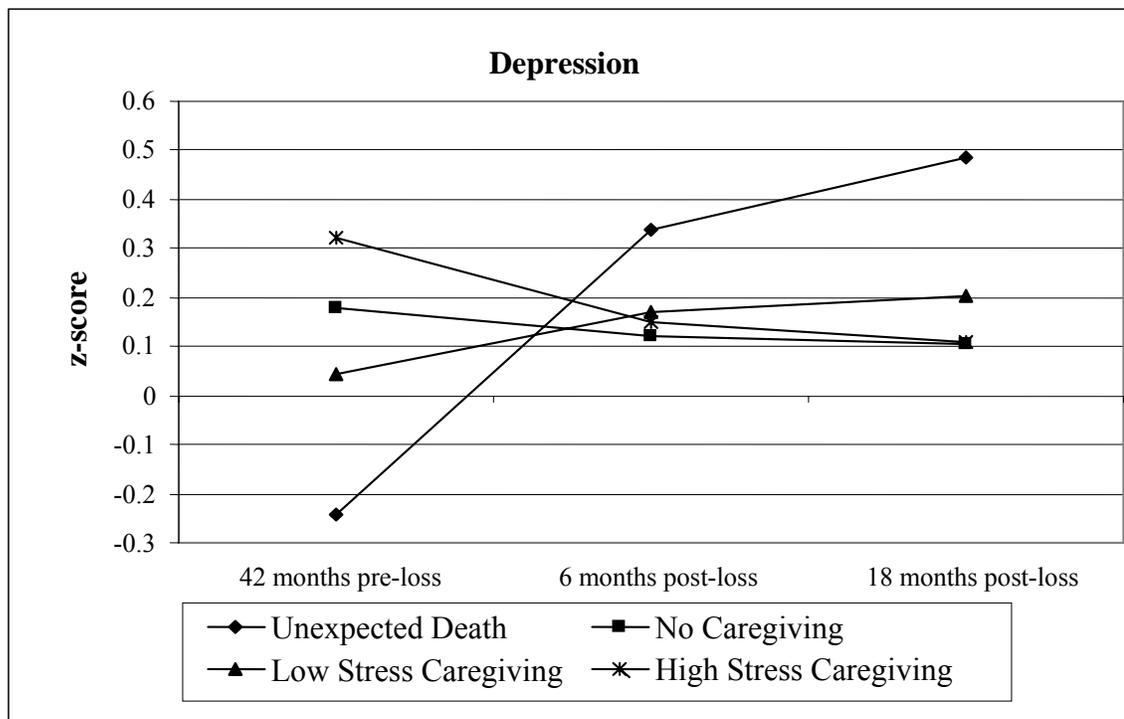
Social Engagement

As shown in Table 2 (see page 24), for frequent contact with children and grandchildren we found a significant time effect and a significant group by time

interaction. As shown in Figure 2 (see page 22), the unexpected death (estimate=.127, s.e.=.045, p=.007) and no caregiving (estimate=.089, s.e.=.024, p<.001) groups showed significant improvements in their frequency of contact with children and grandchildren over time, while the low stress caregiver group showed a trend towards this pattern (estimate=.046, s.e.=.024, p=.069); however the high stress caregiver group (estimate=.039, s.e.=.036, p=.282) remained relatively stable on this measure at both the 6-month and 18-month follow-up points.

Figure 2. Frequent Contact with Children and Grandchildren change as a function of
     Time and Caregiving Status
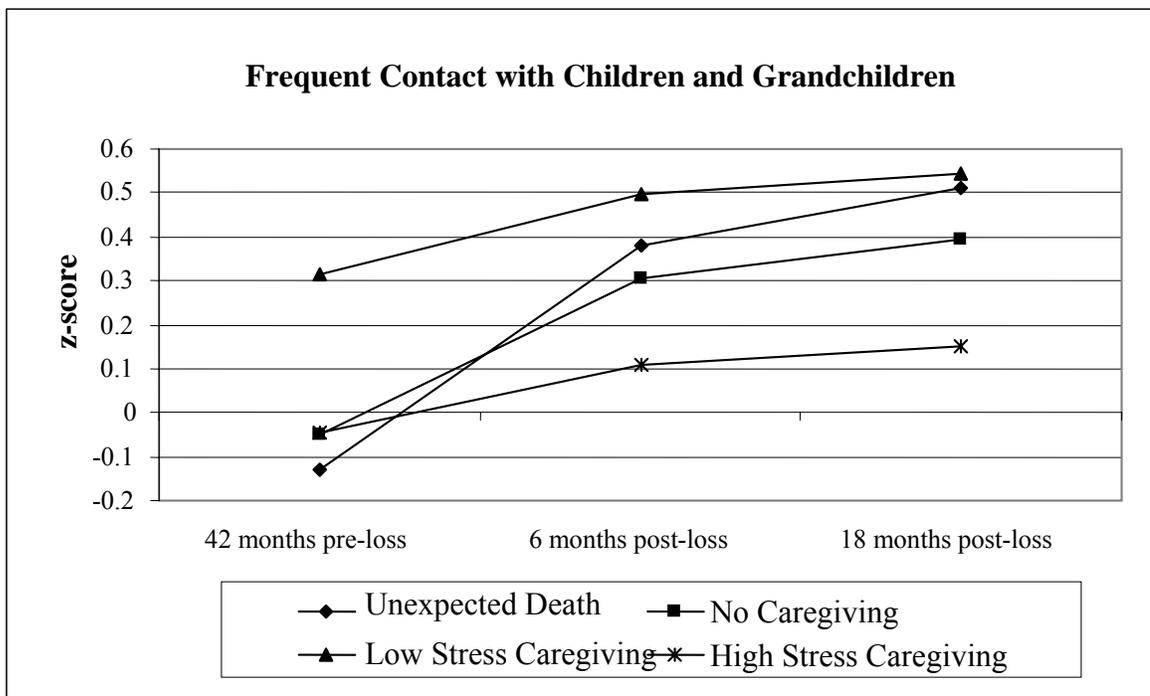
Positive support from all sources demonstrated a significant time effect and a trend (p=.070) toward a significant group by time interaction according to the mixed model analyses, as shown in Table 2. In addition, Figure 3 (see page 23) shows that the

unexpected death (estimate=.103, s.e.=.028, p=.001), no caregiving (estimate=.088, s.e.=.023, p<.001), and low stress caregiving (estimate=.096, s.e.=.032, p=.005) groups showed significant improvements in their perceptions of positive support at both the 6-month and 18-month follow-up points; however the high stress caregiver (estimate=.023, s.e.=.027, p=.408) group remained relatively stable over time.

Figure 3. Positive Support from All Sources change as a function of Time and Caregiving
Status
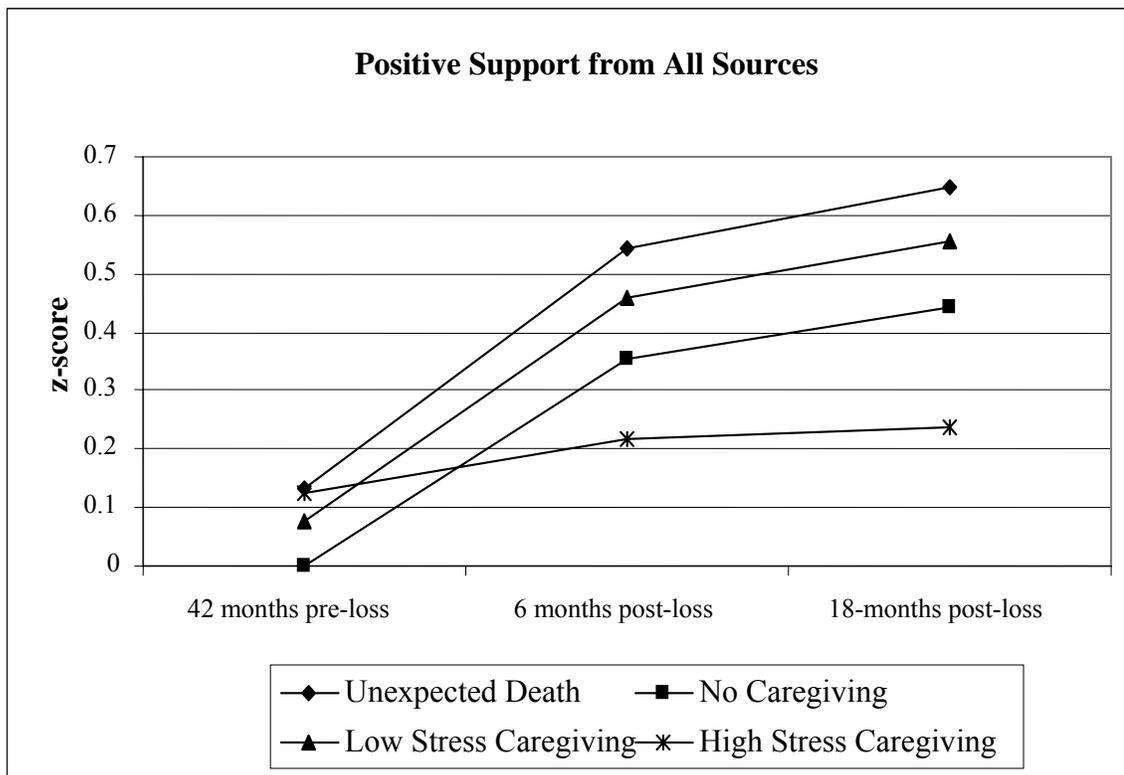
Physical Health

Neither of the health indicator variables in this study, satisfaction with good health and difficulty with activities, was shown as having significant time effects, group effects, or group by time interaction effects in the mixed model analyses.

Table 2. Summary of Mixed Model Analyses

	Model 1		Model 2		Model 3	
	Estimate(SE)	p-value	Estimate(SE)	p-value	Estimate(SE)	p-value
Depression						
Intercept	.16 (.06)	.007	.17 (.06)	.006	.22 (.16)	.152
Time			.02 (.02)	.306	.14 (.05)	.004
Group					-.02 (.06)	.711
Group x Time					-.05 (.02)	.008
Residual Variance	.72 (.05)		.48 (.05)		.48 (.05)	
Variance Intercept (UN 1,1)			.55 (.08)		.55 (.08)	
Variance Slope (UN 2,2)			.03 (.01)		.03 (.01)	
Frequent Contact with Children and Grandchildren						
Intercept	.24 (.04)	<.0001	.28 (.04)	<.0001	.35 (.10)	.001
Time			.08 (.02)	<.0001	.15 (.04)	<.0001
Group					-.03 (.04)	.452
Group x Time					-.03 (.01)	.034
Residual Variance	.46 (.03)		.17 (.02)		.17 (.02)	
Variance Intercept (UN 1,1)			.27 (.03)		.27 (.03)	
Variance Slope (UN 2,2)			.04 (.01)		.04 (.004)	
Positive Support from All Sources						
Intercept	.30 (.07)	<.0001	.34 (.06)	<.0001	.54 (.16)	.001
Time			.08 (.01)	<.0001	.14 (.04)	<.0001
Group					-.08 (.06)	.174
Group x Time					-.02 (.01)	.070
Residual Variance	.40 (.03)		.26 (.03)		.26 (.03)	
Variance Intercept (UN 1,1)			.63 (.08)		.62 (.08)	
Variance Slope (UN 2,2)			.02 (.004)		.01 (.004)	

Discussion

Results support the importance of examining circumstances of death and caregiving when studying bereavement. The findings from this study demonstrate that the idea of stability following the loss of a spouse can be seen in multiple domains of bereavement outcomes, particularly positive affect, self-esteem, satisfaction with health, and difficulty with physical activities. Both of our positive psychological outcome measures showed no change over time, indicating that all four of our groups maintained stable levels of positive affect and self-esteem throughout the study period and adding to the literature which suggests that positive and negative affect variables are separate and distinct concepts and should be examined as such in future research. Findings from the literature on positive and negative affect variables have demonstrated that these two concepts are not opposite sides of the same construct and that each has a distinct set of correlates and predictors (i.e., Lawton, 1983; Diener & Emmons, 1984; Watson & Tellegen, 1985). In addition, contrary to our hypotheses, bereavement showed no impact on self-reported heath or difficulty with activities in our sample.

For depression, the unexpected death group was associated with worsening depression after bereavement, while the other groups remained stable over time. The finding that spouses who experienced an unexpected death showed high levels of depression at both the 6 month and 18 month post-loss points was consistent with previous research. Our hypothesis that highly stressed caregivers would show improvements in well-being was not supported; instead, stability was found for all of the groups with an expected loss. Thus our results suggest that, for predicting changes in

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well-being after bereavement, unexpected death was a more important predictor than the nature of the caregiving experiences.

Both of our social well-being outcome measures, frequent contact with children and grandchildren and positive support from all sources showed marked increases by 6 months post-loss and these increases remained steady at the 18 month follow-up point for the unexpected death, no caregiving, and low stress caregiving groups. The increases were found on both an objective and subjective measure within the social well-being domain, indicating that not only does the amount of actual contact increase but also the survivor's satisfaction with the quality of that contact. Highly stressed caregivers, however, showed no increase over time, suggesting that they may be at risk for social isolation during bereavement. We have found no previous studies that demonstrate this effect. Highly stressed caregivers may be particularly likely to experience role engulfment (Aneshensel et al., 1995; Pearlin, Mullan, Semple, & Skaff, 1990) and thus to have difficulty retaining social roles while caregiving; our results suggest that these effects may continue after bereavement. Similar to the resource depletion hypothesis discussed by Schulz et al. (1997), caregivers who become disengaged socially may find it difficult to develop such relationships after bereavement. Zettel and Rook (2004) found that rekindling of old ties was the most common way that widows altered their social networks after bereavement; such rekindling may be difficult if, for example, highly stressed caregivers have experienced a lack of support or negative support, which is associated with stressful caregiving (Robinson-Whelen et al., 2001).

Overall our findings highlight the importance for continued research that systematically examines the relationship between caregiving and bereavement using

sophisticated methodology and prospective data with multiple post-loss follow-up interviews. The impacts of bereavement vary according to both whether or not a loss is expected and the nature of caregiving, with effects varying across domains of well-being. Since psychological interventions for grief and bereavement have generally had disappointing effects (Schut, Stroebe, van den Bout, & Terheggen, 2001), it is important to more fully understand how bereavement puts some widows and widowers at high risk, and to understand which consequences of bereavement may be most appropriate as targets of interventions.

Chapter Three

Patterns of caregiving and bereavement trajectories

Abstract

Prior literature has identified five core bereavement trajectories: common grief, chronic grief, chronic depression, improvement during bereavement, and resilience. Participants (n=175) in the Changing Lives of Older Couples study who experienced the death of a spouse were categorized into four groups: unexpected loss, expected loss without caregiving, or caregiving with either high or low stress. Participants completed measures of depressive symptoms pre-loss and at 6 and 18 months post-loss, and were assigned to trajectory patterns using previously published decision rules. The correspondence between caregiving status and bereavement trajectories was examined using chi-square analysis. Results showed that unexpected death was associated with higher prevalence of chronic grief, highly stressed caregiving was associated with higher rates of chronic depression, and low stress caregivers exhibited distributions similar to those of the non-caregiving group. Across all groups the highest number of participants fell into the resilient category. The results suggest that further examination of the complicated relationship between caregiving and bereavement is warranted, and advantages of trajectory analysis are discussed.

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Introduction

Spousal bereavement is one of the most stressful events that an individual may encounter over the course of his or her lifetime (Stroebe & Stroebe, 1987). Previous research has demonstrated that the death of a spouse has a profound effect on an individual's well-being. Some of these documented effects include increased incidence of depression, decreased life satisfaction and social activities, and physical health decrements (i.e., Bonanno, Notarius, Gunzerath, Keltner, & Horowitz, 1998; Carr, House, Wortman, Nesse, & Kessler, 2001; Davis & Nolen-Hoeksema, 2001; Folkman, 2001; Schulz & Beach, 1999; Stroebe, Stroebe, Abakoumkin, & Schut, 1996). While it has been well established in the bereavement literature that certain types of deaths, such as suicide or homicide, are particularly stressful and that unexpected death may be particularly difficult for the survivors (Carr et al., 2001), there is little known about how family caregiving experiences affect the course of bereavement.

One relatively recent development in the literature is the identification of bereavement trajectories. Two recent studies by Bonanno and his colleagues (Boerner, Wortman, & Bonanno, 2005; Bonanno, Wortman, Lehman, Tweed, Haring, et al., 2002) have identified five core bereavement trajectories, based on prospective data collected both pre-loss and at three time points post-loss: common grief, chronic grief, chronic depression, depressed-improved, and resilience. Common grief follows the pattern that is traditionally considered to be a "normal" grieving pattern: low levels of depression pre-loss, followed by a spike in depressive symptomatology at short-term follow-up, and then

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a return to baseline levels of depression at long-term follow-up points. Chronic grief and chronic depression are both characterized by consistently high levels of depression following the loss of a spouse, however they are differentiated by the level of depression pre-loss; individuals who exhibit chronic grief show low levels of depression pre-loss, while individuals who exhibit chronic depression show high levels at this time point. The depressed-improved trajectory is noted by high levels of depression pre-loss followed by low levels of depressive symptomatology at all post-loss follow-up points; the resilient group shows low levels of depression at all time points, both prior to and after the death of a spouse. For more detailed information on these trajectories and how the researchers developed them, please see Bonanno et al. (2002).

Spousal bereavement frequently follows informal caregiving for older adults who die after chronic illness, and this caregiving experience is often extensive and stressful (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Minino & Smith, 2001). Family caregiving experiences, particularly for spouses, often place individuals at risk for a variety of mental and physical health decrements; some of these documented effects include increased incidence of depression, slower wound healing, and increased mortality (i.e., Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser,1996; Pinquart & Sorensen, 2003; Schulz & Beach, 1999; Schulz, O'Brien, Bookwala, & Fleissner, 1995). While the previous study by Bonanno and his colleagues (2002) examined level of caregiving as a context variable as part of the larger study, it was not a major focus and our goal is to expand on this prior research and attempt to gain a better understanding of how caregiving experiences lead to divergent bereavement trajectories.

The current study is designed to further address the issue of the relationship between caregiving and the bereavement experience by using information from the Changing Lives of Older Couples (CLOC) study, a project that includes both pre- and post-loss data. This project utilized four groups: unexpected death, expected death with no caregiving, expected death with low levels of stress associated with the caregiving experience, and expected death with high levels of stress associated with the caregiving experience and examined how these varying levels of caregiving experience were related to previously established bereavement trajectories. Based on the prior Bonanno et al. (2002) study and the caregiving and bereavement literatures, we expect to see a higher number of individuals who experience an unexpected death to experience chronic grief, attributable to the circumstances surrounding the loss. In addition, prior research has shown that individuals who report low levels of stress while caregiving experience grief reactions similar to those of individuals who are not involved in caregiving activities, and we expect similar results in the current study (i.e., Schulz, Beach, Lind, Martire, Zdaniuk, et al., 2001). As for highly stressed caregivers, we expect to see a higher number of these individuals experience chronic depression, based upon prior literature (Schulz et al., 2001).

Methods

Participants

The current study utilized the data obtained from bereaved individuals who participated in the Changing Lives of Older Couples (CLOC) study, a prospective study of a two-stage area probability sample of 1532 married men and women from the Detroit Standardized Metropolitan Statistical Area. In order to be eligible for the study, individuals had to meet the following criteria: English-speaking, married, residing in a household in which the husband was at least 65 years of age, non-institutionalized, and able to participate in a two hour face-to-face initial interview (University of Michigan, n.d.). In addition, the researchers who designed the study oversampled women in order to obtain the highest number of bereaved spouses possible during the study period. Baseline interviews for the CLOC study were conducted between June 1987 and April 1988, and approximately 68% of individuals contacted participated in the initial interview, a response rate that is consistent with other studied conducted in the Detroit area (see the University of Michigan CLOC website for additional details).

Researchers utilized the daily obituaries in the Detroit-area newspapers and monthly death record tapes provided by the state of Michigan in order to identify the initial participants who had experienced the loss of a spouse. The National Death Index (NDI) was used to confirm the deaths and to obtain the causes of death. Of the initial sample, 316 individuals lost their spouse during the study period and were asked to participate in a follow-up interview six and eighteen months after the loss of their spouse; 195 individuals (62%) agreed to participate in both of these interviews. For the purposes of this study, the two cases that reported death as a result of murder, suicide, or homicide have been excluded because of the unique attributes associated with a loss of this nature (Sheskin & Wallace, 1976). An additional reason for non-inclusion in this study was the

classification of a participant into a bereavement trajectory that accounted for less than 5% of the dataset. The final sample for the current study was 175 (55% of the original dataset) with the primary reasons for non-participation being ill health or death and refusal.

The mean age of this sample was 69.99 (s.d.=6.79) at the baseline interview and 87.40% (n=153) female. In addition, 149 (85.10%) of these participants identified themselves as Caucasian American and 26 (14.90%) as African American and had on average 11.57 years of education. The four groups did not differ significantly (p>.05) on any of the demographic characteristics except for race/ethnicity, as shown in Table 3. Chi-square analyses revealed a significant, non-random distribution of participants into the four groups utilized in this study by race/ethnicity (χ^2=8.419, df=3, p=.038). African Americans who participated in this study were more likely to have a spouse who died unexpectedly and less likely to have a spouse who was diagnosed with a serious ongoing condition but did not require care than their Caucasian American counterparts.

Table 3. Demographic Characteristics of the Sample by Caregiving Status

	Unexpected Death	No Caregiving	Low Stress Caregiving	High Stress Caregiving
N	35	59	40	41
Age, mean years (SD)	70.37 (5.78)	70.59 (6.99)	69.95 (5.84)	68.83 (8.13)
% Female	88.60	88.10	85.00	87.80
% White	74.30%	94.90%	85.00%	80.50%
Education, mean years (SD)	11.48 (2.68)	11.42 (2.25)	11.67 (2.58)	11.76 (2.50)
Baseline CES-D, mean (SD)	-.31 (.72)	.14 (1.14)	-.03 (.99)	.11 (1.10)

Measures

Pre-loss Caregiving Status

The four groups for this study were chosen based upon their response to three questions: the first asking whether the spouse died of either an ongoing serious condition, an accident, murder, or suicide, or an unspecified cause indicated as not being an ongoing serious condition, the second asking those whose spouses died of a serious ongoing condition whether or not they provided care for their spouse 6 months prior to death, and the third asking individuals who reported providing care for their spouses how stressful they found the experience to be. For the question regarding stressfulness of the

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caregiving experience, participants were asked to provide a response based upon a 5-point Likert-type scale with responses ranging very stressful to not at all stressful. Individuals who responded to this question as either very stressful or quite stressful were included in the high stress group and individuals who responded as somewhat stressful, not too stressful, or not at all stressful are included in the low stress group. Participants were divided into the following four categories: individuals whose spouses died unexpectedly (n=35), individuals whose spouses died from a serious ongoing medical condition but did not provide care six months prior to the death (n=59), individuals whose spouses died from a serious ongoing medical condition who did provide care six months prior to the death and reported low levels of stress associated with the caregiving experience (n=40), and individuals whose spouses died from a serious ongoing medical condition who did provide care six months prior to the death and reported high levels of stress associated with the caregiving experience (n=41).

Bereavement Trajectories

The bereavement trajectories utilized in this study are identical to those identified in studies published by Bonanno and his colleagues with the CLOC dataset (Boerner et al., 2005; Bonanno et al., 2002). They developed these trajectories using scores on the Center for Epidemiologic Studies-Depression (CES-D; Radloff, 1977) scale obtained at three time points: approximately 3 years pre-loss, and 6 and 18 months post-loss. The first step in developing these trajectories involved categorizing participants as either having high or low pre-loss depression (using the 80th percentile as the cut-point); next change scores were calculated for two time points: pre-loss to 6 months post-loss and 6

months to 18-months post-loss. These change scores were then used to develop three categories: a grief reaction was defined as a depression increase relative to pre-loss by 1 standard deviation (SD) or better, improved functioning was defined as a depression decrease by greater than 1 SD, or no change if the depression scores remained constant or varied by less than 1 SD. The SD was defined separately for the high and low pre-loss depression groups. For participants with high pre-loss depression, .88 standard units was used to define meaningful change, and for participants with low pre-loss depression, .57 standard units was used. In addition, in order to compensate for the fact that pre-loss depression scores tended to cluster around the mean, a grief reaction was assigned when post-loss depression scores increased to greater than the 50th percentile for the overall dataset (N=1532, z=0). The change scores for each of the two time points were combined to create eight possible bereavement trajectories, and only those that were exhibited by at least 5% of the sample were used. The five patterns used in the final analysis included 185 participants and fell into the following categories: 1) common grief, n=18 (10.3%); 2) depressed-improved, n=20 (11.4%); 3) resilient, n=92 (52.6%); 4) chronic grief, n=30 (17.1%); 5) chronic depression, n=15 (8.6%). (see Bonanno et al., 2002 for additional details).

Statistical Analysis Plan

Chi-square analyses were conducted in order to assess the relationship between caregiving group and bereavement trajectories. In order to gain a better understanding of the relationship between these two variables, significant chi-square analyses were

followed up with a comparison of distributions for all groups using the group of individuals whose spouses died of a serious ongoing condition but did not provide care as a referent group.

Results

The chi-square analysis of this data revealed a significant, non-random distribution across the five bereavement patterns (χ^2=23.43, df=12, p=.024). Table 4 shows the results of the chi-square analysis and the varying distributions of bereavement trajectories for our four caregiving groups. Using the group of individuals whose spouses died of a serious ongoing condition but did not provide care as a referent group, we can see that there are distinct variations in the distributions. It is important to note that we obtained distributions similar to those reported by Bonanno et al. (2002) however there are some differences in the overall distributions, attributable largely to the slight variation in the sample.

Table 4. Results of the Chi-Square Analysis for Bereavement Trajectories by Caregiving Status

	Common Grief	Depressed-Improved	Resilient	Chronic Grief	Chronic Depression	Total
Unexpected Death						
Actual	2.0	0.0	17.0	13.0	3.0	35.0
Expected	3.6	4.0	18.4	6.0	3.0	35.0
% Group	5.7%	0.0%	48.6%	37.1%	8.6%	100.0%
% Trajectory	11.1%	0.0%	18.5%	43.3%	20.0%	20.0%
No Caregiving						
Actual	10.0	10.0	28.0	6.0	5.0	59.0
Expected	6.1	6.7	31.0	10.1	5.1	59.0
% Group	16.9%	16.9%	47.5%	10.2%	8.5%	100.0%
% Trajectory	55.6%	50.0%	30.4%	20.0%	33.3%	33.7%
Low Stress Caregiving						
Actual	4.0	5.0	22.0	7.0	2.0	40.0
Expected	4.1	4.6%	21.0	6.9	3.4	40.0
% Group	10.0%	12.5%	55.0%	17.5%	5.0%	100.0%
% Trajectory	22.2%	25.0%	23.9%	23.3%	13.3%	22.9%
High Stress Caregiving						
Actual	2.0	5.0	25.0	4.0	5.0	41.0
Expected	4.2	4.7	21.6	7.0	3.5	41.0
% Group	4.9%	12.2%	61.0%	9.8%	12.2%	100.0%
% Trajectory	11.1%	25.0%	27.2%	13.3%	33.3%	23.4%
Total						
Actual	18.0	20.0	92.0	30.0	15.0	175.0
Expected	18.0	20.0	92.0	30.0	15.0	175.0
% Group	10.3%	11.4%	52.6%	17.1%	8.6%	100.0%
% Trajectory	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

When comparing the unexpected death group to the referent group, we see that individuals whose spouses died unexpectedly are less likely to experience a common grief (5.7% compared with 16.9%) or depressed-improved (0.0% compared with 16.9%) bereavement reaction, but are more likely to experience a chronic grief reaction (37.1% compared with 10.2%). When comparing the low stress caregiving group to the referent group, we see that the low stress caregivers experience a very similar distribution to the non-caregiving group, with only slight differences across the five trajectories. When examining the differences between the high stress caregivers and the non-caregiving groups, we see that the high stress caregivers are less likely to experience a chronic grief reaction (4.9% compared to 16.9%), more likely to fall into the resilient category (61.0% compared to 47.5%), and slightly more likely to experience chronic depression (12.2% compared to 8.5%).

Discussion

The results from this study were consistent with those in the prior work by Bonanno and his colleagues (2001) and also the hypotheses based upon prior caregiving and bereavement literature as it relates to depression outcomes for individuals who experience varying levels of stress while caregiving (Schulz et al., 2001). Our sample does reiterate the idea that individuals who experience unexpected losses are more likely to experience chronic grief, and this is not surprising given the difficult circumstances surrounding these losses. However, our results also indicate that almost half (48.6%) of the spouses who experienced an unexpected loss fell into the resilient category. This is a

finding that deserves attention and warrants further investigation, particularly aimed at gaining a better understanding of the protective factors that account for low levels of depression both at short and long term bereavement follow-up points.

Our hypothesis that individuals who reported a low level of stress associated with the caregiving experience would show similar bereavement patterns to those who did not provide care was confirmed by the analysis, while there were differences when comparing the highly stressed caregivers to the non-caregiving group. The highly stressed caregivers were slightly less likely than non-caregivers to experience a common grief reaction which we did not hypothesize, and slightly more likely to experience chronic depression, which we did hypothesize. Interestingly, however, even though the highly stressed caregivers were more likely to experience chronic depression, the actual percentage was quite low (12.2%). These findings are consistent with the literature and indicate that the subjective appraisal of the stressfulness of the caregiving experience has an effect on mental health outcomes (Schulz et al., 2001), but also leaves us with a number of questions about the type of grief experienced by the majority of the widowed spouses. As with the unexpected death group, the bereavement pattern that was demonstrated by the highest percentage of individuals in each caregiving group was resilience. Approximately 55.0% of low stress caregivers and 61.0% of high stress caregivers demonstrated consistently low levels of depression both pre-loss and at both short and long term bereavement follow-ups. This indicates that the majority of individuals who experience spousal loss (52.6% of our sample) do not show low levels of depression either pre-loss or during bereavement, regardless of pre-loss caregiving experience, and also leads researchers to further examine the individual characteristics

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that enable widowed spouses to exhibit this mental health outcome. It is also important to note that although the descriptive analyses showed that African Americans who participated in this study were more likely to have a spouse who died unexpectedly and less likely to have a spouse who was diagnosed with a serious ongoing condition but did not require care than their Caucasian American counterparts, we were unable to interpret these results due to the small number of African American participants. However the fact that we did find this difference suggests that future research needs to include a diversity of participants in order to examine the differing caregiving experiences of multiple racial and ethnic groups.

It should be noted that the approach used to classify participants into bereavement trajectories utilized a conservative method that may potentially bias the sample towards resilience. Future research could attempt to replicate the creation of bereavement trajectories by using slightly less conservative criteria to denote change. One possible approach that may be potentially utilized is prediction analysis (Hildebrand, Laing, & Rosenthal, 1977). This type of analyses was used by Whitlatch, Zarit, and von Eye (1991) to reanalyze data from a previous study examining the efficacy of caregiver interventions (Zarit, Anthony, & Boutselis, 1987) and involves the comparison of observed frequencies of outcome scores with predicted outcomes that take into account the initial levels of dependent measures. This reanalysis found that a systematic evaluation of initial levels of dependent measures in the participants is important in detecting change. Although this was outside the scope of this work, we believe that it does need to be incorporated into future research. A second potential approach is the use of a relatively new procedure that is designed to isolate distinct trajectories and fit a

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mixture model to calculate the probability of membership in each latent class for each

participant (Jones, Nagin, & Roeder, 2001). The benefit of this approach is that it would

allow the development of the trajectories to be data-driven and it may produce

trajectories that are different from the ones developed by Bonanno and his colleagues.

One possible area for future research is the utilization of the revised stress process

model recently published by Folkman (2001) to attempt to gain a better understanding of

how individuals use various coping mechanisms which result in either positive or

negative mental health bereavement outcomes. This model includes increased attention

to issues such as the use of meaning-based coping and the benefits of caregiving which

need to be addressed in future research and could potentially offer insight into the

mechanisms which allow individuals to adjust to spousal loss in a healthy way. In

addition, the continued examination of the role of social support and its possible

protective factors against negative mental health outcomes both during caregiving and

following the loss of a spouse would be highly beneficial both for researchers and

practitioners (Robinson-Whelen, Tada, MacCallum, McGuire, & Kiecolt-Glaser, 2001;

Zettel & Rook, 2004). Prior literature has shown that highly stressed caregivers may be

particularly likely to experience role engulfment (Aneshensel et al., 1995; Pearlin,

Mullan, Semple & Skaff, 1990) and thus to have difficultly retaining social roles while

caregiving. Similar to the resource depletion hypothesis (Schulz, Newsom, Fleissner,

Decamp, & Nieboer, 1997), caregivers who become disengaged socially may find it

difficult to develop such relationships after bereavement. Future research that

systematically examines the maintenance of social roles and social support both during

caregiving and subsequent loss and their impact on mental health is needed in order to

address these issues. There is also a growing interest and body of literature that focuses on the positive aspects of caregiving and adaptation to bereavement, and the findings from our study contribute to the ideas presented in a recent study which also suggests that this is a very important direction to be taken (Boerner, Schulz, & Horowitz, 2004). This study found that higher levels of post-loss depression and grief were associated with higher levels of caregiver benefit (as measured by an 11-item scale assessing the caregiver's mental-affective state in relation to the caregiving experience), and that this relationship was particularly strong for grief. The authors of this study concluded that individuals who experience more positive aspects of the caregiving experience may have a more difficult adjustment period due to the simultaneous loss of both a family member and a meaningful role and suggested that future research focus on the whole picture of the caregiving experience.

A significant portion of the picture of the relationship between caregiving and bereavement is not captured by focusing only on negative outcomes, such as depression, and researchers need to expand their outcome variables to include positive measures, such as enjoyment of caregiving and empowerment, in order to begin to fill in these gaps. In order for effective interventions to be developed which decrease negative outcomes during bereavement, researchers need to have a clearer picture of all of the pre-loss characteristics that contribute to mental health outcomes during bereavement.

Overall the results from our study highlight the importance for continued research on the relationship between caregiving and bereavement that focuses on a variety of both positive and negative outcome domains. The findings related to the high prevalence of a resilient bereavement trajectory, regardless of caregiving status, is promising both for

widowed spouses and practitioners, however it should lead us to further examine the

individual characteristics of these resilient widows in order to gain a better understanding

of the underlying mechanisms.

Chapter Four

Predictors of well-being in bereaved former hospice caregivers:

The role of caregiving stressors, appraisals, and social resources

Abstract

The current literature on caregiving and bereavement indicates that the relationship between these two common life events is complex and needs to be further studied in order to gain a more comprehensive understanding of their interaction. In the current project, 50 spouses of hospice patients were assessed while caregiving and at an average of 4 months after the death on a variety of measures, including caregiving stressors, appraisals, social resources, and well-being. A stress process model was utilized in order to examine which pre-loss factors were associated with post-loss depression, life satisfaction, and grief in hierarchical multiple regression models. Our results indicated that caregiver appraisals (stressfulness of functional impairment and positive aspects of caregiving) were not predictors on any of our well-being outcomes. However, fewer months caregiving was a significant predictor of both higher depression and grief post-loss. In addition, lower levels of social activities, smaller social networks, and satisfaction with social support were significantly associated with higher post-loss depression. Results support both the resource depletion and anticipatory grief

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hypotheses, and suggest that short-term bereavement outcomes are largely independent of factors that predict well-being while caregiving. Future studies should address whether long-term bereavement outcomes differ by baseline caregiving characteristics to guide intervention research.

Introduction

The death of a spouse is one of the most stressful events that an individual may encounter over the course of his or her lifetime (Stroebe & Stroebe, 1987). Previous bereavement research has demonstrated that the loss of a spouse has a profound effect on an individual's well-being, including increased incidence of depression, decreased life satisfaction and social activities, and deterioration of physical health (i.e., Bonanno, Notarius, Gunzerath, Keltner, & Horowitz, 1998; Carr, House, Wortman, Nesse, & Kessler, 2001; Davis & Nolen-Hoeksema, 2001; Folkman, 2001; Schulz & Beach, 1999; Stroebe, Stroebe, Abakoumkin, & Schut, 1996).

For older adults who die after a chronic illness, spousal bereavement frequently follows extensive and stressful periods of informal caregiving (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Minino & Smith, 2001). Family caregiving, particularly for spouses, places an individual at risk for a variety of mental and physical health decrements as a result of the caregiving experience. Some of the health effects that have been documented in the literature include increased incidence of depression, slower wound healing, and increased mortality (i.e., Kiecolt-Glaser, Marucha, Malarkey,

Mercado, & Glaser,1996; Pinquart & Sorensen, 2003; Schulz & Beach, 1999; Schulz, O'Brien, Bookwala, & Fleissner, 1995).

Hospice caregivers may be at particular risk for these mental and physical health declines, as they are often highly engrossed in the caregiving experience while simultaneously facing the loss of a loved one. One recent study comparing hospice caregivers to non-caregivers found that spousal caregivers of hospice patients spent an average of approximately 97 hours/week in the caregiving role and were at an increased risk for depression, decreased life satisfaction, and health problems compared with demographically matched non-caregiving controls (Haley, LaMonde, Han, Narramore, & Schonwetter, 2001).

Stress Process Models and their Application in Caregiving and Bereavement

Stress process models are increasingly used for studying both caregiving and bereavement (i.e., George, 1990; Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Pearlin, Mullan, Semple, & Skaff, 1990; Stroebe & Schut, 1999). This theoretical framework posits that the relationship between a stressful life event and the effect of that event on an individual's well-being is a function of the unique interaction of the appraisal of the stressor and the resources the individual has available. Applied to the study of caregiving and bereavement, stress process theories suggest that well-being outcomes, such as depression or life satisfaction, are not solely based on an individual's exposure to caregiving stressors such as functional impairments or duration of caregiving. Each individual appraises the stressfulness of the situation as well as examines the availability of resources, such as social support, and the combination of all of these factors affect the

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degree to which that stressor affects the caregiver's well-being. This theoretical approach

can be helpful in examining two opposing hypotheses in the caregiving and bereavement

literature: resource depletion and relief. Resource depletion theory is based on the idea

that a depletion of resources results from prolonged exposure to caregiving stressors

leaving the surviving spouse more vulnerable to negative outcomes during widowhood.

Alternatively, relief theory states that the reduction in caregiving burden following the

loss of a spouse results in improvements in mental and physical health outcomes (Schulz,

Newsom, Fleissner, Decamp, & Nieboer, 1997). The first theory is based on the ideas

that resources, such as social support, buffer the effects of stressful life events, and that

the demands of caregiving lead to a depletion of these resources. Thus, when the death

occurs, the bereaved caregiver is at risk for increased distress due to a depletion of

resources over time. The second hypothesis is based on the idea that the loss of the

burden of caregiving also means the removal of an important individual stressor and that

this change in circumstances may lead to improvements in bereavement outcomes. In

addition to the resource depletion and relief hypotheses, stress process models can also be

used to examine anticipatory grief. The anticipatory grief hypothesis is based on the idea

that individuals who have time to psychologically prepare themselves for the loss of a

loved one may be at a decreased risk for difficulties after the death.   It is believed by

some researchers that this theory may be particularly important within the context of

caregiving and bereavement, although the research to date is inconclusive (Schulz et al.,

1997).

The studies using stress process models to examine well-being outcomes during

caregiving have been inconclusive about the effect of objective measures of caregiving

stressors (Beery, Prigerson, Bierhals, Santucci, Newsom, et al., 1997; Given & Given, 1996; Haley & Bailey, 1999; Kurtz, Kurtz, Given, & Given, 1995; Sales, Schulz, & Biegal, 1992). However the findings related to subjective appraisals are more consistent and suggest that caregivers are more likely to be depressed if they appraise caregiving tasks as stressful, feel incapable of fulfilling their caregiving roles adequately, or are unable to find meaning or satisfaction in their role as caregiver (i.e., Folkman & Moskowitz, 2000; Haley & Bailey, 1999; Oberst, Gass, & Ward, 1989; Weitzner, Haley, & Chen, 2000). Taken together, the research examining the role of social support finds that caregivers with larger social networks, increased participation in social activities, and higher perceived satisfaction with social support are less likely to experience distress (i.e., Northouse, 1988; Schulz et al., 1995; Weitzner et al., 2000). However, there is some question as to whether caregivers who are highly involved in their caregiving roles are able to maintain adequate levels of social support and social interaction. Research suggests that highly stressed caregivers may be particularly likely to experience role engulfment (Aneshensel et al., 1995; Pearlin et al., 1990) and thus to have difficulty retaining social roles while caregiving.

While there is a fairly extensive body of literature which examines the impact of stressors, appraisals, and social resources on mental and physical health during caregiving, very few studies have been conducted to date examining the impact of these variables on bereavement outcomes. The research to date that examines objective measures of caregiving stressors and their impact on well-being outcomes during bereavement has been sparse. Of the studies that are available, most utilized one post-loss interview, which took place between four and six months after the loss. Collectively,

the findings from these studies (discussed below in greater detail) found that longer duration of caregiving, negative appraisals of the caregiving experience, and lower social resources were related to poorer well-being outcomes during bereavement. The one study related to caregiving stressors found that longer duration of caregiving was correlated with higher levels of relief experienced by the caregivers following the death (Cleiren, van der Wal, & Diekstra, 1988). It is possible that this finding relating longer duration of caregiving with higher levels of relief is evidence of anticipatory grief; however, the findings in this area have not been definitive (Schulz et al., 1997). The handful of studies that have been conducted related to caregiving appraisals and bereavement outcomes have focused on the stressfulness of the caregiving experience. Overall these studies suggest that caregiver dissatisfaction with caregiving abilities and higher levels of stressfulness of the caregiving experience are related to higher levels of depression and distress during bereavement (Bass & Bowman, 1990; Cleiren et al., 1988; McHorney & Mor, 1988). One study (discussed in detail below) that focused on positive aspects of caregiving found that higher pre-loss caregiving perceptions of benefit from caregiving was associated with higher levels of post-loss depression and grief (Boerner, Schulz, & Horowitz, 2004). Social resource variables are the most commonly examined in this body of literature, with the findings suggesting that higher levels of social resources and satisfaction with these resources while caregiving are associated with better bereavement outcomes (Bass & Bowman, 1990; Cleiren et al., 1988; McHorney & Mor, 1988).

There have been two studies conducted to date that included extensive information about circumstances during caregiving, and utilized longer term follow-up

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points during bereavement. The first study examined caregiving stressors and their relationship to bereavement outcomes one year post-loss and found that the higher the amount of assistance with functional impairments while caregiving, the higher the levels of depression post-loss (Mullan, 1992). To our knowledge, there are no studies currently available examining appraisals of the caregiving experience and their relationship to bereavement utilizing prospective, long term follow-up points. For the domain of social resources, one relatively small qualitative study that conducted unstructured interviews with bereaved caregivers on an average of 18 months post loss (range was 3 months to 4 years) found results similar to those previously discussed. Individuals who reported higher levels of social support while caregiving also reported easier adaptation to bereavement (Sankar, 1991).

Pre-loss depression is generally believed to be significantly associated with post-loss depression and grief and this association has been seen in previous caregiving and bereavement literature (Boerner et al., 2004). Researchers need to place more emphasis on studying the relationship between caregiving context and bereavement outcomes. A clearer picture of the pre-loss characteristics that affect post-loss well-being is needed so that they can be used to develop effective interventions that can then be implemented with at risk caregivers.

To our knowledge, only one study has been published to date that focuses on the positive aspects of caregiving as an appraisal variable within the context of adaptation to bereavement. The findings from this recent study suggest two things; the first that this is a very important direction to be taken, and the second that this relationship may be more complex than it seems from a theoretical standpoint (Boerner et al., 2004). This study

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found that higher levels of post-loss depression and grief were associated with higher levels of pre-loss caregiver benefit (as measured by questions pertaining to positive emotions related to the caregiving experience), and that this relationship was particularly strong for grief. The authors of this study concluded that individuals who experience more positive aspects of the caregiving experience may have a more difficult adjustment period due to the simultaneous loss of both a family member and a meaningful role and suggested that future research focus on a more comprehensive picture of the caregiving experience. In addition this study highlighted the concept that grief and depression are outcomes representing different facets of bereavement with unique pathways and need to be addressed as such in future research.

One area of the literature that is particularly important in helping both practitioners and researchers to gain a better understanding of the relationship between caregiving and bereavement is the examination of multiple measures of well-being outcomes. There is some debate in the literature at this time as to whether or not positive and negative affect variables are mutually exclusive. As previously discussed, bereavement researchers are increasingly aware of the differences between grief and post-loss depression and the need to address them as distinct facets of well-being during bereavement. The current study will add to this growing body of literature within the context of bereavement by examining the relationship between caregiving stressors, appraisals of those stressors, and the availability of resources, and how they interact with multiple outcome measures, both positive and negative.

The Current Study

The current study addresses the extent to which stressors, appraisals, social support, and well-being while caregiving predict well-being during bereavement. More specifically, we were interested in the following questions: How do caregiving stressors (duration of caregiving, hours/week caregiving, and functional impairments), appraisals (stressfulness of functional impairments and positive aspects of caregiving), and objective (size of social network, overall social support, number of visits and social activities) and subjective (satisfaction with social support) measures of social support while caregiving affect post-loss depression, life satisfaction, and grief in bereaved former hospice caregivers? In order to address this question, we used a subset of a dataset that recruited elderly spousal caregivers of terminally ill patients from a large, non-profit hospice. This dataset includes both pre- and post-loss data and includes a variety of widely used and validated measures that allow for the examination of caregiving stressors, appraisals, and social support and their effect on both positive and negative well-being outcomes during bereavement

Drawing on prior literature and the tenets of stress process theory, we hypothesized that higher pre-loss levels of both depression and life satisfaction would be associated with higher post-loss levels of both depression and life satisfaction. As far as the relationship between caregiving stressors and our three outcome measures, resource depletion theory predicted that higher pre-loss levels of caregiving stressors (hours/week caregiving, duration of caregiving, and ADL/IADL impairment) would be associated with higher levels of depression and grief and lower levels of life satisfaction post-loss after controlling for baseline. However, the anticipatory grief hypothesis predicted that individuals who experienced longer duration of caregiving would be associated with

lower levels of grief and depression post-loss. Within the domain of appraisals, resource

depletion hypothesis suggested that higher pre-loss levels of perceived stressfulness of

the caregiving experience and lower positive aspects of caregiving would be associated

with higher levels of post-loss depression and grief and lower levels of post-loss life

satisfaction after controlling for baseline well-being measures. Alternatively, the relief

hypothesis predicted that higher levels of perceived levels of stressfulness of caregiving

and higher levels of positive aspects of caregiving would be associated with a greater

sense of relief post-loss, particularly higher levels of life satisfaction and lower levels of

depression and grief after controlling for baseline well-being measures. In relation to

social resources, the resource depletion hypothesis predicted that after controlling for

baseline well-being measures, higher levels of objective (size of social network, overall

social support, number of visits and social activities) and subjective (satisfaction with

social support) levels of social support pre-loss would be associated with lower levels of

post-loss depression and grief and higher levels of post-loss life satisfaction.

Methods

Participants

     Spousal caregivers of terminally ill older patients diagnosed with either end-stage

dementia or lung cancer were recruited as part of a larger research project conducted by

the LifePath Hospice of Tampa, Florida, and the faculty at the School of Aging Studies at

the University of South Florida, Tampa, Florida. The current project involves a follow-

up of these participants. Full details regarding the recruitment of the original sample are

provided in another paper (Haley et al., 2001). Briefly, the original project involved the recruitment of eighty (N=80) spousal caregivers over the age of 50 who were caring for terminally ill dementia or lung cancer hospice patients from LifePath Hospice of Tampa, Florida, patient records. All patients were diagnosed by their family physicians with either end-stage dementia (N=40) or lung cancer (N=40) and were certified by their family physicians as having six (6) months or less of life expectancy. To be eligible for the research project, elderly spousal caregivers had to meet the following eligibility criteria: (a) confirmation that they were either the husband or wife of the patient; (b) confirmation that they were the primary caregiver for the patient; and (c) confirmation that they were able to understand the spoken and written English language.

Data Collection Procedure

Each eligible caregiver was contacted via telephone by a trained research assistant and asked if he or she would be interested in participating in the research project. Those who agreed were interviewed in their homes by a trained research assistant. The appointments were usually scheduled within two weeks of the patient's admission to hospice. The caregivers received no financial compensation for their participation in the research project.

The current project utilized fifty (50) of the original eighty (80) elderly spousal caregivers of either end-stage dementia (N=21) or lung cancer (N=29) patients. For the current sample, the mean length of time between initial interview and the death of the patient was approximately four (4) months, however this varied by patient diagnosis

(mean of 145 days for dementia patients and 57 days for cancer patients). It is important to note that an average of four months of stay in hospice is atypical and the current mean length of stay for most hospice patients is 55 days with a median of 22 days (National Hospice and Palliative Care Organization, n.d.). The bereaved caregivers were recruited in the same manner as described previously and were again administered a comprehensive structured personal interview and questionnaire in their homes, usually within four and one half (4 ½) months following the date of the patient's death. The minimum time elapsed from the patient death to the caregiver bereavement interview was one month and the maximum time elapsed from the patient death to the caregiver bereavement interview was ten months.

Attrition from Time 1 to Time 2

The average amount of time that elapsed between the Time 1 (T1-Pre-loss) Interview and the Time 2 (T2-Post-loss) Interview was eight (8) months. The minimum amount of time that elapsed between the T1 and the T2 interviews was approximately two (2) months and the maximum amount of time that elapsed between the T1 and T2 interviews was approximately two (2) years. During this period of time, thirty (30) participants were lost from the study (13 declined participation, 9 moved out of the area, and 8 were not recertified by LifePath Hospice). The participants who remained in the study did not differ significantly (p>.05) from those who were not included in the follow-up interview on any of the demographic characteristics or baseline variables used in this study.

Measures

Caregiver Demographics

Caregiver demographic and descriptive information, specifically age, gender, education, and race/ethnicity, were assessed through caregiver self-report during the pre-loss interview.

Caregiving Stressors

To assess caregiving stressors, information was gathered during the pre-loss interview on a variety of indicators including: duration of caregiving in months, hours of caregiving per week, patient self-care problems, and patient diagnosis. Duration of caregiving and hours per week caregiving were assessed using self-report. Patient self-care problems (alpha=.89) included impairments in both functional abilities (Activities of Daily Living; ADL; Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963), such as bathing and dressing, and higher-level functioning abilities, such as managing finances and completing household chores (Independent Activities of Daily Living; IADL; Lawton & Brody, 1969), with higher scores indicating more self-care problems. Patients included in this study were diagnosed with either dementia or lung cancer, and were identified as such when initially recruited into the study.

Appraisals

Stressfulness of ADL and IADL impairments (alpha=.87) was assessed during the pre-loss interview using a 0 to 3 Likert-type scale, with responses ranging from "not at all

stressful" to "very stressful" for each of the functional abilities (Katz et al., 1963; Lawton & Brody, 1969). Stressfulness scores were adjusted for the number of problems experienced by the patient, so scores reflect the average subjective stressfulness of problems, independent of how many problems the caregiver faced, with higher score indicating more stressful appraisals.

Positive aspects of caregiving (alpha=.80) were assessed during the pre-loss interview using an 11-item self-report measure developed by Schulz and his colleagues (Schulz, Newsom, Mittelmark, Burton, Hirsch & Jackson, 1997). Each item begins with "Providing help to (care recipient) has…" and contains specific items such as "given more meaning to my life" and "made me feel useful." The participants were asked to rate each item using either a "yes" or "no" response, with higher scores indicating more caregiving benefit.

Social Resources

Social activities (alpha=.62) were assessed during the pre-loss interview using the 16 item Multilevel Assessment Inventory (MAI; Lawton, Moss, Fulcomer & Kleban, 1982), which utilizes a 5 point Likert-type scale with responses ranging from "0" indicating "never" and 5 indicating "12 or more times" to examine level of caregiver participation in social activities during the previous month. Some of the items included in this measure are eating at a restaurant with friends and relatives, attending club activities, and doing volunteer work, with higher scores indicating higher number of social activities.

Size of the social network (alpha=.74) was assessed during the pre-loss interview

using an 8 item measure from the revised Lubben Social Network Index (Lubben, 1988).

Two types of questions are included in this measure: number of contacts and frequency

of contact. Participants were asked to list the number of relatives and friends they hear

from or feel close to using a 6 point Likert-type scale with responses ranging from 0

indicating "zero" and 6 indicating "nine or more." For questions addressing the

frequency of contact with a close friend or relative, the same response range was used,

with responses indicating "less than monthly" to "daily." Higher scores on this measure

indicated a larger social network.

Social support (alpha=.76) and satisfaction with social support (alpha=.63) were

assessed during the pre-loss interview using a 14 item scale by Krause and Borawski-

Clark (1995). Specifically, to assess social support, participants were asked to rate how

often others have provided tangible, emotional, and informational support during the past

month using a 4 point Likert-type scale with responses ranging from 1 indicating "never"

and 4 indicating "often." Satisfaction with social support was assessed by participant

ratings for each of the three types of social support using the same response range with

responses indicating "not at all" to "very" satisfied. For both of these measures, higher

scores indicate higher levels of received social support and satisfaction with social

support.

Well-Being

Depression (alpha=.81) was assessed during both the pre-loss and post-loss

interviews using the 20 item Center for Epidemiological Studies-Depression Scale (CES-

D; Radloff, 1977). Participants rated how often they experienced symptoms associated

with depression, such as restless sleep, poor appetite, and feeling lonely, over the past week using a 4 point Likert-type scale with responses ranging from 0 indicating "rarely or none of the time (less than once a day)" to 3 indicating "most of the time (5-7 days)" with four items, such as enjoying life, feeling happy, and feeling hopeful about the future reverse coded. Higher scores on the CES-D indicate higher frequency/severity of depressive symptomatology.

Life satisfaction (alpha=.76) was assessed during both pre-loss and post-loss interviews using the 13 item Life Satisfaction Index-Z (LSI-Z; Wood, Wylie, & Sheafor, 1969). Participants were asked to indicate if they agreed, disagreed or were uncertain about items related to general statements about life, such as "I am just as happy as when I was younger" and "I have made plans for things I'll be doing a month or year from now." In addition five items in this measure, including "this is the most hopeless time of my life" and "most of the things I do are boring or monotonous," were reverse-coded. Higher scores on the LSI-Z indicate higher levels of overall life satisfaction.

Grief (alpha=.88) was measured during the post-loss interview using 13 items from the Texas Revised Inventory of Grief (TRIG; Faschingbauer, Zisook, & DeVaul, 1987). This scale assessed symptoms associated with separation distress, such as "sometimes I very much miss the person who died" and "I am unable to accept the death of the person who died," using a 5 point Likert-type scale with responses ranging from 1 indicating "completely false" to 5 indicating "completely true." Higher scores on this scale indicate higher levels of grief.

Statistical Analysis Plan

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The first step was to examine correlations between the demographic characteristics, specifically age, gender, education, and race/ethnicity, and the three outcome measures, depression, life satisfaction, and grief, to determine if any were needed as covariates in the regression analyses. Due to the small sample size, only demographic characteristics and pre-loss caregiving well-being variables that were significantly correlated ($p<.05$) with the dependent variables were utilized in the regression analyses.

The second step was to conduct univariate analyses in order to get an understanding of which variables were significant predictors of post-loss depression, life satisfaction, and grief. The domains of variables used for this step of the analysis include pre-loss caregiver well-being, caregiving stressors, appraisals, and social resources. This step allowed us to determine which predictors to use in the regression models.

The third step was to utilize three hierarchical multiple regression models (one for depression, one for life satisfaction, and one for grief) using the significant predictors from the previous analyses in order to gain a better understanding of the relationships between pre-loss characteristics and their effect on post-loss well-being outcomes. In addition, using this rationale for selection of predictor variables allowed us to limit the number of predictors in order to accommodate the limited sample size. The order of entry for the regression models was as follows: (1) any necessary covariates (as determined by step one) and pre-loss caregiver well-being measures, (2) objective measures of caregiving, (3) subjective appraisals of the caregiving experience, and (4) objective and subjective measures of social support.

Results

Demographics and Basic Descriptive Analysis

As shown in Table 5, the mean age of the sample was 72.84 at the pre-loss interview and predominantly female. In addition, these spousal hospice caregivers identified themselves as primarily Caucasian American (n=39), with 3 participants identifying themselves as African American, 7 as Hispanic American, and 1 as Asian American (for the purpose of the statistical analyses, race/ethnicity was examined as a dichotomous variable, with individuals categorized as either White or Non-White). Table 5 also indicates that the education level of the participants in this study varied.

Table 5. Demographic Characteristics of the Sample

Age, mean years (SD)	72.84 (10.21)
% Female	80.00
% White	78.00
Education	
% <8th grade	34.00
% High School/Some College	52.00
% College Degree	14.00

In order to gain a better understanding of the caregiving stressors, appraisals, social resources, and well-being of our participants, Table 6 shows the means and standard deviations for all variables utilized in the univariate and regression analyses.

Table 6. Means and Standard Deviations for all Study Variables

Variable	Actual Range	Mean	SD
Well-Being Measures			
Pre-loss Depression	0-60	16.42	9.17
Pre-loss Life Satisfaction	0-26	15.58	5.67
Post-loss Depression	0-60	23.28	10.11
Post-loss Life Satisfaction	0-26	14.38	5.47
Post-loss Grief	1-5	3.81	.79
Caregiving Stressors			
Duration (months)	n/a	25.18	32.86
Hours/week	n/a	94.74	70.10
ADL/IADL Impairments	0-14	11.28	3.33
Diagnosis	n/a	n/a	n/a
Appraisals			
Stressfulness of ADL/IADL Impairments	0-3	.80	.74
Positive Aspects of Caregiving	0-11	8.18	2.90
Social Resources			
Social Activities	0-80	9.36	6.12
Social Network	0-40	25.54	6.92
Social Support	11-44	26.52	6.12
Satisfaction w/ Social Support	3-12	10.36	1.76

The initial set of analyses indicated that only one correlation was significant between the caregiver demographics and our three outcome measures (post-loss depression, post-loss life satisfaction, and post-loss grief): race/ethnicity and post-loss depression (see Table 7). This significant negative correlation indicates that Non-White hospice caregivers report higher levels of depressive symptomatology in our sample.

Univariate Analyses

The results of the univariate correlational analysis for all of the variables included in this study are displayed in Table 7. The results of these analyses indicated that lower baseline depression, fewer months caregiving, lower levels of social activities, smaller size of social network, and lower satisfaction with social support were all significantly correlated with higher post-loss depressive symptomatology. Neither of our pre-loss measures of appraisal of the caregiving experience, stressfulness of ADL/IADL impairments and positive aspects of caregiving, was significantly correlated with post-loss depression.

Higher levels of satisfaction with social support while caregiving was the only variable significantly correlated with higher levels of life satisfaction post-loss. None of the caregiving stressor, appraisal, or objective social resource measures, or life satisfaction pre-loss were significantly correlated with life satisfaction post-loss. (Follow-up regression analysis was not conducted for post-loss life satisfaction due to the fact that only one variable was significantly correlated with this outcome variable.)

Table 7. Correlation Matrix for all Study Variables

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
Caregiver Demographics																			
1. Age	1.00	-.10	.21	.20	-.10	.02	.12	.51**	-.39*	.17	-.09	-.15	.01	-.29*	-.06	.22	-.13	.18	-.27
2. Gender		1.00	-.28**	.22	.11	-.17	.04	.18	.01	-.12	-.16	.03	.03	.20	.41**	.16	-.04	-.08	.02
3. Education			1.00	.16	-.20	.31	.32*	-.08	.06	-.20	.07	.01	.26	-.14	-.11	-.04	-.21	.03	-.28
4. Race/Ethnicity				1.00	-.07	.25	.10	-.05	-.39**	-.01	-.09	-.08	.22	.22	.18	.22	-.41**	.28	-.27
Caregiving Stressors																			
5. Duration (months)					1.00	-.15	.30	-.48**	-.08	.14	.08	-.03	.12	.07	-.15	.15	-.31*	.25	-.35*
6. Hours/week						1.00	.04	.323*	.31*	.11	-.26	.01	-.02	-.08	.06	-.10	.05	-.01	.13
7. ADL/IADL Impairments							1.00	-.52**	.26	.08	.20	-.30*	.01	-.18	.18	.15	-.17	.02	-.31*
8. Diagnosis								1.00	.18	.08	-.14	.26	.06	-.03	.14	.06	.08	-.04	.26
Appraisals																			
9. Stressfulness of ADL/IADL Impairments									1.00	.28*	.03	-.11	-.15	-.20	.15	-.11	.10	-.01	.16
10. Positive Aspects of Caregiving										1.00	-.21	.23	.30*	.23	-.37**	.19	-.01	-.01	.11
Social Resources																			
11. Social Activities											1.00	.18	-.07	.17	-.20	.33*	-.28*	.09	-.27
12. Social Network												1.00	.54**	.42**	-.26*	.12	-.33*	.22	.08
13. Social Support													1.00	.53**	.24	.07	-.25	.17	-.05
14. Satisfaction w/ Social Support														1.00	-.46**	.28	-.41**	.31*	-.07
Well-Being Measures																			
15. Pre-loss Dep															1.00	-.46**	-.29*	-.24	.20
16. Pre-loss LS																1.00	-.13	.22	.01
17. Post-loss Dep																	1.00	-.60**	.61**
18. Post-loss LS																		1.00	-.41**
19. Post-loss Grief																			1.00

* p<.05   **p<.01

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Fewer months in the caregiving role and lower number of ADL/IADL impairments were significantly correlated with grief in the correlational analysis. None of the baseline measures of well-being, appraisal variables, or social resource measures were significantly correlated with grief in our sample.

Regression Models

The regression model with post-loss depression as the dependent variable is shown in Table 8. In the final regression model, being non-White and having fewer months in the caregiving role were associated with higher post-loss depression. The block of social resource variables accounted for significant variance, but none of the individual variables reached statistical significance. The model accounted for 39% of variance in post-loss depression.

The model with grief as the dependent variable was examined using linear regression due to the fact that the two variables that were significantly correlated with grief were both from the same block of the proposed hierarchical regression model (caregiving stressors). The two variables utilized in this regression model were duration of caregiving and ADL/IADL impairments. This block of variables accounted for 17.2% of the variance in the model. When both variables were considered simultaneously the number of ADL/IADL impairments was not associated with higher levels of grief post-loss (B=-.05, β=-.23, p=.111), but fewer months in the caregiving role was associated with higher levels of grief (B=-.01, β=-.29, p=.04).

Table 8. Regression Model for Post-loss Depression

Variable	B	β	R^2	ΔR^2
Step 1: Demographics and Pre-loss Well-Being			.23*	
Race/Ethnicity (Non-White)	-6.52	-.27*		
Depression	.07	.06		
Step 2: Caregiving Stressors			.29*	.06*
Duration of Caregiving	-.08	-.25*		
Step 3: Social Resources			.39*	.10*
Social Activities	-.20	-.12		
Social Network	-.22	-.15		
Satisfaction with Social Support	-1.29	-.22		

*p<.05

Discussion

Although there has been a growing interest in the expansion of both the
caregiving and bereavement literature to include both positive and negative assessment
measures as both predictor and outcome variables, this literature is still relatively small,
particularly when it comes to the relationship between these two life events. This study
sought to identify how pre-loss caregiving experiences were associated with post-loss
depression, life satisfaction, and grief using a stress process theory framework in a
sample of bereaved former hospice caregivers.

Both the univariate and regression analyses highlighted the importance of studying multiple domains of well-being outcomes, as the significant associations and predictors for depression, life satisfaction, and grief showed great variability. The results of the univariate analyses indicated that being non-White, having lower baseline depression, spending fewer months caregiving, having lower levels of social activities, having smaller size of social network, and having lower satisfaction with social support were all significantly correlated with higher post-loss depressive symptomatology. Once these variables were placed into the regression model, being non-White, fewer months caregiving, and having lower levels of social resources remained as significant predictors. The findings from our analyses were consistent with the anticipatory grief hypothesis that longer duration of caregiving was related to better well-being outcomes during bereavement and the resource depletion hypothesis that higher levels of social resources would be associated with lower depression post-loss in our sample. However, neither the resource depletion or relief hypothesis related to the role of appraisals of the caregiving experience was supported in this study. Interestingly, pre-loss depression was not very highly correlated with post-loss depression in our study. Prior studies have found relative consistency in depression scores over time while an individual is still in the caregiving role and much higher correlations between pre-loss and post-loss depression (Boerner et al., 2004; Goode et al., 1998), however the latter finding has not always been consistent (Bonanno et al., 2002). It is likely that the short-term nature of our bereavement follow-up was important in this finding as prior research has shown that it is common for grieving persons to be acutely distressed regardless of their baseline levels of depression, particularly in the short term (Raphael, Minkov, & Dobson, 2001).

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Given the findings from our sample as they relate to depression, it may actually be the concept of anticipatory grief that is playing the most important role. Individuals who had been providing care for a longer period of time exhibited lower levels of depressive symptomatology in our sample suggesting that on an individual level, having time to adjust to the inevitable loss following a debilitating illness may lead to better outcomes during bereavement. The ideas that individuals experience a sense of relief following the loss of a spouse, particularly after a period of extensive caregiving, (Mullan, 1992; Schulz, Mendelsohn, Haley, Mahoney, Allen, et al., 2003) and that unexpected death leads to higher levels of depression (Carr et al., 2001) have both been demonstrated in the bereavement literature. One of the strengths of our study is the tremendous variability in duration of caregiving. Only 32% of our sample had been providing care to their spouse for six months or less and 48% had been involved in caregiving for more than a year. It is possible that the inclusion of such a wide range of caregiving durations allowed us to see the effects of anticipatory grief. Effects such as those related to relief may be more evident on longer term follow-up.

Due to the small sample size and the diversity in the non-White participants, it is beyond the scope of this study to be able to thoroughly interpret the finding that race/ethnicity was associated with post-loss depression. However the strength of the relationship between these two variables suggests that future attention needs to be paid to the differing effects of bereavement on multiple racial and ethnic groups. One study that examined reactions of caregivers of Alzheimer's disease patients to the loss of the care recipient using both White and African American participants found that African American caregivers reported less acceptance of the relative's death, greater perceived

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loss, and less anticipatory grief (Owen, Goode, & Haley, 2001). The authors of this study suggested that ethnic differences in bereavement merit future research, and our finding related to the association between race/ethnicity and depression offer credence to that suggestion. One additional recent study that examined the effects of widowhood on well-being found that African American and Caucasian American widows reported similar levels of overall grief, yearning, intrusive thoughts, shock, depressive symptoms, and anxiety (Carr, 2004). This study did find differences between these two groups on two outcomes, anger and despair, with African Americans reporting significantly lower levels compared to Caucasian Americans. Future studies should include large enough samples to examine differential effects of bereavement on distinct racial/ethnic groups, since cultural variables appear to have a marked impact on end-of-life issues (Kwak & Haley, in press).

The second outcome variable examined in this study was life satisfaction. None of the hypotheses relating to caregiving stressors or appraisals were supported by the research findings, and interestingly only satisfaction with social support was significantly associated with post-loss life satisfaction. These findings lend support to the idea that positive and negative well-being outcome measures are not mutually exclusive and need to be examined independently of each other in order for researchers and practitioners to begin to understand the complex relationship between pre-loss characteristics and bereavement.

Our results related to grief following the loss of a spouse indicated that fewer months in the caregiving role and lower number of functional impairments were significant predictors of higher levels of grief. These findings were both consistent with

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and distinct from those seen in the depression model. The univariate analyses revealed that none of the appraisal or social resource variables was significantly associated with grief, contrary to the tenets of resource depletion and relief hypotheses. As discussed above, it is possible that for our sample, the factor that most protected an individual from experiencing a higher grief reaction was the chance to prepare him or herself for the loss. In addition, caregivers who were exposed to higher levels of functional impairments experienced less grief, suggesting that having to provide assistance to a spouse on everyday tasks such as dressing, toileting, and bathing, may have also been a factor in aiding these individuals in adjusting to the loss with less distress. The fact that social resources were not significant in the grief analyses as they were in depression lends support to the belief by many researchers that grief and depression are distinct concepts that represent different facets of bereavement and need to be examined in the research as such (Boerner et al., 2004; Bonanno, Wortman, Lehman, Tweed, Haring, et al., 2002; Prigerson & Jacobs, 2001). Current bereavement researchers have differentiated between grief and depression in the development of bereavement trajectories (Bonanno et al., 2002), and have also begun to identify symptoms of "traumatic grief" that are distinct from those of depression-related depression and anxiety (see Prigerson & Jacobs, 2001).

Limitations

Our study had a number of limitations that warrant discussion, including a single, relatively short-term follow-up, and the small sample size. Although the use of both pre-loss and post-loss data allowed us to examine predictors, the post-loss interview was conducted in a relatively short amount of time after the death (approximately 4 months).

The inclusion of at least one additional longer-term post-loss data collection point and a control group would have allowed us to examine patterns of depression, life satisfaction, and grief over time. It is also important to note that although the average follow-up data collection interview was four months after the loss, there was variation in the length of time for each participant (range of 1-10 months). Greater power related to a larger sample size, similar to the one used by Boerner et al. (2004), may have produced additional significant predictors; this dataset contained sufficient sample size to detect predictors with a medium effect size, but was insufficient in detecting predictors with a small one (Stevens, 2002). In addition, we were limited in the sophistication of our statistical analyses and were unable to utilize methodologies such as mediating and moderating analysis and structural equation modeling, which have been used by other researchers to evaluate stress process models of caregiving (Goode, Haley, Roth, & Ford, 1998; Haley, Roth, Coleton, Ford, West, et al., 1996). As previously discussed, we were unable to make any inferences about the finding related to race/ethnicity and post-loss depression due to both the small sample size overall and the small numbers of individuals from any particular cultural group.

Future Directions

Taken together the findings from our study contribute to the relatively recent literature that suggests that both positive and negative measures need to be utilized as both predictor and outcome variables in future research in order to begin to develop a more comprehensive picture of the relationship between caregiving and bereavement. While our study did not find a relationship between positive aspects of caregiving and

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bereavement outcomes, either positive or negative, a recent paper using a much larger dataset found that this appraisal measure was significantly associated with both grief and depression post-loss (Boerner et al., 2004). One of the main goals of this area of research is to aid both researchers and practitioners in identifying factors present prior to the loss of a spouse that place caregivers at risk for complications during bereavement. By expanding the domains of variables used in this area of research, it is possible to gain an understanding not only of which factors put an individual at risk for negative outcomes, but also to identify those that are protective factors that lead to a healthy adjustment to bereavement. The findings from our study suggest that caregiving appraisals may not play as significant a role in adjustment to bereavement as they do while caregiving. In addition, the need for continued focus on social resource variables as potential buffers against negative well-being outcomes during bereavement was supported by our study. Our findings also highlight the importance of including caregiving context variables in future research and the inclusion of individuals who have a variety of caregiving experiences. We found evidence in support of both the resource depletion and anticipatory grief hypotheses, however this is still a relatively new area of research and there is much more to be done before interventions targeting at risk caregivers can be developed and implemented in caregiving populations. Researchers may also find it beneficial to examine additional caregiving context variables, such as comorbidities, and their relationship to anticipatory grief in future research. Finally, studies of long-term bereavement outcomes will be necessary to better understand the clinical implications of caregiving experiences, since initial grief reactions may not be predictive of clinically significant, long-term adaptation.

Chapter Five

Conclusions and Future Directions

Conclusions

The overall purpose of this dissertation was to add to the current literature on the relationship between caregiving and bereavement using a series of three studies. As discussed in each of the three articles, there is a large body of literature devoted to caregiving and bereavement respectively, but a relatively limited one that addresses these two life stressors simultaneously using prospective data. In addition there is a relatively new and growing interest in including both positive and negative measures in this area of research, as findings from recent studies have shown that only focusing on negative variables has left out a significant portion of the relationship between caregiving and bereavement.

In order to address these gaps in the literature, we used two datasets that contained both pre-loss and post-loss interviews. The first was the Changing Lives of Older Couples (CLOC) study, which allowed for the examination of a wide variety of variables, including but not limited to caregiving characteristics, bereavement trajectories, social interaction, depression, sociodemographics, self-rated physical health, and positive well-being, and their relationship to involvement in the caregiving

experience. The second was a subset of a dataset collected from a large, local non-profit hospice that recruited elderly spousal caregivers of terminally ill patients. This dataset included a variety of widely used and validated measures collected both before and after the death of the patient and it allowed us to examine caregiving stressors, appraisals, and social support while caregiving and their effect on both positive and negative well-being outcomes during bereavement.

The first study utilized four groups of bereaved individuals based upon the circumstances associated with their spouses' deaths: unexpected death, expected loss without caregiving, low stress caregiving, and high stress caregiving. These individuals were interviewed pre-loss and at 6 and 18 months post-loss using measures of psychological, social, and health functioning. The findings from this study indicated that the unexpected death group experienced marked increases in depression from pre-loss to post-loss, which is consistent with prior research. In addition, the highly stressed caregivers were the only group not to show improvements within the domain of social engagement following the loss. This finding added merit to the theory that highly stressed caregivers may experience role engulfment, thus making it more difficult to maintain social support while caregiving and potentially leading to social isolation during bereavement.

The second study focused on the relationship between the caregiving groups utilized in the first study and five core bereavement trajectories previously identified by bereavement researchers: common grief, chronic grief, chronic depression, improvement during bereavement, and resilience. The results from this study indicated that there were differences in bereavement trajectories based upon caregiving status. The non-caregiving

and low stress caregiving groups exhibited similar distributions across the five trajectories, however unexpected death was associated with higher prevalence of the chronic grief trajectory and highly stressed caregiving was associated with higher rates of chronic depression. Interestingly, the highest number of participants from each of the four groups fell into the resilient category, indicating that there is a need for research that aims to better understand the underlying mechanisms, such as social support, that protect individuals from negative bereavement outcomes.

The last study of this dissertation used a stress process model framework in order to assess how pre-loss measures of caregiving stressors, appraisals, and social resources were related to short term well-being outcomes during bereavement. Interestingly, our study did not find that pre-loss caregiving appraisals, either positive or negative, were significantly associated with well-being outcomes during bereavement. The analyses found that fewer months caregiving and lower levels of social resources were significant predictors of higher levels of depression during bereavement. In addition, two caregiving stressors, fewer months caregiving and lower numbers of functional impairments, were associated with higher grief post-loss, while neither the appraisal nor the social resource variables had a significant impact. We also found that only satisfaction with social support was a significant predictor of life satisfaction during bereavement. These findings lend support to the resource depletion hypothesis and the theory of anticipatory grief, while at the same time highlighting the distinct nature of bereavement well-being measures and the complexity of the relationship between caregiving and bereavement.

Taken together, the findings from this dissertation strongly support the idea that researchers need to continue focusing on a variety of study variables in order to

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understand the complexity in the relationship between caregiving and bereavement. In addition social support and social resources during caregiving may prove to have a similar buffering effect on well-being outcomes during bereavement as have been demonstrated in the broader caregiving literature, but it is only through future longitudinal studies that researchers will be able to assess this. Our studies have provided support to the resource depletion and anticipatory grief hypotheses, and we believe that the inclusion of a wider range of individuals with varying degrees of caregiving experience and duration is necessary in future research in order to continue to test these findings.

Limitations

While this dissertation did address very important gaps in the literature, there were limitations that warrant discussion. While the large sample size and collection of both short and long term bereavement follow-ups in the CLOC dataset allowed us to assess changes over time and utilize a wide variety of variables, we were limited to the measures included by the decisions of the researchers who originally designed the study. One example was the caregiving measures that we needed to use in order to classify participants into groups for the first two studies were assessed during the 6-month post-loss interview, a design of the dataset which limited our ability to examine caregiving characteristics as predictor variables in regression models. It is also important to note that the nature of the data collection method (two hour face-to-face interviews conducted at the location of the participant's choosing) may bias the sample toward participants

with low depression or resiliency. Alternatively, the dataset that was utilized in the third study, while it contained a variety of commonly used and validated measures, included a relatively small and restrictive sample. The size of the sample did not allow us to utilize sophisticated statistical methodology, such as mediator and moderator analyses or structural equation modeling. We also were unable to use large regression models and had to be very concise in our statistical analysis plan. An additional limitation was the inclusion of a single, short term bereavement follow-up interview, although this is a fairly common methodology in this area of research. The inclusion of either one or more longer term bereavement follow-up interviews would have potentially given us the ability to detect additional predictors and changes over time. Overall this dissertation was subject to the limitations of both primary and secondary data analysis. While the utilization of secondary data limited our variable selection to those measures chosen by other researchers, primary data collection was restricted by attrition rates and the need to rely on community organizations for sample recruitment.

Future Directions

Drawing on the findings from this dissertation, future research should focus on the transition between caregiving and bereavement and the short and long term effects on surviving spouses. The findings from this dissertation work have confirmed the impression that most researchers and clinicians have that the experience of caregiving and subsequent death both for the patient and the caregiver is exceedingly complex. The primary goal of future research should be to study the nature of the relationship between

caregiving and bereavement from a theoretically and methodologically sound basis, addressing some of the weaknesses that have been present in prior studies. The research to date has pointed to the need to continue to expand the domains of variables utilized in these studies and also to focus on the role of coping through social support and social networks as potentially having a buffering effect on bereavement outcomes. In addition, it is vitally important to develop an updated longitudinal study that includes widely validated and current measures with multiple interview points both before and after the death. Ideally, a study of this nature would also include pre-loss data from the care recipient in order for assessments of the dyad to also be possible.

The first major long term goal that researchers in this field need to address is the development of an inclusive bereavement theory that draws on prior findings from a variety of disciplines and incorporates pre-loss characteristics. The roots of both caregiving and bereavement research lie firmly in psychology and psychiatry, with stress process theory and attachment theory being the two most common theories used. In addition, the Freudian grief work hypothesis and its concepts of the importance of grief work and the detrimental effects of denial have been ingrained in the work of bereavement researchers from the very beginning, although support for its merits are currently being called into question in the literature (Bonanno & Field, 2001). In an attempt to develop an integrative model of bereavement that focused on the strengths of each of these individual theories, Stroebe and Schut (1999) developed the dual process model of coping with bereavement. While this model had the advantages of utilizing existing research findings, incorporating both male and female coping styles, allowing for pre-loss characteristics and individual differences, and incorporating the potential

advantages of the short term use of denial, its lack of specific pathways and measurable characteristics made it difficult for researchers to study.

The second major goal of research on the relationship between caregiving and bereavement is the use of both the present and future findings from prospective, longitudinal studies utilizing widely validated measures and sophisticated methodology to examine a more comprehensive understanding of these two stressors and how they relate to each other. It is vitally important to conduct research with results that can be applied within the community and lead to the betterment of the lives of both older adults and their families. The long term goal of researchers in this field should be to conduct studies that can eventually lead to the development of an intervention for at-risk caregivers that can be implemented and scientifically tested. Research on bereavement intervention to date has been disappointing, and does not support the use of many conventional grief therapies that are being commonly promoted and used in the community (Neimeyer, 2000; Schut, Stroebe, van den Bout, & Terheggen, 2001). In order for an appropriate intervention to be designed, researchers need to utilize longitudinal data in order to produce a model for the identification of at-risk caregivers that can be used in a community sample. Upon successful identification of an appropriate sample, an intervention program targeted at lowering depression, increasing life satisfaction, and increasing the quality and nature of social support during both caregiving and bereavement could be implemented in the community.

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Appendix

Appendix A: Curriculum Vitae

CURRICULUM VITAE
Allison M. Burton

Business   **Residence**

University of South Florida   9507 West Riverchase Drive
School of Aging Studies, MHC 1305   Tampa, FL 33637
4202 E. Fowler Avenue   Telephone: (813) 914-8395
Tampa, FL 33620-8100
Telephone: (813) 974-2646
Fax: (813) 974-9754
E-mail: amburton@cas.usf.edu

Place of Birth: Houma, LA, USA

Education

2000 – present   University of South Florida-Tampa
                      Doctoral Candidate
                      Major: Ph.D. in Aging Studies

1995 – 2000   Louisiana State University-Baton Rouge
                      Major: B. S. in Psychology

Positions Held

2002 - present   Graduate Teaching Assistant, School of Aging Studies, University
                      of South Florida

2001 - present   Graduate Research Assistant, Dr. William E. Haley's Gerontology
                      Lab, University of South Florida

2003 - 2004   Graduate Research Assistant, Department of Research, LifePath
                      Hospice and Palliative Care, Tampa, FL

2002 - 2003   Graduate Research Assistant, Center for Hospice, Palliative Care,
                      and End-of-Life Research, University of South Florida, including
                      serving as a Research Assistant for LifePath Hospice and Palliative

Care, Inc., Tampa, FL, and Hospice of the Florida Suncoast, Largo, FL

Appendix A (continued)

1998 - 2000   Undergraduate Research Assistant, Dr. Katie Cherry's Developmental Psychology Research Lab, Louisiana State University

Teaching Experience

2003 - present   Death and Dying, a senior-level course, University of South Florida (7 semesters)

2002   Psychology and Aging, a senior-level course, University of South Florida (1 semester)

Journal Publications

Burton, A. M., Haley, W. E., & Small, B. J. (2005). *Bereavement after caregiving or unexpected death: Effects on elderly spouses.* Under review.

Cherry, K. E., Brigman, S., & Burton A. M. (2004). *Perceptions of forgetfulness in adulthood*. Under review.

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.

Haley, W. E., Allen, R. S., Reynolds, S., Chen, H., Burton, A. M., & Gallagher-Thompson, D. (2002). Family issues in end-of-life decision making and end-of-life care. *American Behavioral Scientist, 46*(2), 284-297.

Book Chapters

Burton, A. M., Kwak, J., & Haley, W. E. (2004). Elder Caregiving. In C. Spielberger (Ed.), *Encyclopedia of Applied Psychology* (pp. 703-711). San Diego: Academic Press.

Appendix A (continued)

Haley, W. E., Burton, A. M., LaMonde, L. A. & Schonwetter, R. S. (2004). Family
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Ershler, & M. Extermann (Eds.), *Comprehensive Geriatric Oncology* (2nd ed., pp.
843-852). London: Taylor & Francis.

<u>Presentations at Professional Meetings</u>

Burton, A. M., Haley, W. E., and Small, B. J. (2004, November). The impact of
the caregiving experience on well-being during bereavement: From
baseline to 18-months post-loss. Poster session presented at the annual
meeting of the Gerotological Society of America, Washington, DC.

Burton, A. M. (2003, November). Psychological well-being in bereaved
spouses: From baseline to 18-months post-loss. In W. E. Haley (Chair),
The USF Graduate Student Symposium on the Continuum of Health:
From Wellness to End-of-Life. Symposium presented at the annual
meeting of the Gerongological Society of America, San Diego, CA.

Burton, A. M. (2003, November). Th impact of the caregiving experience on
psychological bereavement outcomes: From baseline to 18-months
post-loss. Poster session presented at the annual conference for the
Center for Hospice, Palliative Care, and End-of-Life Research, Tampa, FL.

Burton, A. M., Haley, W. E., & Kwak, J. (2002, November). Psychosocial and
satisfaction outcomes in bereaved former hospice caregivers. Poster session
presented at the annual meeting of the Gerontological Society of America,
Boston, MA.

Haley, W. E., Burton, A. M., Robb, C., & Schonwetter, R. (2002, February).
Depression in bereaved spousal caregivers of hospice patients. Presented at the
annual meeting of the American Academy of Hospice and Palliative Medicine,
Palm Springs, CA.

Burton, A. M., Haley, W. E., Robb, C., & Schonwetter, R. (2001, November).
Service utilization in bereaved former hospice caregivers. Poster
session presented at the annual meeting of the Gerontological Society of
America, Chicago, IL.

Appendix A (continued)

Burton, A.M. (2001, April). Research experiences of a first-year Ph.D. student.
      In W. E. Haley (Chair), USF Ph.D. in Aging Studies Program: Interdisciplinary
      Student Research on End of Life Issues. Symposium conducted at the annual
      meeting of the Southern Gerontological Society, Lexington, KY.

Cherry, K. E., Brigman, S., Burton, A. M., & Roecke, C. (1999, November).
      Perceptions of forgetfulness in adulthood. Presented at the eighth
      annual Cognitive Aging conference, Atlanta, GA.

Grants Completed

Served as the principal investigator on a pilot grant from the USF Center for
      Hospice, Palliative Care, and End-of-Life Research examining
      psychosocial outcomes and service utilization among bereaved former
      hospice caregivers ($12,000), W. E. Haley.

Honors and Professional Activities

2005	Awarded the Provost's Award for Outstanding Teaching by a Graduate Teaching Assistant, University of South Florida
2004	Awarded the Provost's Commendation for Outstanding Teaching by a Graduate Teaching Assistant, University of South Florida
2003 - 2004	President of the Student Association for Aging Studies, University of South Florida
2003 - 2004	Student Representative to the Ph.D. in Aging Studies Committee, University of South Florida
2002	Attended the CLOC Data Release Conference, Institute for Social Research, University of Michigan
2002 - 2003	University of South Florida Center for Hospice, Palliative Care, and End-of-Life Studies pilot grant/graduate research assistant recipient

| 2001 - present | Member, Gerontological Society of America |

Appendix A (continued)

2002 - present	Member, Center for Hospice, Palliative Care, and End-of-Life Studies, University of South Florida,
2000 - 2001	Institute on Aging Fellowship, University of South Florida,
1998 - 2000	Active member in Psi Chi, including two years as student representative
1995	LSU Presidential Scholarship, five year full tuition and fees, including on campus employment for research

Related Activities

| 2000 –2002 | Patient Volunteer, LifePath Hospice and Palliative Care, Inc., Tampa, FL |
| 1990 – 2000 | Volunteer at various local nursing homes and hospitals |

Ad Hoc Reviews

American Behavioral Scientist
Death Studies

Research Interests and Current Projects

End of Life Issues, specifically hospice care, bereavement, and family caregiving; Interventions for family caregivers.

About the Author

Allison M. Burton received her Bachelor's of Science Degree in Psychology from Louisiana State University in May of 2000. She entered the Ph.D. in Aging Studies program at the University of South Florida in the Fall of 2000 with an interest in caregiving and end-of-life.

While in the Ph.D. program at the University of South Florida, Ms. Burton was involved with two local large non-profit hospices and was employed as a Graduate Teaching Assistant in the School of Aging Studies, primarily responsible for teaching Death and Dying. Ms. Burton co-authored four publications in peer-reviewed journals and two book chapters while enrolled as a student, as well as presenting her research at multiple regional and national conferences.