

EXPLAINING THE SUBJECTIVE WELL-BEING OF INFORMAL CAREGIVERS AFTER
CARE RECIPIENT DEATH: THE INFLUENCE OF CHANGE IN ACTIVITY RESTRICTION

by

TAMAR ESTER SHOVALI

(Under the Direction of Douglas A. Kleiber)

ABSTRACT

The present study examined the role of activity restriction on caregiver well-being in the wake of care recipient death. Objectives were to determine whether and how caregivers' perceptions of activity restriction change from the pre- to post-transition period and the impact of that change on post-transition caregiver subjective well-being. This research also examined whether restrictions in different kinds of activities predict post-transition caregiver well-being differently. Analyses were based on data from 72 caregivers in the second Family Relationships in Late Life (FRILL2) project who relinquished their roles due to care recipient death. Cross-sectional bivariate analyses showed that caregivers who perceived that they were restricted in their routine activities and were more likely to report more depressive symptoms. Extending previous research, greater activity restriction following was related to more depression after care recipient death. Results from t-tests showed that, at the aggregate level, caregivers perceived less activity restriction after care recipient death than during caregiving, with greater decreases found in expressive activity restriction than instrumental activity restriction through the transition. In multivariate analyses using longitudinal data, decreases in activity restriction from

the pre-transition to post-transition period predicted less depression and grief and more relief after care recipient death. Support was found for the differing impact of expressive and instrumental activity restriction on caregiver well-being following care recipient death. Specifically, decreases in expressive activity restriction predicted less depressive symptomology and grief to a slightly greater extent than did decreases in instrumental activity restriction, whereas decreases in instrumental activity restriction predicted greater relief than did decreases in expressive activity restriction. Results provide support for the assumptions of the activity restriction model of depressed affect and the stress-relief hypothesis of bereavement. This study provides information about the processes behind caregiver transitions due to care recipient death and adds to our understanding of the conditions in which caregivers adapt to bereavement after a major life role ends. Study limitations, future directions, and opportunities for intervention are discussed.

INDEX WORDS: Informal caregiving, Transition, Death, Activity restriction, Depression, Grief, Relief

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DEDICATION

This journey would not have been possible without the devoted support of my parents, Uzi and Karen Shovali. Together you have taught me about unconditional love, living life to the fullest, and perseverance in the face of seemingly impossible obstacles. And, to my dearest Briana—I am so fortunate to have you as my sister and my friend, suspecting you know me better than I know myself. With every passing year my love, appreciation, and respect for you grows; I don't know what I would do without you and look forward to a lifetime of continued friendship and laughter. Thank you Holly Wain, my grandmother, for your unending support—I love the laughter we share. And, thank you to my family in Eretz Yisrael who are devoted to my happiness. I would be remiss if I didn't mention my remarkable friends and colleagues who also have been on this journey with me in one way or another: from visits to catch up or reconnect; to coffee shop writing stints; to late night phone calls full of laughter; to impromptu lunches; to pop-up writing rooms; to unexpected adventures; to sharing sweet treats and off-key singing. I am lucky to have been able to draw inspiration and encouragement from such a richly authentic group of people.

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TABLE OF CONTENTS

	Page
ACKNOWLEDGEMENTS	v
LIST OF TABLES	viii
LIST OF FIGURES	ix
CHAPTER	
1 INTRODUCTION	1
2 LITERATURE REVIEW	9
Caregiver Health	9
Caregiving and Changes in Leisure Engagement	11
Activity Restriction: Bridging the Gap	13
Caregiver Bereavement.....	22
3 SPECIFIC AIMS AND HYPOTHESES	30
4 METHOD	34
5 RESULTS	45
6 DISCUSSION	70
Caregiver Perceptions of Activity Restriction Differ before and after Care Recipient Death.....	73
Activity Restriction Predicts Caregiver Well-Being after Care Recipient Death	76
Study Limitations.....	79

Study Implications and Future Directions	84
REFERENCES	87
APPENDICES	107
A MEASURE OF ACTIVITY RESTRICTION.....	107
B MEASURE OF DEPRESSION	108
C MEASURE OF GRIEF/BEREAVEMENT	109
D MEASURES OF RELIEF	110

LIST OF TABLES

	Page
Table 1: Summary of Psychometric Properties of Study Variables at Pre- and Post-Transition	
Interviews.....	41
Table 2: Classification of the ARS Items	42
Table 3: Intercorrelations Among Study Variables at Pre- and Post-Transition	52
Table 4: Paired Samples T-Tests Comparing Activity Restriction Scores Before and After Care	
Recipient Death.....	54
Table 5: Hierarchical Regression Analysis of AR Predicting Post-Transition Depression.....	58
Table 6: Hierarchical Regression Analysis of EAR Predicting Post-Transition Depression	59
Table 7: Hierarchical Regression Analysis of IAR Predicting Post-Transition Depression	60
Table 8: Hierarchical Regression Analysis of AR Predicting Grief.....	61
Table 9: Hierarchical Regression Analysis of EAR Predicting Grief.....	62
Table 10: Hierarchical Regression Analysis of IAR Predicting Grief.....	63
Table 11: Hierarchical Regression Analysis of AR Predicting Relief.....	64
Table 12: Hierarchical Regression Analysis of EAR Predicting Relief	65
Table 13: Hierarchical Regression Analysis of IAR Predicting Relief	66
Table 14: Hierarchical Regression Analysis of AR Predicting Overall Relief.....	67
Table 15: Hierarchical Regression Analysis of EAR Predicting Overall Relief	68
Table 16: Hierarchical Regression Analysis of IAR Predicting Overall Relief	69

LIST OF FIGURES

	Page
Figure 1: FRILL2 Data Points and Sample Sizes	47

CHAPTER 1

INTRODUCTION

Deaths in the United States often are preceded by a period of chronic disability that necessitates care from at least one other individual (Schulz, Newsom, Fleissner, Decamp, & Nieboer, 1997). In the coming years, the large cohort of Baby Boomers will advance through retirement and live longer; thus, the need for care will become even more of a likelihood than it already is. A large percentage (over 78%) of older individuals with complex chronic care needs depend on family members or friends to provide in-home, unpaid assistance prior to death (Thompson, 2000). As caregivers take on this role, their ability to conduct routine activities changes, and when they transition out of the caregiver role, their ability to conduct routine activities may change again. The purpose of this study was to examine informal caregivers' adjustment during the transition associated with care recipient death with a focus on the effects that caregivers' changing perceptions of their activity engagement have on their subjective well-being.

Caregiving "Career" Framework

Caregiving is beset with difficult transitions. Aneshensel, Pearlin, Mullan, Zarit, and Whitlatch (1995) have conceptualized caregiving as a "career" to define the number of transitions that caregivers experience, which often requires changing statuses. The first transition in the caregiving career involves becoming responsible for the care of another individual. Individuals who assume the caregiver role typically experience stress and often perceive changes in their ability to maintain involvement in their normal activities. The

caregiver role eventually ends. In some cases, institutionalization signifies the end of in-home caregiving. However, given that (a) most older adults wish to “age in place,” remaining in their private homes and communities rather than relocating to long-term care communities (Greenberg, 2007; Partners for Livable Communities, 2007), and (b) caregivers usually want to support this preference (Pritchard et al., 1998), institutionalization as the cause of caregiving cessation is less common than is death of the care recipient. This transition has been identified in the caregiving career as role disengagement (Aneshensel et al., 1995). Changes associated with a transition of this nature can impact multiple aspects of caregivers’ emotional well-being. As the term *role disengagement* suggests, when care recipients die, caregivers lose the caregiver identity and are left behind to cope not only with the loss of a family member but also with residual effects of the stress experienced in the caregiver role.

Grief-Relief Model of Bereavement

Following role disengagement, caregivers undergo several emotional responses with varying degrees of intensity. For some, negative emotional reactions to loss may be relatively short-lived (e.g., Chentsova-Dutton et al., 2002; Grant et al., 2002 Thompson, Gallagher-Thompson, Futterman, Gilewski, & Peterson, 1991); for others, bereavement may be more difficult, leading to problematic coping and complications in their course of adjustment that can be lasting and deleterious (e.g., Aneshensel, Botticello, & Yamamoto-Mitani, 2004; Bonanno, Moskowitz, Papa, & Folkman, 2005). For still others, the experience of the death of a care recipient may be accompanied by positive feelings, such as relief from providing care or relief because the care recipient is no longer suffering (Bennett & Vidal-Hall, 2000; Dooley, 2006; Schulz et al., 2003). Much of the literature on the subject has followed one of two opposing hypotheses, stemming from the general stress and coping paradigm: the *complicated-grief*

hypothesis or *stress-relief* hypothesis (i.e., the grief-relief model of bereavement; Bass & Bowman, 1990; George & Gwyther, 1984; Mullan, 1992; Norris & Murrell, 1987; Schulz, Newsom, Fleissner, et al., 1997). Proponents of the complicated-grief hypothesis argue that the chronic strain of providing care depletes caregivers' resources, leaving them vulnerable to stress and unable to cope with additional stressors, such as the death of a care recipient (e.g., Bass & Bowman, 1990). Thus, the stress experienced during caregiving should result in continued strain during bereavement reflecting a "wear and tear" or "depletion" view of transitioning to bereavement. On the other hand, researchers who support the stress-relief hypothesis posit that the death of a care recipient will relieve the chronic stress of caregiving. Caregivers should then be able to re-engage in previously lost roles or activities which should aid in positive adjustment to bereavement. According to this hypothesis, the more difficulty or strain experienced during caregiving, the greater the improvements in well-being that may be expected following the role change (e.g., Schulz et al., 2003).

The majority of research on caregiver adjustment in the context of bereavement has supported a stress-relief perspective (e.g., George & Gwyther, 1984; Li, 2005; Norris & Murrell, 1987, Schulz, Newsom, Fleissner, et al., 1997; Schulz et al., 2003), while a smaller number have supported the complicated-grief hypothesis (e.g., Bass & Bowman, 1990; Dooley, 2006). These studies provide useful information on the effects of care recipient loss, as well as the emotional responses to bereavement. However, very little variance in caregiver mental health outcomes seem to be explained by life events alone (Wortman, Silver, & Kessler, 1993), perhaps reflecting competing influences or mediating factors. In terms of their psychological functioning, the process by which caregivers adjust to transitioning out of the caregiving role remains unclear. Addressing particular explanatory mechanisms that might account for variability in aspects of

emotional well-being during the role disengagement transition may provide better insight into caregivers' changing needs during this time.

The Activity Restriction Model of Depressed Affect

One key factor that has been shown to account for variability in the emotional responses of caregivers is activity restriction. At the onset of caregiving, caregivers' involvement in everyday activities changes in several ways. When acquiring the role and becoming responsible for providing care to a seriously ill or disabled individual, personal activities may be restricted (e.g., Barusch, 1988; Bedini & Guinan, 1996a; Dunn & Strain, 2001; Keller & Tu, 1994; White-Means & Chang, 1994). Some routine activities that are commonly restricted include "caring for yourself," "working on hobbies," and even "maintaining friendships" (Williamson & Schulz, 1992a). These activities not only have been found to be constrained with the onset of caregiving, but their restriction has been associated with other indicators of caregiving stress (Williamson & Schulz, 1992b). Rather than simply measuring the frequency of caregivers' activity engagement during caregiving to understand caregiver stress (e.g., Patterson & Carpenter, 1994; Seltzer & Li, 2000), measuring the extent to which caregivers perceive that their participation in routine activities has been restricted *due to* caregiving responsibilities can provide more information on the role of caregiving in caregiver well-being.

The activity restriction model of depressed affect (ARMDA) proposes that a significant disruption in or restriction of normal activity engagement caused by a major life stressor plays a key role in psychological adjustment, typically resulting in diminished emotional well-being (e.g., Williamson, 1998; Williamson & Shaffer, 2000; Williamson, Shaffer, & Schulz, 1998). Thus, the degree to which caregivers believe that their activities have been restricted by their caregiving responsibilities predicts their emotional well-being, with more perceived disruption in

routine activities eliciting poorer mental health outcomes (Williamson et al., 1998). Researchers, in numerous empirical investigations, have supported this hypothesis when examining variables related to major life stressors (e.g., Chattillion et al., 2012; Mausbach, Patterson, & Grant, 2008; Mausbach, Roepke, et al., 2011; Moore et al., 2011; Williamson, 1995, 2000; Williamson & Schulz, 1992b; see Mausbach, Moore, et al., 2011, for a meta-analysis). In these studies, major life stressors have been conceptualized as illness-related stress (e.g., illness severity, pain) and caregiving-related stress (e.g., care recipient symptom severity, less communal relationships), depressed affect as a potential reaction to these life stressors, and activity restriction as a mediator of the relations between stressors and feelings of depression (Mausbach et al., 2008; Williamson, 1998; Williamson & Schulz, 1992b, 1995; Williamson et al., 1998). Taken together, results from the series of activity restriction studies make clear that the experience of depressive symptoms during caregiving is largely influenced by the extent to which caregivers perceive that their normal activities have been restricted due to caregiving stressors. This may have implications for caregivers facing the transitional life event of role disengagement. For detailed descriptions of the series of activity restriction studies see Chapter 2.

Grief-Relief Model and the ARMDA

In the context of caregivers' transition through role disengagement, there are several possible outcomes. Informed by the grief-relief model of bereavement and the ARMDA, at least two possibilities can be considered: (a) the death of a care recipient may further deplete caregiver resources (e.g., the loss of the care recipient with whom the caregiver may have shared activities) thereby increasing the extent to which the caregiver believes that their activities have been restricted, making it difficult for the caregiver to re-engage in lost roles, or (b) the death of a care recipient may lessen caregiver perceptions of activity restriction resulting in the freedom to re-

engage in roles and activities in which they previously engaged. In the first scenario, individuals who perceive an increase in activity restriction through the transition are theoretically expected to experience more negative emotional responses to the changes associated with role disengagement. On the other hand, those who perceive a decrease in activity restriction through the transition are expected to experience more positive emotional responses compared to those who perceive an increase in activity restriction. In these cases, it is the change in activity restriction due to care recipient death that ought to be of interest. Activity restriction may remain stable through the transition for some caregivers, and these individuals may not experience much change in their symptoms of depression.

Dooley (2006) examined caregivers' adaptation to a transition caused by either nursing home placement or care recipient death and found support for examining the role of activity restriction in the context of those transitions. However, his findings were not in the expected direction, suggesting a depletion of caregivers' resources and continued stress through the role disengagement period. Specifically, greater pre-transition activity restriction was related to greater overall feelings of relief as expected, yet greater activity restriction was unexpectedly related to greater post-transition depression, greater post-transition grief, and less post-transition relief. These results are inconsistent with the predominant findings in the field that support a stress-relief perspective of caregiver adjustment in transitions (e.g., George & Gwyther, 1984; Li, 2005; Norris & Murrell, 1987; Schulz, Newsom, Fleissner, et al., 1997; Schulz et al., 2003). Taken together, researchers have reported both positive and negative consequences of the death of a care recipient. Still, in the context of transitions there are questions that remain unanswered, especially in terms of under what conditions the stress-relief model of bereavement is supported. For instance, do caregivers' perceptions of their activity restriction lessen, increase, or remain

stable when caregiving ends? If so, do changes in activity restriction play a role in caregiver adjustment? This change in activity restriction from caregiving to the period following care recipient death has not yet been examined. Additionally, no studies have explored how loss in different kinds of activities predicts caregivers' adjustment during the bereavement period.

Conceptualization of Activity Restriction Domains

The particular kinds of activities that caregivers believe are restricted also may be important to how caregivers adjust to the caregiving experience and its termination. Using exploratory factor analysis, Loucks-Atkinson (2005) found support for two domains of activity restriction. *Expressive activities* were defined as activities that may hold personal meaning for individuals, such as working on hobbies and engaging in sports and recreation. Activities that are thought to have more functional value, such as self-care and shopping were defined as *instrumental activities*. These activities differ in at least three ways: (a) in the types of needs each domain meets, with instrumental activities meeting basic needs and expressive activities meeting creative and social needs, (b) in the freedom associated with engaging in the activity, with instrumental activities being necessary for independent living and expressive activities being engaged in because of choice, and (c) in the motivational drive to engage in the activity, with instrumental activities being extrinsically motivated and expressive activities being intrinsically motivated (Loucks-Atkinson, 2005). It seems reasonable to hypothesize that restrictions to these two different categories of activity may influence well-being in different ways in the context of transitions.

Practical Significance of Research

Assessment of change in caregiver activity restriction over time is not only informative to the literature but also practical. Perceptions of activity restriction may be more amenable to

intervention than depressive symptoms experienced by caregivers. Although there are resources available to alleviate challenges associated with providing and terminating care, those services often are limited in amount and scope (Thompson, 2004). Additionally, activity restriction has been researched extensively during caregiving but infrequently addressed in the difficult role disengagement transition. Identifying a mechanism through which patterns of caregiver bereavement are influenced can help to better target caregivers' needs when coping with changing roles across transitions. This research will aid in specifying the role of activity restriction in the context of transitions and further refine those findings by addressing whether either expressive or instrumental activities provide a positive context for adjustment.

Study Objectives

Building on the work of Dooley (2006) and Loucks-Atkinson (2005), I examined in greater depth the role of activity restriction on caregiver well-being in the context of transitions. I determined whether and how caregivers' perceptions of activity restriction change from the pre- to post-transition period and the impact of that change on post-transition caregiver subjective well-being. To refine research on activity restriction in transitions, I also examined whether the expressive and instrumental domains of activity restriction predict post-transition caregiver well-being differently. Thus, my general objectives were to (a) establish whether change in activity restriction predicts caregiver well-being in the context of the transition after care recipient death and (b) examine these relations by each activity restriction domain.

CHAPTER 2

LITERATURE REVIEW

To provide background and empirical support for the proposed research aims, I review the informal caregiving and bereavement literature. The physical and mental health outcomes related to providing care to a frail older individual and stressors associated with caregiving are described. Other ways in which providing care impacts the caregiver's life also are summarized, which include changes in leisure and well-being over the caregiving career. Next, the origins of the activity restriction model of depressed affect (ARMDA) and a thorough description of the series of activity restriction studies are reviewed. Finally, a review of the literature on caregiver transitions, caregivers' bereavement experiences, and predictors of bereavement outcomes follows.

Caregiver Health

Although family members may assume the role of caregiver willingly and some may find meaning or satisfaction in the role (for a review of the positive aspects of caregiving see Chen & Greenberg, 2004; Feinberg, Reinhard, Houser, & Choula, 2011; Lopez, Lopez-Arrieta, & Crespo, 2005), caregivers nevertheless experience physical and emotional stress in their role. Family caregivers face subjective and objective health risks, chronic health problems, and increased risk of mortality (e.g., Haley, Roth, Howard, & Safford, 2010; Kiecolt-Glaser et al., 1987; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; Lee et al., 2003; National Alliance for Caregiving and AARP [NAC/AARP], 2009; Pinguart & Sörensen, 2007; Schulz & Beach, 1999; Schulz & Williamson, 1991; Vitaliano, Zhang, & Scanlon, 2003). Compared to

noncaregivers, caregivers have poorer objective and self-rated physical health (e.g., Pinquart & Sörensen, 2003, 2007) and more impaired immune system functioning (e.g., Kiecolt-Glaser et al., 1987; Kiecolt-Glaser et al., 1991), with an increased risk of cardiovascular disease (e.g., Mausbach, Patterson, Rabinowitz, Grant, & Schulz, 2007). Research also shows that caregivers have significantly worse psychological health than noncaregivers of the same age (e.g., Marks, Lambert, & Choi, 2002; Pinquart & Sörensen, 2003; Schulz, Newsom, Mittlemark, et al. 1997; Schulz, O'Brien, Bookwala, & Fleissner, 1995) and higher use of psychotropic drugs (e.g., Clipp & George, 1990).

Not only are there between-group differences (i.e., between caregivers and noncaregivers) in mental and physical well-being, but also there are within-group differences in outcomes related to the experience of caregiving. The impact of strain perceived by caregivers has been examined to help explain why some caregivers adapt more effectively than other caregivers (e.g., Beach, Schulz, Yee, & Jackson, 2000; Schulz & Beach, 1999; Schulz, Newsom, Mittlemark, et al., 1997). In a study comparing strained and nonstrained spousal caregivers, caregivers reporting strain experienced worse mental and physical health than did caregivers who did not report strain (Schulz, Newsom, Mittlemark, et al., 1997). Perceptions of caregiver strain, related to the amount of assistance provided to care recipients, was a predictor of (a) increased caregiver depressive symptoms and anxiety, (b) poorer caregiver perceived health, and (c) increased caregiver health-risk behavior. These results emphasize that when caregiving demands are perceived to be high caregivers are at a greater risk for negative emotional and physical outcomes. Even more concerning is research showing that caregivers who experienced strain while providing care had a 63% higher adjusted mortality risk than did nonstrained caregivers (e.g., Schulz & Beach, 1999). Not only do caregivers experience health changes during

caregiving but also losses in other domains of their lives that may exacerbate physical and mental health difficulties.

Caregiving and Changes in Leisure Engagement

Many caregivers find that their involvement in leisure activities (e.g., working on hobbies, visiting friends) decreases at the onset of caregiving, and some have reported up to a 50% reduction in their involvement in leisure activities (e.g., Dunn & Strain, 2001; Keller & Tu, 1994; Mancini et al., 2010; Rogers, 1999; White-Means & Chang, 1994). Caregivers have described the reduction in leisure time as resulting in feelings of loss, as though their lives have stopped (Rogers, 1999), and rendering leisure nonexistent and unattainable (e.g., Bedini & Guinan, 1996a, 1996b). These declines in leisure participation continue throughout active caregiving, with leisure participation declining further as the care recipient's ailments progress and their needs become more difficult for caregivers to manage (Barusch, 1988). Decreased leisure time has been shown to be related to an increase in emotional and physical stress, lower life satisfaction, and lower positive affect and higher negative affect (e.g., Mausbach, Harmell, Moore, & Chattillion, 2011; White-Means & Chang, 1994). Overall, caregivers seem to experience loss in the frequency with which they participate in leisure activities. Nevertheless, most caregivers value their leisure time (Bedini & Guinan, 1996a, 1996b; Bedini & Phoenix, 2004), and researchers believe that leisure has a stress buffering effect on the negative outcomes that may result from the transitions associated with caregiving (e.g., Bedini & Bilbro, 1991; Coleman & Iso-Ahola, 1993).

Little is known about changes in caregivers' perceptions of their activity engagement following the death of care recipients and how increases or decreases impact changes in indicators of their well-being. There is evidence, however, that leisure activity experiences

change following the death of a close other. For noncaregivers whose husbands die, the frequency of wives' leisure involvement is likely to undergo some change during their transition to widowhood. For example, Janke, Nimrod, and Kleiber (2008) found that some noncaregiving widows maintained or increased their participation in leisure activities (e.g., sports or exercise, involvement in clubs or organizations, visiting or talking with others) while others decreased or ceased involvement in leisure activities. In another study (Seltzer & Li, 2000), the frequency with which caregivers engaged in social and leisure activities decreased when caregiving began and increased following the death of care recipients. The replacement of lost activities can result in a reduction in symptoms of depression for community dwelling older adults but only when those replacement activities are judged to be satisfying (e.g., Benyamini & Lomranz, 2004).

Researchers who have investigated leisure participation have identified the *kinds* of activities that caregivers engage in and documented the *frequency* with which caregivers engage in these activities (e.g., Patterson & Carpenter, 1994; Seltzer & Li, 2000). For example, one study (Seltzer & Li, 2000) measured the frequency of engaging in three types of activities (i.e., working on a hobby, taking trips, and engaging in physical exercise) among caregivers when taking on the caregiving role and transitioning out of the role. Although the literature investigating the effects of objective leisure involvement and change in leisure activity during transitions provides us with important information about the gain or loss of leisure during those transitions, these studies assess only the actual behavior (frequency, intensity and/or duration) with which caregivers engage in those particular activities. The goal of much of the research on this topic is to determine effective leisure interventions to address the leisure-related needs of family caregivers (e.g., Bedini & Phoenix, 1999). While this information can provide a profile of the ways in which caregivers spend their time, the data do not provide information on

caregivers' beliefs regarding whether some of those changes in leisure involvement can be attributed directly to caregiving stressors or transitions. Stevens and colleagues (2004) explained that assessing only the frequency of engaging in activities is insufficient when examining leisure involvement, underscoring that "individuals vary greatly in values and preferences that influence whether leisure is satisfying" (p. 451). Subjective measurements of leisure participation ought to recognize that leisure is associated with "the occurrence of certain types of mental states, attitudes, emotions, cognitions, perceptions, meanings, needs satisfied, and/or experiences" (Kleiber, Walker, & Mannell, 2011, p.58). Therefore, leisure activity may vary considerably in terms of how it is experienced.

Activity Restriction: Bridging the Gap

It may not be what is gained from increasing leisure engagement that contributes to subjective well-being in stressful situations but, rather, overcoming what has been lost that is important. Additionally, the impact of changes in behavior on well-being may be better understood when those changes are associated more directly with the transition itself. The research on activity restriction has responded to these challenges by addressing the theoretical basis for the link between subjective well-being and constraints to routine activities. The ARMDA posits that it is the perception that normal activity engagement (e.g., self-care, visiting or maintaining relationships with friends, going shopping, working on hobbies) has been restricted as a result of a major life stressor that explains, in large part, an individual's psychological state in the wake of stressful events (e.g., Williamson, 1998; Williamson & Shaffer, 2000; Williamson et al., 1998). This hypothesis has been supported in a series of studies with samples ranging from pediatric patients experiencing chronic pain to a general population

of geriatric outpatients (e.g., Walters & Williamson, 1999; Williamson, 2000; Williamson & Schulz, 1992a, 1995; Williamson, Schulz, Bridges, & Behan, 1994).

Researchers addressing activity restriction have conceptualized illness and disability as life stressors, symptoms of depression as an emotional response to life stressors, and activity restriction as a mediator of the association between stress and depressed affect (e.g., Williamson & Shaffer, 2000). In a sample of limb amputees, for example, illness severity was defined as wearing a prosthesis following limb amputation (Williamson et al., 1994). Activity restriction fully mediated the relation between use of prosthesis and depressive symptoms. In this case, disability (i.e., prosthesis use) contributed to feelings of depression primarily to the extent that it interfered with an individual's ability to engage in routine activities.

Pain has frequently been conceptualized as an indicator of illness severity. Activity restriction mediates the cross-sectional relations between (a) pain and depressive symptoms in geriatric outpatients (e.g., Williamson & Schulz, 1992b), (b) chronic pain of pediatric patients and caregiver depression (e.g., Walters & Williamson, 1999), and (c) pain and depressed affect in a sample of breast cancer patients (Williamson, 2000). Williamson (2000) tested for the independent contribution of activity restriction to symptoms of depression and established that, beyond the effects of the correlates of depressed affect, activity restriction explained significant additional variance in depression. These studies highlight activity restriction as a strong mediator of the relation between indicators of illness severity (a health-related stressor) and depressive symptoms at the same point in time. These results also hold true over time. In one longitudinal examination of activity restriction, as pain increased so did activity restriction, which in turn predicted increases in depressed affect eight months later among recurrent cancer patients (Williamson & Schulz, 1995). The chief tenet of the ARMDA is supported because

major life stressors have reliably been shown to contribute to negative emotional outcomes largely to the extent that individuals' perceive that their usual activities are restricted by the stressor.

To extend these findings to caregivers, the Activity Restriction Scale (ARS; e.g., Williamson et al., 1998) previously used with noncaregiving samples was modified for use with caregivers. Specifically, spousal caregivers of older cancer patients were asked about the extent to which their normal activities, such as doing household chores and visiting friends, were restricted *by caregiving*. In these studies, activity restriction was conceptualized as an indicator of caregiving-related stressors. Williamson and colleagues (1998) examined the predictors of activity restriction and its intervening role in the relation between care recipients' illness-related variables (i.e., cancer symptom severity) and their spousal caregivers' emotional outcomes (i.e., depressive symptoms, resentment). In their sample of caregivers with poor quality pre-illness relationships with care recipients: (a) activity restriction was predicted by severity of patient symptoms, (b) caregiver resentment and depressive symptomatology were predicted by activity restriction, and (c) activity restriction mediated the association between patient symptom severity and caregiver resentment and depressive symptomatology. Thus, the explanatory value of the ARMDA was supported in the context of caregiving.

Support for the ARMDA also has been replicated in a comparison of Alzheimer's caregivers and noncaregiver controls (e.g., Mausbach et al., 2008). Dementia spousal caregivers in this study experienced both increased activity restriction and increased depressive symptoms compared with noncaregiving spousal controls. Activity restriction was central in explaining the depressive symptoms of the Alzheimer's caregivers (accounting for 86.8% of the variance in depressive symptoms) and mediated the relationship between caregiving status and depressive

symptoms. Activity restriction with low engagement in pleasant activities also has been associated with decreased caregiver well-being (e.g., depression, poor coping skills, worse overall health, high blood pressure; e.g., Chattillion et al., 2011; Mausbach, Roepke, et al., 2011). This research supports the ARMDA (e.g., Williamson, 1998, 2000; Williamson & Shaffer, 2000) and provides strong additional evidence for the relation between activity restriction and increased depressed affect, especially when caregivers are no longer engaging in pleasant activities.

Findings from longitudinal caregiving studies confirm and extend previous cross-sectional findings. Smith, Williamson, Miller, and Schulz (2011) tested whether changes in several caregiving stressors (i.e., more caregiver activity restriction, poorer caregiver physical health, and more care recipient manipulative and controlling behavior) predicted changes in caregiver depression one year later. As caregivers' activity restriction increased, so did their symptoms of depression. The authors of this study demonstrated the predictive value of caregiver activity restriction in explaining variance in caregiver depression over time.

Other researchers (e.g., Nieboer et al., 1998) focused on the effects of increasing and decreasing caregiving demands related to care recipient illness factors (i.e., the caregiving stressor) on symptoms of depression (i.e., emotional well-being) and examined activity restriction as an explanatory mechanism for changes in depression during caregiving. For the spousal caregivers in the study who underwent changes in their caregiving demands: (a) greater caregiving duties were related to greater depressive symptomatology at the bivariate level, (b) activity restriction mediated the association between greater caregiving duties and greater depressive symptomatology in cross-sectional analysis, and (c) greater activity restriction predicted changes in depressive symptomatology (i.e., depression increased) over time.

However, these longitudinal studies did not address the predictive value of activity restriction in the context of caregiver transitions due to the death of a care recipient.

Work by Dooley (2006) is an exception to this and was the first to examine activity restriction in the context of caregiver transitions occurring because of role disengagement. Dooley utilized longitudinal data from the first and second Family Relationships in Late Life projects which allowed for examination of prospective reports of caregivers' experiences when faced with transitions.

Activity Restriction and Caregiver Transitions

Dooley (2006) addressed the ways in which pre-transition stressors predict post-transition indicators of well-being in two groups of transitioned caregivers (i.e., care recipient nursing home placement or care recipient death). When controlling for the cause of caregiver transition, care-related stress variables, of which pre-transition activity restriction was one, accounted for 9% of the total variance in post-transition grief, post-transition depressive symptoms, and post-transition relief among caregivers. However, these variables were not correlated in the expected directions. The results of this study do not support the leading stress-relief perspective identified in the literature (i.e., that greater pre-transition should predict better adaptation during transitions). Rather, Dooley found that caregivers who experienced more role strain and social isolation while caregiving did not experience relief or less depression and grief during transitions when controlling for pre-transition depressive symptoms, suggesting an accumulation of stress for transitioned caregivers and the depletion of their resources. One exception to these findings was that overall post-transition relief (i.e., a one-item measure asking participants how they generally feel about the care recipient's death) as opposed to the more comprehensive measure of relief (i.e., a six-item measure reflecting cognitive, emotional, and psychological indicators of

relief) was predicted by greater pre-transition activity restriction supporting a stress-relief perspective. It is possible that post-transition activity restriction is a better indicator of feelings of relief.

Dooley (2006) found that pre-transition activity restriction was highest among the group of caregivers whose care recipients died. These transitioned caregivers were providing significantly more assistance with activities of daily living (ADLs) at the time preceding the transition than caregivers who had not yet transitioned. Relief following the death of a care recipient could be associated with freedom from the stress of providing day-to-day care to a frail elder or, perhaps, the opportunity to reengage in one's social or recreational life. The finding that activity restriction decreases following care recipient death has the potential to specify more clearly the role of activity restriction in changes of caregiver well-being in the context of the role disengagement transition.

To better understand the link between caregiving stressors and the stress-relief perspective, caregiver activity restriction should be operationalized as an indicator of objective caregiver stress (e.g., amount of care provided) and mediator of that objective caregiver stress and emotional responses to those stressors rather than being examined as the independent variable. Whether major caregiving stressors contribute to post-caregiving positive emotional outcomes is better understood than whether this relationship depends on the extent to which individuals perceive that their engagement in routine activities have lessened. To further refine Dooley's (2006) findings and determine under what conditions the stress-relief hypothesis is supported consideration will be given to the type of activity restriction that is lessened, particularly whether different kinds of activities are more or less critical to the understanding of activity restriction in the context of caregiver transitions.

Activity Restriction Domains

The personal values that caregivers attach to certain activities differ. Engagement in meaningful activities may provide a positive context for adjustment during difficult transitions (e.g., Fry, 2001; Gallagher-Thomson et al., 2000). Loucks-Atkinson (2005) addressed whether there are distinct qualities to activities that are restricted as a result of caregiving and whether losses in different kinds of activities impact the well-being of caregivers providing care to frail older adults. The nine-item Activity Restriction Scale (ARS; Williamson & Schulz, 1992a) assesses caregivers' perceptions that their activities have been restricted since assuming caregiving duties. Loucks-Atkinson (2005) explored whether the nine items of the ARS formed distinct categories of activity domains. Her analyses provided statistical support for the creation of two subscales from the composite measure of the ARS: (a) expressive activities and (b) instrumental activities.

Activities that are expressive in nature (e.g., working on hobbies, socializing) are engaged in for their own sake and may provide a positive context for adjustment during transitions because they may hold more personal significance for individuals in the face of stressors (Csikszentmihalyi, 1993; Kleiber, 1999; Kleiber, Hutchinson & Williams, 2002; Waterman, 1990). Instrumental activities, on the other hand, are defined as more functional, perhaps with immediate survival value (Loucks-Atkinson, 2005). Activities such as caring for oneself or doing household chores, for example, are more intrinsic to daily living, but may not have the same personal meaning attached to them as do expressive activities. Rather, instrumental activities are interconnected with everyday living and are more essential to independent living. Given the distinct values associated with the domains of activity restriction, the domains may be related to indicators of caregiver well-being in differing ways.

Additional analyses determined the predictive nature of both domains of activity restriction in a sample of caregivers who were currently providing care to frail older adults (e.g., Loucks-Atkinson, 2005; Loucks-Atkinson, Kleiber, & Williamson, 2006). Greater expressive and instrumental activity restriction predicted more depressive symptoms when controlling for socio-demographic factors in cross-sectional analyses and in prospective analyses (i.e., 12 months later and 24 months later). Expressive activity restriction explained more variance in depression 12 months later than did instrumental activity restriction. Conversely, instrumental activity restriction explained more variance in depression 24 months later than did restriction in expressive activities (e.g., Loucks-Atkinson et al., 2006). At the individual level of analysis, expressive activity restriction showed differences in rate of change over 24 months, while instrumental activity restriction did not show individual differences in its rate of change over that time span (Loucks-Atkinson, 2005). Specifically, caregivers with lower baseline expressive activity restriction reported greater increases in restriction over 24 months than those with higher expressive activity restriction at baseline, who showed a slower rate of change in restriction over 24 months (Loucks-Atkinson, 2005). These results provide support for examining expressive activity restriction and instrumental activity restriction separately as predictors of individual change in well-being, particularly when predicting symptoms of depression.

While Loucks-Atkinson's (2005) study provided valuable information on the rate of change in activity restriction during caregiving it did not address changes in those domains to examine well-being in the context of caregiving transitions. The death of a care recipient may elicit changing perceptions about restrictions to caregiver's activities in either domain (i.e., expressive or instrumental). Caregiving itself has been described as a context within which leisure activities may be experienced (e.g., Dupius, 1999). Care recipient death, for example,

may represent the loss of the individual with whom caregivers participated with in routine activities. Changes in activity restriction domains across this transition are of particular interest to changes in caregiver well-being. Theorists have suggested that when faced with a major life stressor such as the death of a close other (e.g., a spouse or parent care recipient) expressive activities that offer meaning and purpose for life may be among the greatest contributors to positive adjustment (e.g. Fry, 2001; Kleiber et al., 2002). Given the conceptualization of expressive activities as having intrinsic qualities, caregivers may find that such activities contribute to their well-being in meaningful ways when care recipients die.

Conclusions

Taken together, the series of activity restriction studies provide important information about the ways in which activity restriction can be conceptualized, its role in predicting emotional outcomes, and how activity restriction may change over time. Additionally, considering activities that are characteristic of the expressive activity domain of the ARS, such as spending time with friends, participating in sports, and working on hobbies, have been found to reduce stress in samples of recently bereaved individuals (e.g., Patterson, 1996). However, the specific roles of expressive and instrumental activities in caregiver transition through bereavement have yet to be fully identified. Although the impact of activity restriction has been addressed extensively in the context of the second stage of the caregiving career (i.e., caregiving enactment), it has been infrequently addressed in arguably one of the most difficult transitions that caregivers undergo (i.e., role disengagement). In this study, I will address this gap in the literature.

Caregiver Bereavement

Studies on the course of bereavement following caregiving have been based on cross-sectional, retrospective, and more recently, prospective data. These caregiving studies provide information on the effects of care recipient death as well as caregiver responses to bereavement.

Multiple Indicators of Well-being

Following care recipient death caregivers have been found to experience both negative and positive emotions (e.g., Collins, Liken, King, & Kokinakis, 1993; Dooley, 2006). In terms of negative emotions, depression and grief have been used interchangeably and have been shown to be highly and positively correlated (e.g., Dooley, 2006). This allows for comparison of symptom intensity between bereaved and non-bereaved control groups (Hansson & Stroebe, 2007) and suggests that measures of depression such as the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977) provide a valid assessment of grief reactions. However, theorists have recently suggested that this practice should be questioned. In their review of bereavement in late life, Hansson and Stroebe (2007) rationalized that grief symptomatology is comprised of more than depressive symptoms (i.e., other affective, cognitive, behavioral, and physiological-somatic symptoms directly related to loss). Although moderately to highly correlated, scores on depression and grief scales do not appear to measure the same construct (Hansson & Stroebe, 2007). Depression may indicate a genetic vulnerability that is (a) more pervasive, (b) responsive to medication, (c) related to lower self-worth, and (d) more likely to occur spontaneously compared to grief, which is more reactive to a specific loss experience (e.g., Martwit & Meuser, 2002; Wijngaards-de-Meij et al., 2005). Additionally, there is theoretical support for the idea that stressful transitional events can have positive effects on well-being. For example, Wheaton's (1990) model emphasized that when preceded by chronic

stressors, transitional life events (e.g., retirement, divorce) can be beneficial to mental health, at least in reducing the level of depressive symptoms and contributing to a sense of relief. Given that depression, grief, and relief are highly relevant to transitional life events and particularly, those related to the death of a close other, empirical research related to these variables will be reviewed in the sections that follow.

Findings on Depression, Grief, and Relief

Researchers who have examined short-term and long-term adjustment to care recipient death have focused on caregiver depression. Less research exists on grief within the context of informal caregiving in late life, and even fewer studies have addressed caregiver relief following caregiver role disengagement.

Depression. Researchers have shown that caregiver depression scores decline for up to six months following care recipient death (e.g., Grant et al., 2002; Mullan, 1992), in some cases declining to levels lower than pre-bereavement levels among dementia caregivers (e.g., Schulz et al., 2003). In other cases, depression may spike immediately following care recipient death for a period of up to three months but then decline for up to 15 months post-bereavement to levels equivalent to noncaregivers (e.g., Mullan, 1992; Taylor, Kuchibhatla, Østbye, Plassman, & Clipp, 2008). Studies that followed caregivers for longer periods of time, from six months to one year post-bereavement, reported that bereaved caregivers' symptoms of depression significantly diminished over time (e.g., Chentsova-Dutton et al., 2002; Thompson et al., 1991). Few studies have followed caregivers after bereavement for more than one year, but those that did noted further declines in depressive symptoms. For example, some caregivers experience depression that increases immediately after care recipient death followed by a substantial decrease in depression that remains stable with little declines thereafter (e.g., Aneshensel et al., 2004). Other

longitudinal studies have shown declines in caregiver depression up to four years following loss (e.g., Li, 2005). These results are consistent with the stress-relief hypothesis but do not address the factors associated with diminished depression.

Grief reactions. In studies of both the general population (e.g., Bonanno et al., 2002) and caregivers (e.g., Aneshensel et al., 2004), grief has been identified as a heterogeneous experience, following a number of different emotional trajectories. Although depression may subside over the first 12 months following care recipient death, distress related to the loss itself (i.e., grief) is likely to persist for a number of years. For some spousal caregivers, feelings of grief are evident up to two and a half years following care recipient death (e.g., Thompson et al., 1991). Some researchers report that feelings of grief are greatest immediately following the death of a care recipient (e.g., Chentsova-Dutton et al., 2002) and significantly diminish over time (e.g., Chentsova-Dutton et al., 2002; Schulz, Boerner, Shear, Zhang, & Gitlin, 2006). Determining when improvements in emotional well-being occur among caregivers is complicated by the fact that grief, although directly related to the bereavement experience, has been infrequently measured. Additionally, grief may go unnoticed when feelings of depression are high.

Relief. Although not often assessed, caregivers may experience feelings of relief following care recipient death (e.g., Dooley, 2006). One study obtained data from Alzheimer's caregivers on the extent to which care recipient death was a relief to the caregiver and thought to be a relief to the deceased (Schulz et al., 2003). The majority (i.e., over 70%) of caregivers in this study believed that death was a relief both to themselves and deceased care recipients, and when caregiving had been more distressing caregivers were more relieved. Caregivers of individuals with dementia may begin grieving well before care recipients' death, while following

the loss they tend to feel relieved and less depressed (e.g., Collins et al., 1993; Collins, Stommel, Wang, & Given, 1994; Dooley, 2006; Jones & Martinson, 1992). Providing care for someone with a terminal illness can result in heightened stress because of the anticipation for the care recipient's death as the disease progresses (Gilbar & Ben-Zur, 2002). Dementia caregivers also provide more assistance with daily tasks than do nondementia caregivers (e.g., NAC/AARP, 2009; Ory, Yee, Tennstedt, & Schulz, 2000). In general, providing high levels of assistance is associated with greater relief upon care recipient death. Indeed, using in-depth qualitative narratives, researchers found that caregiving widows who provided high levels of assistance during caregiving experienced relief after the deaths of their husbands (e.g., Bennett & Vidal-Hall, 2000).

Empirical Support for Grief-Relief Model of Bereavement

The course of emotional adjustment partly depends on the conditions faced during the role enactment stage of caregiving (Mullan, 1992). Caregiver strain experienced prior to loss has been found to be an important factor in rate of decline of caregiver depressive symptoms following death of a care recipient with dementia (e.g., Schulz et al., 2003). The grief-relief model of bereavement refers to the idea that caregiving is stressful and when the care recipient dies, the caregiver will either experience continued stress resulting in no relief from caregiving strain (i.e., complicated-grief hypothesis) or will feel relieved from the strain of caregiving (i.e., stress-relief hypothesis) through the transition. Empirical support lies heavily on the stress-relief side of this debate (e.g., George & Gwyther, 1984; Li, 2005; Norris & Murrell, 1987, Schulz, Newsom, Fleissner, et al., 1997; Schulz et al., 2003). However, a number of studies support the complicated-grief hypothesis (e.g., Bass & Bowman, 1990; Dooley, 2006). This disagreement may be the outcome of the cross-sectional nature of some studies examining the bereavement

transition or differences in sample characteristics (e.g., dementia versus nondementia caregivers) studied.

Complicated-grief model of bereavement. In support of the complicated-grief hypothesis, Burton, Haley, and Small (2006) reported that caregivers who experienced highly stressful caregiving situations prior to loss were *less* likely to see improvements in social well-being and were at higher risk for social isolation following loss compared to those who experienced less stressful caregiving. However, it should be noted that social well-being, defined as frequency of contact with children and grandchildren, was examined by Burton and colleagues (2006) as opposed to psychological well-being. While the frequency of social contact is observable, psychological well-being is different because it emphasizes the cognitive evaluation that one is experiencing negative emotions. Difficulties experienced during caregiving have been shown to be related to caregiver mental health in bereavement. Caregivers who reported care recipient problem behavior or who regarded caregiving as difficult, compared to those who did not, were more likely to evaluate care recipient death and bereavement as problematic and to experience greater bereavement strain (i.e., depression) subsequent to care recipient death (e.g., Bass & Bowman, 1990; Li, 2005). Prior research has found that care recipient problem behavior diminishes the resources of the caregiver (i.e., psychological and social; Aneshensel et al., 1995; Skaff & Pearlin, 1992), the result of which may be slower recovery following care recipient death as caregivers attempt to regain well-being. Dooley (2006) examined care-related stress (e.g., dementia diagnosis, care recipient controlling behavior) as a predictor of caregiver well-being following loss and found that, although caregivers experienced both negative and positive emotions following care recipient death, they remained stressed through the transition. Additionally, caregivers who experienced caregiving

burden suffered from more symptoms of clinical mental disorders while providing care and experienced worse mental health following the death of care recipients (Kapari, Addington-Hall, & Hotopf, 2010). These data suggest that the experience of strain related to caregiving responsibilities may deplete caregivers of their resources (e.g., restrictions in activities, disrupted social relationships), resulting in greater difficulty coping with the changes associated with care recipient death. However, change in activity restriction was not addressed as a predictor of caregiver well-being by researchers in these studies.

Stress-relief model of bereavement. The predominant view in the field is that, although caregiving is stressful and restrictive in many ways, caregivers feel relieved and become less stressed through transitions to bereavement. In one sample, strained caregivers exhibited improved health practices and no increase in depressive symptoms after the death of a spousal care recipient (e.g., Schulz et al., 2001). And in another study, caregivers who reported high feelings of role overload during caregiving experienced a faster decline in depression following care recipient death than did those with low feelings of overload during caregiving (e.g., Li, 2005; Mullan, 1992). There also is evidence that when caregiving is more strain-provoking, dementia and nondementia caregivers are more relieved (i.e., in terms of overall relief or death coming as a relief) following care recipient death (e.g., Dooley, 2006; Schulz et al., 2003). Improvements in caregiver subjective well-being following care recipient death have been attributed to increased mastery (i.e., in dementia caregivers; Mullan, 1992; Skaff, Pearlin, & Mullan, 1996), decreased anger (Aneshensel et al., 1995), decreased hostility and anxiety (Chentsova-Dutton et al., 2002), and increased agreeableness (i.e., in dementia caregivers; Gold, Reis, Markiewicz, & Andres, 1995). Features of caregiving, such as longer time in the caregiver role are also central to caregiver positive improvement following care recipient death (e.g.,

Keene & Prokos, 2008; Richardson, 2010). When caregiving is perceived to be more distressing, perhaps because of a perception that factors related to caregiving infringe on caregivers' everyday lives, it may be possible that the death of a care recipient will lessen the effects of those restrictions, allowing caregivers to adjust to role changes in a positive way.

Further support for the stress-relief model of bereavement is found in Wheaton's (1990) model in which he emphasized that transitional life events (e.g., retirement, divorce) are beneficial to one's mental health when preceded by chronic stressors related to the previous role. In the context of informal caregiving situations, Wheaton suggested that when highly demanding and stressful caregiving ceases, caregivers should experience feelings of relief and improved mental health. I hypothesize that one mechanism by which this occurs may be through changing perceptions of activity restriction over time. A characteristic of highly demanding and stressful caregiving is loss (Aneshensel et al., 1995), and this loss is particularly evident in the area of activity engagement. The perception that coping resources, such as expressive and instrumental activities, are lost should not only be an indicator of intensified caregiving involvement but also poor emotional well-being.

Limitations of Bereavement Studies

One aim of this study is to examine caregiver transitions through bereavement by addressing some of the limitations of past studies. Some researchers (e.g., Mullan, 1992; Thompson et al., 1991) examining transitions have employed cross-sectional design to compare bereaved individuals to nonbereaved individuals rather than following the same group of caregivers before and after care recipient death. In other cases (e.g., Kapari et al., 2010), retrospective reports were used. Retrospective reports are vulnerable to recall bias since bereaved, distressed caregivers may evaluate their experiences more negatively than they would

have if they were interviewed before their loss. Some studies using longitudinal designs (i.e., following caregivers from role enactment through role disengagement) have attempted to overcome these drawbacks. However, the findings have been inconsistent with some supporting a stress-reduction perspective and others suggesting a chronic strain trajectory (e.g., Boerner, Schulz, & Horowitz, 2004; Ferrario, Cardillo, Vicario, Balzarini, & Zotti, 2004; Kelly et al., 1999; Li, 2005), indicating the need for more discriminating research. In particular, more prospective research is needed to determine the relationship between caregivers' changing activity restriction over time and their later adjustment to care recipient loss. The second Family Relationships in Late Life project (FRILL2; Gail M. Williamson, Principal Investigator) offers an ideal study design for examining caregiver well-being over transitions because it contains data from caregivers obtained prior to and following care recipient death. FRILL2 overcomes limitations of previous studies (e.g., retrospective reports from bereaved caregivers) allowing for examination of change in caregiver experiences through the role disengagement transition.

CHAPTER 3

SPECIFIC AIMS AND HYPOTHESES

Researchers who developed the activity restriction model of depressed affect (ARMDA) theorized that when normal activity engagement is perceived to be restricted by a major life stressor, individuals experience decreased subjective well-being (e.g., Williamson, 1998; Williamson & Shaffer, 2000). Support for the association of activity restriction to caregiver adjustment in transitions was found by Dooley (2006) who examined the adaptation of individuals who transitioned out of the caregiver role either because of nursing home placement or care recipient death. His findings suggested a depletion of caregivers' resources and continued stress through the transitions rather than a reduction of stress and better adaptation. Specifically, greater pre-transition activity restriction was unexpectedly related to greater post-transition depression, greater post-transition grief, and less post-transition relief. These results are contrary to the predominant views in the field that support a stress-relief perspective of caregiver adjustment following care recipient death (e.g., George & Gwyther, 1984; Li, 2005; Norris & Murrell, 1987; Schulz, Newsom, Fleissner, et al., 1997; Schulz et al., 2003), perhaps because the sequence of secondary caregiving stressors on later well-being was not fully considered. That is, *change* in perceptions of activity restriction due to care recipient death may play a role in explaining variation in post-transition caregiver well-being.

With respect to the transition occurring due to care recipient death, there are questions that remain unanswered, especially regarding what facilitates adaptation. Change in activity restriction from caregiving to the period following care recipient death has not yet been fully

examined. Additionally, it may be that restrictions to certain activities are more problematic than the restriction of others. As noted earlier, Loucks-Atkinson (2005) distinguished between two kinds of activities that may be restricted: expressive activities (e.g., working on hobbies, socializing) and instrumental activities (e.g., doing household chores, caring for oneself). Loucks-Atkinson's research indicated that expressive activity restriction and instrumental activity restriction should be examined individually and supported the idea that caregiver activity restriction impacts their later well-being (e.g., Loucks-Atkinson et al., 2006). However, these two domains of activity restriction had not yet been considered in the context of caregiver transitions.

Building on the work of Dooley (2006) and Loucks-Atkinson and her colleagues (2005, 2006) this research went into greater depth on the relation of activity restriction to caregiver well-being in the context of transitions. The ARMDA (e.g., Williamson, 1998; Williamson & Shaffer, 2000) was used as a framework for my specific aims as well as to inform predictions about the relations between activity restriction and caregiver subjective well-being. My hypotheses were guided by the grief-relief model of bereavement (e.g., Bass & Bowman, 1990; George & Gwyther, 1984; Mullan, 1992; Norris & Murrell, 1987; Schulz, Newsom, Fleissner, et al., 1997) with a focus on determining the conditions under which caregivers become relieved following care recipient death.

I first established cross-sectional relations between study variables to re-consider previous research findings and extend earlier work by examining perceived activity restriction in the period following care recipient death. I then examined change in perceived activity restriction from the pre- to post-transition period and whether that change predicted post-transition caregiver subjective well-being. Additionally, to refine previous work I examined

whether the expressive and instrumental domains of activity restriction predict post-transition caregiver well-being differently. Caregiver well-being (i.e., caregiving outcomes) was defined as depressive symptoms, relief, and grief. Change in activity restriction was examined as a predictor of the relations caregiver well-being at post-transition.

Specific Aim 1. Examine cross-sectional relations between pre-transition study variables.

Hypothesis 1a. Consistent with prior research on activity restriction (e.g., Williamson et al., 1998) total activity restriction (AR) and depressive symptoms will be positively related. That is, more AR will be related to more symptoms of depression during caregiving.

Hypothesis 1b. Expressive activity restriction (EAR) and instrumental activity restriction (IAR) will be positively associated with depressive symptoms and amount of assistance provided. Expressive activity restriction will be more strongly related to depressive symptoms and amount of assistance provided than will IAR.

Specific Aim 2. Establish cross-sectional relations between post-transition study variables and across-time associations between pre- and post-transition study variables.

Hypothesis 2a. Activity restriction following death of the care recipient will be positively correlated with depressive symptoms and grief, and negatively correlated with relief. That is, being more restricted in routine activities post-transition will be related to more symptoms of depression, more grief, and less relief.

Hypothesis 2b. Expressive activity restriction will be more strongly related to depressive symptoms, grief, and relief than will IAR.

Hypothesis 2c. More pre-transition activity restriction (i.e., total AR, EAR, and IAR) will be related to less post-transition depressive symptoms, less grief, and more relief.

Specific Aim 3. Determine whether caregivers' perceptions of AR change across the pre- to post-transition period (i.e., before and after care recipient death).

Hypothesis 3a. Mean level of perceived total AR will be lower following care recipient death than it was while providing care. That is, caregivers will perceive that they are more able to participate in their routine activities after death of the care recipient than while they were providing care.

Hypothesis 3b. Perceptions of EAR will decrease to a greater extent than will IAR from pre- to post-transition.

Specific Aim 4. Determine whether changes in caregiver AR across the pre- to post-transition period predict caregiver well-being following care recipient death.

Hypothesis 4a. Change in total AR from pre- to post-transition will account for additional variance in post-transition caregiver well-being (i.e., depressive symptoms, grief, and relief). That is, decreases in total AR from the pre- to post-transition period will predict higher relief and lower depression and grief, supporting the stress-relief perspective of adjustment to bereavement. Caregivers who perceive an increase in AR during that period will experience strain and a depletion of their resources, supporting a complicated-grief perspective of adjustment to bereavement.

Hypothesis 4b. Decreases in EAR will account for more variance in relief, depression, and grief than will decreases in IAR.

CHAPTER 4

METHOD

Procedure

Analyses were based on data from interviews from the second Family Relationships in Late Life Project (FRILL2), a multi-site, longitudinal study of informal care provided to cognitively or physically impaired community-dwelling adults age 55 or over. The sample was recruited from Athens, GA, Pittsburgh, PA, Tuscaloosa, AL, and their surrounding areas. To be eligible for the study, caregivers had to live in the same household as the care recipient and be primarily responsible for providing unpaid help with at least one basic activity of daily living (e.g., bathing, toileting) or two instrumental activities of daily living (e.g., paying bills, medication management). Following the initial interview (Time 1 [T1], $n = 448$), interviews were repeated twice at 18-month intervals (Time 2 [T2], $n = 285$; Time 3 [T3], $n = 180$; see Figure 1 for the FRILL2 timeline). If caregivers relinquished their role due to care recipient death during the study, they were asked to participate in follow-up interviews (First follow-up interview [FU1], $n = 76$) designed to examine adjustment following the transition at six month intervals (see Figure 1). Time between interviews was calculated for each participant based on the date of the last caregiver interview obtained prior to care recipient death and the date of the first interview following care recipient death (i.e., first follow-up interview). The first follow-up interviews occurred about 15.1 ($SD = 5.8$) months after the last interview occasion of the main study (median = 15.4 months, range = 3.1 – 26.4 months).

A primary goal of FRILL2 was to oversample African American caregiving dyads in order to obtain data sufficient to address issues conspicuously missing in previous research on the quality of informal elder care (e.g., longitudinal comparisons between White and African American caregivers). Within these constraints, the goal was to obtain as representative a sample as possible, using the services of the Survey Research Center at the University of Georgia. Initial sampling to locate participants in the areas including and surrounding the data collection sites was based on a combination of targeted random digit dialing (RDD) and list-assisted techniques known to dramatically increase the probability of finding qualified participants. Targeted RDD sampling relied on ethnic density in the geographic areas under study; households with higher proportions of African American individuals were sampled from census tracts. Age-targeted, list-assisted sampling relied on secondary sources to increase the incidence rate of our specified age group. Secondary sources were white pages telephone directories, supplemented by voter registration data and driver's license information. The resulting sample should be more representative than samples attained through traditional convenience sampling methods and also more productive in terms of effort required to locate potential participants. Combining these techniques greatly increases the incidence rate of reaching households with the desired characteristics and the likelihood of locating households in the defined population universe with the required characteristics.

During the RDD recruitment phase, a total of 32,753 phone numbers were dialed which resulted, through initial screening, in 877 potential dyads. Of these, 35% refused to be interviewed, 5.6% could not later be reached because of technical phone problems, and 18% were subsequently determined to be ineligible on the basis of additional screening for study criteria. RDD methods produced more eligible White than African American dyads. To increase

the number of African American participants, we used community-based snowball referral methods at the Georgia site, in which enrolled African American dyads were re-contacted and asked to provide the names and telephone numbers of other potentially eligible dyads. Project staff then called and screened these individuals. Snowballing methods produced 95 potential dyads, of which 14.7% refused participation.¹

In sum, recruitment efforts resulted in 771 eligible dyads, 321 (42%) of which declined participation, leaving a sample of 450 dyads (58% participation rate; approximately 56% White dyads and 44% African American dyads). We do not propose that these caregivers represent the overall U.S. population but, rather, that this combination of recruitment methods produced a sample consistent with the purposes of this study.

Face-to-face structured interviews, lasting between 1.5 and 2 hours, were conducted in respondents' homes by pairs of carefully trained interviewers. Each participant (whether caregiver or care recipient) was paid \$25. To prevent data contamination, caregivers and care recipients were interviewed separately and simultaneously.

The study was approved by the Institutional Review Boards of the Universities of Alabama, Georgia, and Pittsburgh. The consent form advised participants that suspected cases of abuse or neglect would be reported to the proper authorities. For reporting purposes, cases of suspected abuse or neglect were indicated if (a) the care recipient reported being physically or psychologically abused or neglected, (b) such treatment was reported and not perceived as a threat but the interviewer suspected that the disclaimer was given under duress (e.g., fear of caregiver retaliation), and/or (c) signs of abuse or neglect sufficient to indicate immediate likelihood of danger to the care recipient were observed by the interviewer. No reportable cases

¹ Participation rates (i.e., completing the T1 interview) varied by recruitment strategy. In the initial RDD, refusal rates were about 42%; in the Age-Targeted RDD, refusal rates were 26.7%; and in the snowballing phase, refusals were only 14.7%.

were observed, and no participants refused to be interviewed after being informed of the obligation to report suspected cases of abuse or neglect.

Sample Characteristics

Of the 448 caregivers with data recorded at baseline (i.e., T1), three caregivers either had enough missing data or were deemed to be ineligible for the study resulting in 445 providing data at T1 and 72 caregivers with available data at T1 and the first follow-up interview (i.e., FU1). Caregivers with available data at T1 and FU1 ($n = 72$) were, on average, 63.4 years of age ($SD = 12.4$, range = 22 – 85) and providing care to individuals with a mean age of 80 years ($SD = 10.4$, range = 55 – 100) at T1. Nearly eighty percent (78.7%) of caregivers were women, and were either White (64%) or African American (36%). A requirement for participating in this study was that caregivers be providing informal, unpaid assistance to care recipients residing in the same household. Therefore, caregivers were mostly family members (49.3% spouses or equivalent, 45.3% adult children, 5.3% other relatives such as siblings, grandchildren, or in-laws).

At the interview before care recipient death (i.e., pre-transition interview), caregivers had been providing care for approximately 6.3 years (range < 1 – 40 years, $SD = 7.4$). Thirty nine percent (38.7%) were caring for someone who had received a diagnosis of dementia or another neurological disorder that causes memory problems (e.g., Alzheimer's disease, Parkinson's disease) during the period immediately preceding care recipient death. Other impairments characterizing care recipients in this sample at pre-transition interviews were primarily physical. On average care recipients had four health conditions, including high blood pressure (52.5%), arthritis (49.2%), heart conditions (47.5%), vision or hearing problems (37.1%), diabetes (32.3%), chronic lung diseases (e.g., bronchitis, 24.2%), stomach problems (e.g., stomach ulcers,

22.6%), kidney problems (21%), stroke (17.7%), cancer (12.9%), and serious liver problems (e.g., cirrhosis, 8.1%) . Nearly half (48%) of caregivers had at least a high school education or equivalent (range = < 7 years – graduate degree) and a median household income of \$20,000 to \$29,999 (range = < \$5,000 – > \$100,000).

Missing data. Treatment of missing data proceeded in stages. First, instances of missing values were examined in order to determine the reason for missingness (e.g. question was not applicable, participant does not know answer, participant refused to answer). For primary study variables, the missing data was examined both between and within caregivers (i.e., whether missing data are coming from the same subjects or over several subjects). The missing data were determined to be coming from several different subjects and missing completely at random (MCAR; Cohen & Cohen, 1983, Roth, Switzer, & Switzer, 1999; see Graham, 2009 for detailed discussion of missing data classifications). Following inspection of missing data points and patterns mean_{item} imputation (Roth et al., 1999) was used to replace individual item values missing within a scale when no more than 80% of the scale was missing values, which was the case for all data that were not missing at the scale-level. In the one case where data were missing at the scale-level (i.e., the subject was missing data for an entire scale), complete cases analysis (i.e., listwise deletion) was used rather than pairwise deletion. One concern with listwise deletion is that it may result in reduced statistical power and yield biased estimates of population parameters. Nevertheless, when loss of cases because of missing data is less than 5%, as is the case in this study (i.e., only one caregiver was missing data for a variable of interest at the scale-level), loss of power and biases are of no great concern (Graham, 2009). Additionally, if the data are MCAR, as was determined in this case, results should not be biased because the cause of missingness is due to chance (Graham, 2009).

Measures

Caregiver activity restriction. The Activity Restriction Scale (ARS; Williamson & Schulz, 1992a) is a nine-item instrument that assesses the extent to which caregivers perceive their activities (e.g., doing household chores, going shopping, visiting friends, participating in sports and recreation, maintaining friendships) have been restricted due to a life stressor (0 = *never or seldom did this*, 4 = *greatly restricted*; see Appendix A for questions and details on prompts used at different time points). Prior research has shown the ARS to be internally consistent (e.g., Williamson & Shaffer, 2000; Williamson & Schulz, 1992a, 1992b; Williamson et al., 1994; Williamson et al., 1998) with Cronbach's α ranging from .78 to .87 (e.g., Williamson & Schulz, 1992a, 1992b, 1995; Williamson et al., 1998). See Table 1 for pre- and post-transition psychometric properties for the present sample.

Loucks-Atkinson (2005) explored whether the ARS items formed two distinct categories of activities (i.e., expressive activities and instrumental activities). In her analyses she used three samples: (a) 310 caregivers from the first FRILL project (FRILL1), (b) 268 cancer outpatients (see Williamson & Schulz, 1995 for eligibility criteria and details of sample), and (c) 230 cancer outpatients (see Williamson & Schulz, 1995). Loucks-Atkinson (2005) provided statistical support for creating two subscales from the composite ARS measure: (a) expressive activity restriction (i.e., "sports and recreation," "visiting friends," "working on hobbies," "maintaining friendships"), and (b) instrumental activity restriction (i.e., "caring for yourself," "caring for others," "doing household chores," "going shopping"). The item "going to work" was not appropriately categorized as an instrumental activity and was excluded from the final measure of instrumental activity restriction (See Table 2 for classification of the ARS items into the two-factor model). This two-factor model fit the data better than a more parsimonious general-factor

model in a sample of caregivers from the FRILL1 study. Similar to the composite measure of the ARS caregivers responded on a 4-point scale (0 = *never or seldom did this*, 4 = *greatly restricted*, see Appendix A), with higher scores indicating greater activity restriction in that domain. See Table 1 for psychometric properties at pre- and post-transition interviews.

Caregiver depression. The 20-item Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977), a self-report instrument with high internal consistency, test-retest reliability, and validity (e.g., Hertzog, Van Alstine, Usala, & Hultsch, 1990; Radloff, 1977), assessed caregiver depressed affect. Caregivers indicated how frequently each symptom had occurred in the past week (0 = *rarely or none of the time [less than 1 day]*, 3 = *most or almost all the time [5 – 7 days]*; see Appendix B), with higher scores indicating more depressed affect. At T1 interviews, 30.8% of caregivers in the present sample scored 16 or higher, placing them at risk for clinical depression. See Table 1 for psychometric properties at pre- and post-transition interviews.

Caregiver grief. A 16-item instrument assessed grief following care recipient death (see Appendix). Seven items were adapted from the Revised Grief Experience Inventory (Lev, Munro, & McCorkle, 1993), and the remaining nine items were adapted from the work of Bass and Bowman (1990) and Pruchno, Moss, Burant, and Schinfeld (1995). These items assess transitioned caregiver appraisals (e.g., “[The care recipient’s] death is the most difficult problem I have ever faced”), negative feelings, and psychological distress associated with specific types of transition (e.g., “I feel lost without [care recipient] around”). Participants responded on a 5-point scale (0 = *strongly disagree*, 5 = *strongly agree*; see Appendix C), with higher scores

Table 1

Summary of Psychometric Properties of Study Variables at Pre- and Post-Transition Interviews (N = 72)

	Possible Range	Pre-transition				Post-transition			
		<i>M</i>	<i>SD</i>	α	Actual Range	<i>M</i>	<i>SD</i>	α	Actual Range
Total Activity Restriction	0-36	15.49	6.94	.84	1-36	12.18	5.02	.79	5-28
EAR	0-16	7.15	3.82	.77	0-16	5.42	2.97	.78	1-16
IAR	0-16	7.11	3.25	.78	0-16	5.76	2.34	.67	3-13
CES-D	0-60	11.22	9.68	.89	0-47	14.47	10.54	.89	0-50
Grief/Bereavement	0-80	^a	^a	^a	^a	43.57	10.97	.90	20-73
Relief	6-30	^a	^a	^a	^a	16.71	4.55	.80	7-26
Overall Relief (1-item)	1-4	^a	^a	^a	^a	2.54	.91	^b	1-4

Note. EAR = expressive activity restriction; IAR = instrumental activity restriction; CES-D = Center for Epidemiologic Studies Depression Scale. ^aNot measured at pre-transition interviews, ^bnot applicable because overall relief is a one-item measure.

Table 2

Classification of the ARS Items

Instrumental	Expressive
Caring for yourself	Visiting friends
Caring for or helping others	Working on hobbies
Doing household chores	Sports and recreation
Going shopping	Maintaining friendships

Note. Two-factor model from Loucks-Atkinson (2005); the item ‘going to work’ is unclassified.

indicating more grief symptomatology. See Table 1 for psychometric properties at post-transition interviews.

Caregiver relief. The relief scale used in FRILL2 was derived from a review of literature examining relief either qualitatively or quantitatively (e.g., Collins et al., 1993; Pruchno et al., 1995; Rosenthal & Dawson, 1991). Transitioned caregivers were asked to indicate the degree to which they agreed with six declarative statements (e.g., “I have regained a part of my life that was lost,” “I feel as though a weight has been lifted from my shoulders,” “[Care recipient] is better off now;” see Appendix D) on a scale of 1 (*strongly disagree*) to 5 (*strongly agree*), with higher scores reflecting more relief. Work by Dooley (2006) showed that a single-item measure assessing overall caregiver relief (i.e., “How do you generally feel about [care recipient’s] death?”) was correlated with predictors of the summary score; this item will be included in the present analyses (see Appendix D). Bereaved caregivers responded to the question on a 4-point scale (1 = *very troubled*, 2 = *somewhat troubled*, 3 = *somewhat relieved*, 4 = *very relieved*), with higher scores indicating greater relief. See Table 1 for psychometric properties for the six-item composite measure and one-item measure of relief at post-transition interviews.

Power Analysis

The G*Power 3.1 power analysis program (Faul, Erdfelder, Buchner, & Lang, 2009) was used to conduct *a priori* power analyses for the proposed study. Statistical power analysis is based on the relations among the four variables involved in statistical inference: computing the necessary sample size (N) as a function of power level ($1-\beta$ error probability), significance level (α), and the to-be-detected population effect size (f^2) specified by the researcher. For bivariate analysis, a total sample size of 53 is required (2-tailed, correlation $\rho_{H1} = .60$, $\alpha = .01$, $1-\beta = .99$).

For the paired samples t-test, assuming a .3 *SD* difference as meaningful and using a directional test, a sample size of 71 will give power of .80 with $\alpha = .05$. For the series of hierarchical multiple regressions, the sample sizes were based on the computation for a fixed model, R^2 increase. This analysis requires that the researcher have some idea about the degree to which the H_0 is believed to be false (i.e., f^2 ; Cohen, 1992). Researchers who have examined the period following care recipient death have reported effect sizes ranging from .26 to .33. Thus, a medium effect size (i.e., .30) was determined to be meaningful for the proposed analyses. Given specifications of $\alpha = .05$, $1-\beta = .95$, $f^2 = .30$ and an estimated five total number of predictors, these analyses require a total sample size of at least 72.

CHAPTER 5

RESULTS

Analyses proceeded in stages. First, attrition analyses were conducted. Next, bivariate (cross-sectional and across-time) analyses were conducted to examine associations between caregiver demographic and study variables to: (a) determine if demographic variables should be included in subsequent analyses as controls, and (b) establish cross-sectional relations between study variables at each time point and across-time. Third, aggregate-level change in activity restriction (AR) was examined, followed by hierarchical regression analyses to determine whether change in AR over time predicted caregiver well-being following the death of the care recipient (CR). Statistical significance was defined as the conventional 95% level ($p = .05$ or better; $\alpha = .05$, 2-tailed). In multivariate analyses, measures of effect size (e.g., R^2 for regressions) were used to describe the proportion of variance in dependent variables accounted for by predictor variables. Analyses were conducted using IBM SPSS software, version 21.

The focal questions of this research were whether perceptions of AR differ from the period when caregivers were providing care to the period following CR death and whether that change is related to caregiver well-being after the transition. The longitudinal analyses focused on the last pre-transition interview and the first post-transition interview time points. These data provided information on whether perceptions of AR are different prior to and after CR death and whether changes in AR predict changes in post-transition depression, grief, and relief.

Attrition Analyses

Of the 445 caregivers who completed the initial interview (T1), a total of 163 caregivers did not complete the second interview (T2). About 37% ($n = 105$) of the 285 caregivers who completed T2 interviews did not complete the third interview (T3; see Figure 1 for study timeline and full sample sizes at each time point). Of the 163 caregivers who did not complete T2 interviews, three (1.8%) died prior to the T2 interview, 49 (30.6%) were no longer providing care due to the death of the CR, and seven (4.3%) had relinquished care to another person or their care recipient had been institutionalized (1.8%, $n = 3$). The remaining (61.9%, $n = 101$) either withdrew from the study or could not be located to complete T2 interviews. Of the 105 caregivers who completed T2 interviews but did not complete T3 interviews, three (2.8%) died prior to the T2 interview, 25 (23.8%) were no longer providing care due to the death of the CR, one (0.9%) had relinquished care to another person, or their care recipient had been institutionalized (2.8%, $n = 3$). The remaining (69.5%, $n = 73$) either withdrew from the study or could not be located to complete T3 interviews.

If caregivers were no longer providing care causing them to attrit from the main study, they were asked to participate in the follow-up study. Seventy-six caregivers attrited from the main study due to CR death and completed the first follow-up (FU1) interview. Of the 76 caregivers who completed FU1 interviews, one (1.3%) caregiver did not have any pre-transition data recorded. Additionally, three caregivers reported that they had not provided help with any activities of daily living (ADLs) or instrumental activities of daily living (IADLs) at the interview immediately preceding CR death and were determined to be ineligible for the present study. In two of the three cases, CRs reported that they had received help with at least one ADL.

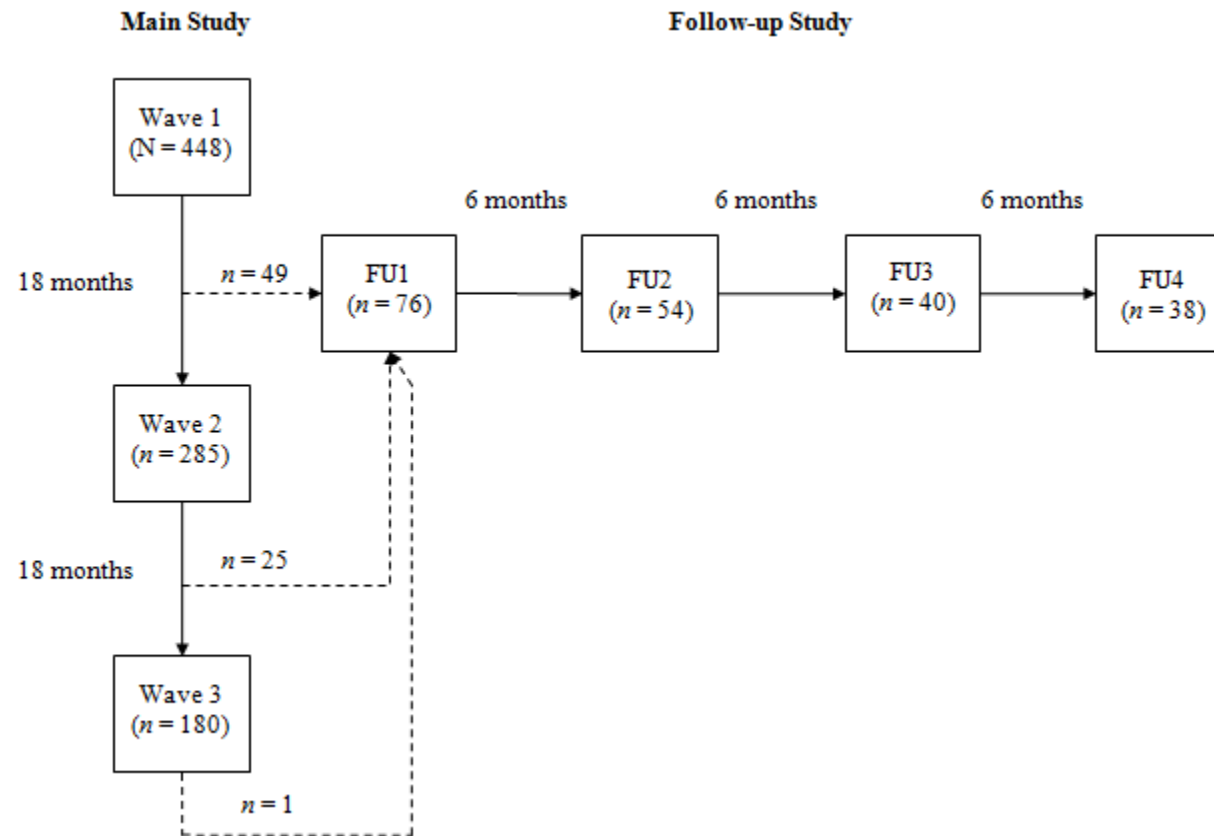


Figure 1. FRILL2 included (a) three phases of data collection with both caregivers and care recipients (i.e., T1, T2, and T3) occurring every 18 months, and (b) follow-up interview with transitioned caregivers (i.e., FU1, FU2, FU3, and FU4) occurring every six months following transition. Full sample sizes are shown here. During the primary phase of the study, project staff at each site contacted caregivers by telephone at three month intervals for various purposes, one of which was to identify those who met criteria for transition (e.g., the care recipient died). When transitioned caregivers were identified, they were immediately removed from the list of uncompleted 18-month interviews and scheduled for their first post-transition interview. When possible, they continued to be interviewed every six months for up to four follow-up data collection points.

However it is unknown who (e.g., the caregiver who was interviewed, another individual not interviewed, formal service provider) was providing the assistance when caregivers reported that they had not provided help to the CR with the task. These four cases (i.e., the one caregiver not interviewed at pre-transition and the three caregivers not providing assistance with ADLs or IADLs at pre-transition interviews) were omitted from analyses. The exclusion of these four cases resulted in available data at both pre-transition and follow-up interviews for a total of 72 caregivers. Of these, 63.9% ($n = 46$) transitioned to the follow-up study after T1, 34.7% ($n = 25$) transitioned to the follow-up study after T2, and 1.4% ($n = 1$) transitioned to the follow-up study following T3 (see Figure 1 for study timeline).

Approximately 83% of caregivers interviewed at T1 did not experience the death of CRs and were not in the follow-up (FU1) study. Multivariate analysis of variance (MANOVAs) were used to compare caregivers who completed only T1 interviews ($n = 373$) to those who completed T1 and FU1 interviews ($n = 72$) on relevant demographic and CR illness-related factors (e.g., kinship, age, gender, race, CR dementia status) and all primary study variables (e.g., caregiver depression, caregiver AR) at T1. These analyses revealed the following differences between the attrited (i.e., those who completed only T1) and full samples (i.e., those who completed T1 and FU1): caregivers who completed T1 and FU1 were providing care to older CRs, $F(1, 443) = 16.48, p < .001$ ($M_s = 74.7$ and 79.9 years for the attrited and full FU1 samples, respectively); providing care for a shorter length of time, $F(1, 443) = 5.07, p = .025$ ($M_s = 7.2$ and 5 years for the attrited and full FU1 samples, respectively); and more likely to be women, $F(1, 443) = 3.85, p = .05$ (67.6% and 79.2% female for the attrited and full FU1 samples, respectively). The caregivers who completed T1 and FU1 also perceived greater total AR, $F(1, 443) = 8.83, p = .003$ ($M_s = 13.0$ and 15.4 for the attrited and full FU1 samples, respectively); as well as greater

expressive activity restriction (EAR), $F(1, 443) = 7.30, p = .007$ ($M_s = 5.9$ and 7.1 for the attrited and full FU1 samples, respectively); and greater instrumental activity restriction (IAR), $F(1, 443) = 7.59, p < .001$ ($M_s = 5.9$ and 7.0 for the attrited and full FU1 samples, respectively). These two groups did not differ in whether they were providing care to a CR with dementia, nor did they differ in caregiver-care recipient kinship, caregiver race, caregiver age, caregiver education, or depressive symptoms (all $F_s \leq 3.19, ns$).

Preliminary Analyses

Tests of normality. Prior to conducting analyses, I conducted tests of normality to determine whether the outcome variables (i.e., depression, grief, and relief measures) were normally distributed. As a rule of thumb, normality can be assumed if the skewness value is less than two times the standard error of skewness. The skewness value exceeded twice the amount of the standard error of skewness for both pre-transition depression scores (skewness = 1.31, $SE = .28$) and post-transition depression scores (skewness = .96, $SE = .28$). Scores on relief and grief measures met assumptions of normality. The Kolmogorov-Smirnov test of normality was then conducted to confirm the skewness of the depression scores, of which the outcome was significant for both pre-transition depression scores (K-S statistic = .16, $p < .001$) and post-transition depression scores (K-S statistic = .15, $p < .001$), indicating that these scores were skewed. Thus, log transformations were computed for pre- and post-transition depression scores and used for all subsequent analyses.

Bivariate correlations among study variables and demographics. Zero order correlations were conducted to determine associations between background characteristics (e.g., caregiver gender, caregiver-care recipient kinship) measured at pre-transition interviews and all primary study variables at pre-transition and post-transition interviews. To adjust for Type I

error due to the large number of correlations being conducted between demographic and study variables, only correlations at $p < .01$ or better were determined to be meaningful to retain the variable as a future control variable.

Care recipient dementia status at the interview immediately preceding CR death was positively correlated with pre-transition total AR ($r = .40, p < .001$), pre-transition EAR ($r = .41, p < .001$), and pre-transition IAR ($r = .36, p = .002$), indicating that when providing care to an individual with dementia caregivers are more likely to perceive greater AR on the total scale and in both AR domains as would be expected. Care recipient dementia status was not related to post-transition study variables. Length of care provided, caregiver age, caregiver education, caregiver race, and CR age were not related to any study variable at pre- or post-transition time points (all $r_s \leq .28, ns$).

There is some evidence that CR illness-related factors, such as whether CRs have been diagnosed with dementia, are associated with caregiver adaptation following CR death (e.g., Collins et al., 1993; Collins et al., 1994; Dooley, 2006; Jones & Martinson, 1992). Based on this empirical evidence and the significant results of the bivariate analysis, care recipient dementia diagnosis was controlled, rather than included as variables of special interest, in subsequent multivariate analyses to more clearly specify the associations between AR and outcome factors independent of CR dementia status. In addition, time between interviews as previously described in Chapter 4 was controlled for in all multivariate analyses because the length of time between main study interviews and follow-up interviews varies from caregiver to caregiver, which may affect their adaptation following CR death.

Cross-sectional and longitudinal bivariate correlations among study variables. Next, to address Specific Aims 1 and 2, I examined the associations between study variables at the

same point in time (i.e., concurrent correlations) and over time. That is, the associations between (a) AR (i.e., total AR, EAR, IAR) and (b) measures of well-being (i.e., depression, grief, and relief) were examined at each time point (i.e., within pre-transition and within post-transition) and across time (i.e., between pre- and post-transition).

Cross-sectional correlations among pre-transition study variables. As expected, greater total AR and greater IAR were associated with greater depressive symptoms among caregivers before CR death (see Table 3). Steiger's Z-test (Steiger, 1980) showed that the correlations between AR and IAR with depression did not differ in strength ($z = -.27, p = .607$). The positive correlation between these variables supports previous cross-sectional findings that when caregivers perceive that they are more restricted in their routine activities overall during caregiving they experience greater depressed affect (e.g., Mausbach et al., 2008; Williamson et al., 1998). Unlike IAR, greater EAR was not related to greater symptoms of depression at pre-transition, contrary to hypotheses. As would be expected AR, EAR, and IAR were positively correlated.

Cross-sectional correlations among post-transition study variables. As shown in Table 3, greater total AR, EAR, and IAR were related to greater grief and greater post-transition symptoms of depression. Less total AR, EAR, and IAR were related to greater overall relief. Steiger's Z-test (Steiger, 1980) showed no differences in the strength of the correlations between EAR or IAR and grief ($z = .62, p = .268$), depression ($z = 1.16, p = .124$), or overall relief ($z = -.58, p = .718$); or in the strength of the correlations between AR and EAR or IAR (all z s $\leq 1.93, ns$). Supporting previous research (e.g., Dooley, 2006), greater composite relief

Table 3

Intercorrelations Among Study Variables at Pre- and Post-Transition

Variable	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.
1. Pre-trans depression	-										
2. Pre-trans AR	.26*	-									
3. Pre-trans EAR	.18	.90***	-								
4. Pre-trans IAR	.28*	.86***	.65***	-							
5. Post-trans AR	.18	.16	.17	.17	-						
6. Post-trans EAR	.17	.27*	.28*	.23	.87***	-					
7. Post-trans IAR	.06	-.01	-.01	.07	.79***	.44***	-				
8. Post-trans depression	.40***	.14	.19	.13	.41***	.40***	.27*	-			
9. Grief	.17	.04	.05	.02	.34**	.33**	.25*	.46***	-		
10. Relief (6-item)	.07	.23*	.25*	.09	-.05	.02	-.21	-.10	-.39***	-	
11. Overall relief	-.16	-.19	-.12	-.23	-.36**	-.28*	-.35**	-.48***	-.51***	.45***	-

Note. Pre-trans = pre-transition; AR = total activity restriction; EAR = expressive activity restriction; IAR = instrumental activity restriction; Post-trans = post-transition. * $p \leq .05$, ** $p \leq .01$, *** $p \leq .001$.

was related to greater overall relief. Greater composite relief also was related to less grief, but not symptoms of depression. As expected, more symptoms of depression was related to more grief ($r = .46, p < .001$) supporting earlier research showing that depression and grief are moderately to highly correlated among bereaved caregivers (e.g., Dooley, 2006) and co-occur for caregivers following the death of care recipients (e.g., Collins et al., 1993). More depression following care recipient death was associated with less overall relief, also supporting previous research (e.g., Dooley, 2006). And, less relief and less overall relief were related to more grief.

Longitudinal correlations between pre- and post-transition study variables. Little evidence for across-time correlations was found at the bivariate level (see Table 3 for intercorrelations). The relation between more pre-transition depressive symptoms and more post-transition depressive symptoms supports previous longitudinal research (e.g., Dooley 2006). Contrary to predictions, pre-transition AR was not related to any post-transition outcome variable, although greater pre-transition EAR was related to greater relief supporting the stress-relief hypothesis. Additionally, greater pre-transition AR and greater pre-transition EAR were related to greater post-transition EAR.

Primary Analyses

Before examining whether change in AR predicted post-transition caregiver well-being, I tested whether AR declined or increased through the transition period.

Pre- to post-transition differences in AR. To address Specific Aim 3, I determined whether perceptions of AR differed after CR death from during caregiving (i.e., the pre- to post-transition period). Dependent samples t-tests were used to test the mean-level difference in scores of (a) total AR, (b) EAR, and (c) IAR (see Table 4). At the aggregate level, caregivers

Table 4

Paired Samples T-Tests Comparing Activity Restriction Scores Before and After Care Recipient Death

Variable	<i>M (SD)</i> ^a		<i>t</i>	df	<i>p</i>	95% CI	
	Pre-transition	Post-transition				Lower	Upper
ARS	15.49 (6.94)	12.18 (5.02)	3.78	71	.000	1.56	5.05
EARS	7.15 (3.82)	5.42 (2.97)	3.77	71	.000	.82	2.62
IARS	6.99 (3.20)	5.76 (2.34)	2.83	71	.006	.36	2.08

Note. ARS = Activity Restriction Scale; EARS = Expressive Activity Restriction Scale; IARS = Instrumental Activity Restriction Scale. ^aHigher scores = greater restriction

perceived that they were less restricted in total AR, EAR, and IAR at post-transition than they were in the pre-transition period, indicating that former caregivers perceive that they are less restricted in their routine activities since the death of CRs. As expected, EAR declined to a greater extent than IAR following CR death with a mean difference of 1.73 for EAR and 1.23 for IAR across the pre- to post-transition period. These findings indicate that former caregivers felt less restricted in activities such as working on hobbies and visiting with friends following CR death than they did instrumental activities like shopping or taking care of others.

Change in AR as a predictor of post-transition caregiver well-being. A series of hierarchical regressions were conducted to address Specific Aim 4 – to determine whether post-transition AR predicts post-transition depression, grief, and relief when controlling for AR at pre-transition. One model was tested for each outcome variable (i.e., depression, grief, relief, overall relief) and for each measure of AR (i.e., total AR, EAR, IAR). In each of the hierarchical regressions described in this section, control variables, between interviews and CR dementia status, were entered in the first step. Next, the relevant pre-transition predictor variables were entered, including the pre-transition measurement of the outcome when available. In the last step, the primary predictor variable was entered. Significant beta weights in the final step of regressions were interpreted as change in values of the primary variable for predicting variation in the criterion measure (see Smith, 2010, for additional description of this method). Residual plots were examined for all models to assess whether the observed error (residuals) was consistent with random error. The unstandardized residuals were symmetrically centered on zero throughout the range of unstandardized predicted values, indicating that the residuals were randomly and normally distributed. Thus, these analyses proceeded without residualizing variables.

Depressive symptoms. The first three models tested the effect of change in AR on post-transition depressive symptoms. These models were run with total AR, EAR, and IAR to determine the contribution of these variables to caregiver depression following CR death. As shown in Table 5, the strongest predictor of greater post-transition depression was greater pre-transition depression ($\beta = .38, p = .001$) and greater post-transition total AR ($\beta = .34, p = .002$). The overall model with total AR as the predictor explained the greatest amount of additional variance (10%) in post-transition symptoms of depression than did the addition of post-transition EAR or IAR (see Tables 5-7). Similar to total AR, decreases in post-transition EAR predicted less depressive symptoms ($\beta = .32, p = .006$), and the overall model accounted for a similar amount of variance (34%) in depressive symptoms as did the overall model with total AR (33%; see Table 6). As expected, the overall model with EAR as the predictor accounted for 6% more of the variance in post-transition symptoms of depression than did the overall model with IAR as the predictor (see Table 7), indicating that decreases in EAR predicted less depression to a greater extent than did decreases in post-transition IAR.

Grief. The next three models tested change in AR (i.e., total AR, EAR, and IAR) as a predictor of grief reactions. As shown in Tables 8-10, decreases in total AR, EAR, and IAR predicted lower levels of grief as hypothesized. Total AR explained the same amount of additional variance (10%) in grief as did EAR. As expected, EAR explained more variance in grief than did IAR, which did not explain as much additional variance in grief. These findings indicate that when caregivers perceive they are less restricted in activities since the death of the CR they experience less grief, with decreases in EAR accounting for more of the variance in grief than decreases in IAR.

Relief. Contrary to predictions, total AR and EAR did not predict composite relief or explain additional variance in relief (see Tables 11 and 12). IAR did predict relief in the expected direction, with decreases in IAR predicting more relief and accounted for an additional 8% of the variance in relief (see Table 13). These results suggest that when caregivers are able to engage in routine activities that have functional value (e.g., going shopping, doing household chores) following CR death they feel as though their lives are getting back to normal to a greater degree than if they were still as restricted in participating in instrumental activities as they were before the death of the CR.

Overall Relief. Total AR, EAR, and IAR did predict overall relief in the expected directions with decreases in total AR, EAR, or IAR from pre- to post-transition predicting more overall relief (see Tables 14-16), indicating that caregivers generally feel relieved since care recipient death when they perceive less AR. Unexpectedly, the overall model with IAR as the predictor accounted for a greater amount of variance in overall relief than the overall models with total AR or EAR as predictors. As shown in Table 16, IAR accounted for an additional 12% of the variance in overall relief, which is 1% more than did total AR (see Table 14) and 5% more than EAR (see Table 15).

Table 5

Hierarchical Regression Analysis of AR Predicting Post-Transition Depression (N = 72)

Predictor Variable	R^2_{change}	Standardized Beta
Step 1	.03	
Days between interviews		.13
Dementia status ^a		-.09
Step 2	.21***	
Pre-trans CES-D		.38***
Pre-trans ARS		.18
Step 3	.10**	
Post-trans ARS		.34**
Total R^2	.33***	

Note. Pre-trans = pre-transition; Post-trans = post-transition; CES-D = Center for Epidemiologic Studies Depression Scale; ARS = Activity Restriction Scale. ^a0 = no, 1 = yes. * $p \leq .05$. ** $p \leq .01$. *** $p \leq .001$.

Table 6

Hierarchical Regression Analysis of EAR Predicting Post-Transition Depression (N = 72)

Predictor Variable	R^2_{change}	Standardized Beta
Step 1	.03	
Days between interviews		.13
Dementia status ^a		-.09
Step 2	.23***	
Pre-trans CES-D		.38***
Pre-trans EARS		.24*
Step 3	.08***	
Post-trans EARS		.32**
Total R^2	.34***	

Note. Pre-trans = pre-transition; Post-trans = post-transition; CES-D = Center for Epidemiologic Studies Depression Scale; EARS = Expressive Activity Restriction Scale. ^a0 = no, 1 = yes. * $p \leq .05$. ** $p \leq .01$. *** $p \leq .001$.

Table 7

Hierarchical Regression Analysis of IAR Predicting Post-Transition Depression (N = 72)

Predictor Variable	R^2_{change}	Standardized Beta
Step 1	.03	
Days between interviews		.13
Dementia status ^a		-.09
Step 2	.20***	
Pre-trans CES-D		.39***
Pre-trans IARS		.13
Step 3	.06*	
Post-trans IARS		.24*
Total R^2	.28***	

Note. Pre-trans = pre-transition; Post-trans = post-transition; CES-D = Center for Epidemiologic Studies Depression Scale; IARS = Instrumental Activity Restriction Scale. ^a0 = no, 1 = yes. * $p \leq .05$. ** $p \leq .01$. *** $p \leq .001$.

Table 8

Hierarchical Regression Analysis of AR Predicting Grief (N = 71)

Predictor Variable	R^2_{change}	Standardized Beta
Step 1	.03	
Days between interviews		.10
Dementia status ^a		-.12
Step 2	.02	
Pre-trans ARS		.14
Step 3	.10**	
Post-trans ARS		.33**
Total R^2	.14*	

Note. Pre-trans = pre-transition; Post-trans = post-transition; ARS = Activity Restriction Scale.

^a0 = no, 1 = yes. * $p \leq .05$. ** $p \leq .01$. *** $p \leq .001$.

Table 9

Hierarchical Regression Analysis of EAR Predicting Grief (N = 71)

Predictor Variable	R^2_{change}	Standardized Beta
Step 1	.03	
Days between interviews		.10
Dementia status ^a		-.12
Step 2	.02	
Pre-trans EARS		.14
Step 3	.10**	
Post-trans EARS		.33**
Total R^2	.14*	

Note. Pre-trans = pre-transition; Post-trans = post-transition; EARS = Expressive Activity Restriction Scale. ^a0 = no, 1 = yes. * $p \leq .05$. ** $p \leq .01$. *** $p \leq .001$.

Table 10

Hierarchical Regression Analysis of IAR Predicting Grief (N = 71)

Predictor Variable	R^2_{change}	Standardized Beta
Step 1	.03	
Days between interviews		.10
Dementia status ^a		-.12
Step 2	.01	
Pre-trans IARS		.11
Step 3	.06*	
Post-trans IARS		.25*
Total R^2	.10	

Note. Pre-trans = pre-transition; Post-trans = post-transition; IARS = Instrumental Activity Restriction Scale. ^a0 = no, 1 = yes. * $p \leq .05$. ** $p \leq .01$. *** $p \leq .001$.

Table 11

Hierarchical Regression Analysis of AR Predicting Relief (N = 72)

Predictor Variable	R^2_{change}	Standardized Beta
Step 1	.01	
Days between interviews		.06
Dementia status ^a		.09
Step 2	.01	
Pre-trans ARS		.12
Step 3	.04	
Post-trans ARS		-.21
Total R^2	.06	

Note. Pre-trans = pre-transition; Post-trans = post-transition; ARS = Activity Restriction Scale.

^a0 = no, 1 = yes. * $p \leq .05$. ** $p \leq .01$. *** $p \leq .001$.

Table 12

Hierarchical Regression Analysis of EAR Predicting Relief (N = 72)

Predictor Variable	R^2_{change}	Standardized Beta
Step 1	.01	
Days between interviews		.06
Dementia status ^a		.09
Step 2	.02	
Pre-trans EARS		.15
Step 3	.03	
Post-trans EARS		-.20
Total R^2	.07	

Note. Pre-trans = pre-transition; Post-trans = post-transition; EARS = Expressive Activity Restriction Scale. ^a0 = no, 1 = yes. * $p \leq .05$. ** $p \leq .01$. *** $p \leq .001$.

Table 13

Hierarchical Regression Analysis of IAR Predicting Relief (N = 72)

Predictor Variable	R^2_{change}	Standardized Beta
Step 1	.01	
Days between interviews		.06
Dementia status ^a		.09
Step 2	.00	
Pre-trans IARS		-.02
Step 3	.08*	
Post-trans IARS		-.29*
Total R^2	.09	

Note. Pre-trans = pre-transition; Post-trans = post-transition; IARS = Instrumental Activity Restriction Scale. ^a0 = no, 1 = yes. * $p \leq .05$. ** $p \leq .01$. *** $p \leq .001$.

Table 14

Hierarchical Regression Analysis of AR Predicting Overall Relief (N = 72)

Predictor Variable	R^2_{change}	Standardized Beta
Step 1	.01	
Days between interviews		.02
Dementia status ^a		.11
Step 2	.09**	
Pre-trans ARS		-.34**
Step 3	.11**	
Post-trans ARS		-.36**
Total R^2	.22**	

Note. Pre-trans = pre-transition; Post-trans = post-transition; ARS = Activity Restriction Scale.

^a0 = no, 1 = yes. * $p \leq .05$. ** $p \leq .01$. *** $p \leq .001$.

Table 15

Hierarchical Regression Analysis of EAR Predicting Overall Relief (N = 72)

Predictor Variable	R^2_{change}	Standardized Beta
Step 1	.01	
Days between interviews		.02
Dementia status ^a		.11
Step 2	.05	
Pre-trans EARS		-.25
Step 3	.07*	
Post-trans EARS		-.30**
Total R^2	.14*	

Note. Pre-trans = pre-transition; Post-trans = post-transition; EARS = Expressive Activity Restriction Scale. ^a0 = no, 1 = yes. * $p \leq .05$. ** $p \leq .01$. *** $p \leq .001$.

Table 16

Hierarchical Regression Analysis of IAR Predicting Overall Relief (N = 72)

Predictor Variable	R^2_{change}	Standardized Beta
Step 1	.01	
Days between interviews		.02
Dementia status ^a		.11
Step 2	.11**	
Pre-trans IARS		-.36**
Step 3	.12**	
Post-trans IARS		-.36**
Total R^2	.20***	

Note. Pre-trans = pre-transition; Post-trans = post-transition; IARS = Instrumental Activity Restriction Scale. ^a0 = no, 1 = yes. * $p \leq .05$. ** $p \leq .01$. *** $p \leq .001$.

CHAPTER 6

DISCUSSION

The goals of this study were to determine: (a) whether and how caregivers' perceptions of activity restriction change in the wake of care recipient death; (b) how such changes affect post-transition caregiver subjective well-being; and (c) whether restrictions to expressive activities (that hold special personal meaning) or restrictions to instrumental activities (that have functional value) impact caregiver well-being differently in this context. The overarching objective was to determine how caregivers adjust to care recipient death with a focus on the conditions in which the stress-relief hypothesis of bereavement is supported. Overall, results of both cross-sectional and longitudinal analyses support the stress-relief idea that care recipient death allows caregivers to reengage in previously lost roles, aiding in turn a positive adjustment to bereavement. Cross-sectional analyses at the bivariate level are consistent with previous research on the activity restriction model of depressed affect (ARMDA; e.g., Williamson, 1998; Williamson & Shaffer, 2000; Williamson et al., 1998), showing that activity restriction and depressed affect were positively intercorrelated in this study. The findings provide additional information that activity restriction decreases through the role disengagement period and that caregivers feel particularly less restricted in their ability to engage in expressive activities following care recipient death. Multivariate analyses with longitudinal data helped to establish that changes in activity restriction through the transition explain a modest amount of variability in caregiver subjective well-being after care recipient death. Rationale for these results, acknowledgement of study limitations, and discussion of implications and future directions are provided.

Cross-Sectional Relations between Pre-Transition Study Variables

Bivariate results between pre-transition study variables suggest that caregivers who were unable to continue in routine activities were more depressed, supporting previous research on the ARMDA (e.g., Mausbach et al., 2008; Williamson et al., 1998). Moreover, caregivers who were restricted in instrumental activities were more likely to be depressed than those who were restricted in expressive activities suggesting that restrictions to certain activities (e.g., caring for yourself, going shopping) may be more harmful to caregiver well-being than others.

Cross-Sectional Relations between Post-Transition Study Variables

The associations between the post-transition outcome variables are consistent with earlier work (e.g., Dooley, 2006) and indicate that depression at post-transition and grief are moderately related. Although depression and grief are moderately correlated in this study, they represent different facets of the role disengagement transition. Depression represents generalized feelings of dysphoria, and even a genetic or psychosocial vulnerability, while grief encompasses feelings directly related to care recipient loss (Hansson & Stroebe, 2007). The findings discussed thus far confirm previous work, while the results of the bivariate analysis between the other post-transition variables of interest and outcome variables extend our understanding of caregivers' experiences in the context of transitions. For one thing, results suggest that even after care recipient death, caregivers who are more restricted in participating in their routine activities are more depressed, consistent with assumptions of the ARMDA and my hypotheses (H2a). This is the first study, to my knowledge, that has examined these associations in the period *following* care recipient death.

Additionally, my expectation (H2b) that caregivers who were less restricted in expressive activities or instrumental activities at post-transition would be less depressed and experience less

grief was supported, although there was no evidence that expressive activities were more strongly associated to these variables. The finding that caregivers who are less restricted in expressive activities at post-transition are more likely to be relieved overall was expected, while the hypothesis that caregivers who are less restricted in expressive activities at post-transition would be more relieved was not supported with the six-item measure of relief. The case could be made that, since the six-item measure of relief asks caregivers to respond to items such as “I feel relieved that I no longer have primary responsibility for [care recipient’s] well-being,” responses might be influenced by caregivers’ desires to present themselves favorably on this sensitive topic, perhaps because they do not feel disclosing that they are relieved because of the care recipient death would be socially acceptable (Mick, 1996; Podsakoff & Organ, 1986). Overall, relations between post-transition EAR and IAR with the outcome measures were consistent with earlier work, with restrictions to either expressive or instrumental activities at post-transition associated with greater depression at post-transition.

Across-Time Relations between Pre- and Post-Transition Study Variables

Few associations between pre- and post-transition study variables were statistically significant. Despite this, correlations between these variables were in the expected directions. In support of the stress-relief hypothesis as predicted (H2c), greater activity restriction during caregiving, especially in the domain of expressive activities, was related to greater relief (six-item). Caregivers of individuals with dementia were more likely to perceive that they are more restricted in participating in routine activities during caregiving than their counterparts; so it is possible that being more restricted in participating in activities due to provision of care is so taxing that relinquishing care is a welcome experience. This possibility is supported by previous findings from one narrative study of bereaved caregiver wives who provided high levels of care

and experienced relief after the deaths of their husbands, with one former caregiver, for example, stating “So, when he did die, I’d shed all my tears in those two years I’d been taking care of him. And it was a relief to me, because life was so hard” (Bennett & Vidal-Hall, 2000, p. 417). Thus, relief may be a result of the end of demanding caregiving, feelings that the restrictions of being a primary caregiver have been lifted, or feelings that the care recipient is no longer suffering (e.g., Schulz et al., 2003). The fact that a similar result was not found for grief may be consistent with the distinction between depressive symptoms and grief made by Hansson and Stroebe (2007). It could be argued that grief is more closely associated with the loss experience than the caregiving experience. That is, care recipient death may alleviate the restrictions that providing care imposes as well as the depressive symptoms associated with those restrictions; and while grief does involve feelings of dysphoria, similar to depressed affect, its cognitive components are more tied to the loss experience itself (e.g., visualizing the deceased as being alive, speaking with the deceased, longing for the deceased).

Caregiver Perceptions of Activity Restriction Differ before and after

Care Recipient Death

The hypothesis that caregivers would feel less restricted in routine activities by the first interview following care recipient death than when they were providing care was supported. To refine these results, I investigated the decline by each activity restriction domain, which helped to explain the kinds of activities caregivers feel less restricted in, and to what extent, during the short time following care recipient death. As expected (H3b), at the aggregate level caregivers were less restricted in expressive activities than instrumental activities after care recipient death compared with the period before care recipient death. In fact, caregivers were slightly less restricted in instrumental activities during caregiving (also shown by Loucks-Atkinson, 2005),

whereas they were slightly less restricted in expressive activities after caregiving. This signifies, per Loucks-Atkinson's (2005) distinctions, that caregivers in this sample felt that they were more able to engage in intrinsically motivated activities than extrinsically motivated activities when caregiving ends. This may have to do with instrumental activities being viewed as characteristic of functional caregiving tasks in which caregivers feel less involved since care recipient death, such as shopping, laundry, and preparing meals, all of which are similarly described in the IAR scale items "doing household chores" and "going shopping." Thus, it could be argued that although providing end-of-life care to a frail individual can have a negative impact on normal activity engagement, the typical caregiving responsibilities provide some opportunity for caregivers to engage in activities that have "survival value" (i.e., instrumental to everyday living) as described Loucks-Atkinson (2005, p. 11).

These findings contribute to the literature in providing evidence of caregivers' changing perceptions of activity restriction in the context of the role disengagement transition, previously examined only in terms of leisure engagement and within the role acquisition or role enactment periods of the caregiving career (e.g., Barusch, 1998; Dunn & Strain, 2001; Keller & Tu, 1994; Mancini et al., 2010; Rogers, 1999; White-Means & Chang, 1994). In other words, although activity restriction increases as individuals enter the caregiving role and continues to increase as caregivers engage in care provision, we also now have evidence that activity restriction decreases once caregiving ends due to care recipient death. Additionally, these findings extend those of Janke and colleagues' (2008) showing that levels of leisure involvement increase among recently widowed *non*caregivers. The current data on caregiver activity restriction subsequent to care recipient death also are more comprehensive than those of Seltzer and Li (2000) that addressed only the frequency with which caregivers engaged in three types of activities before and after

care recipient death. Neither of those other studies addressed caregivers' beliefs regarding whether the change in leisure involvement can be attributed directly to care recipient death.

Although this research provides compelling evidence that caregivers perceive restrictions to instrumental and expressive activities differently during caregiving than after caregiving, this study did not address perceptions of activity restriction prior to the start of caregiving. There is an obvious need to determine perceptions of activity restriction *before* caregiving and how they change from the pre-caregiving period, through role enactment, and then through the role disengagement period and beyond, as caregivers continue to readjust to normalcy. Determining whether perceptions of activity restriction are actually rebounding to pre-caregiving levels can facilitate understanding of the extent of caregivers' adaptation. Additionally, role disengagement encompasses not only care recipient death, but also other reasons for ending in-home care such as care recipient institutionalization or relinquishing responsibility for primary care of the care recipient to another individual. Because this study does not address all possible reasons for role disengagement, the need for further research is clear; there may be differences in perceptions of activity restriction in instances other than care recipient death, particularly with respect to what kinds of activities are perceived to be affected. For example, in cases of role disengagement due to care recipient institutionalization caregivers likely remain involved in care provision to some degree (e.g., monitoring formal nursing care, making routine visits to the nursing home) and may not perceive a decrease in activity restriction or feel a sense of relief to the extent that they would had care provision been completely terminated.

Activity Restriction Predicts Caregiver Well-Being after Care

Recipient Death

Results of multivariate analyses support most predictions advanced in this study and are generally more consistent with the stress-relief hypothesis (e.g., George & Gwyther, 1984; Li, 2005; Norris & Murrell, 1987; Schulz, Newsom, Fleissner, et al., 1997; Schulz et al., 2003) than the complicated-grief hypothesis (e.g., Bass & Bowman, 1990; Dooley, 2006). Findings suggest that the death of the care recipient reduced the chronic strain of caregiving for the caregiver, allowing her/him to re-engage in previously lost roles or activities and affording a positive adjustment to role disengagement, even when accounting for care recipient illness-related characteristics, time between interviews, and pre-transition measurements of activity restriction. Specifically, decreases in activity restriction through the role disengagement transition predicted lower levels of depressive symptoms and grief, and higher levels of relief in the period following care recipient death as expected (H4a). Other researchers have made the argument that relief following care recipient death stems from no longer being responsible for care provision, it appears that change in activity restriction also plays a role in predicting caregiver outcomes.

Results reported here are contrary to previous findings that caregivers will experience continued stress (i.e., complicated-grief hypothesis) through the role disengagement period (e.g., Dooley, 2006; Bass & Bowman, 1990). Dooley (2006), specifically, showed that more pre-transition activity restriction unexpectedly predicted more depression, more grief, and less overall relief. However, Dooley's (2006) analyses did not take post-transition activity restriction into account. The results of the current study were somewhat different in terms of caregiver outcomes related to the bereavement experience when changes in activity restriction from the pre- to post-transition period were considered, showing that decreases in activity restriction

account for less negative and more positive emotional responses in the context of the role disengagement transition. Better caregiver well-being is predicted by caregiver perceptions that they felt less restricted in activities when caregiving ended.

Although not all findings of this investigation were in the predicted directions, the study provides evidence for the differing impact of change in the two activity restriction domains on subjective well-being; thus, providing some refinement to our knowledge of the contribution of activity restriction to caregivers' adaptation in the context of transitions. My expectation (H4b) that being less restricted in expressive activities would be a better predictor of, and account for more variance in, depression, grief, and relief was partly supported. Decrease in EAR is a better slightly predictor of depression and grief, whereas decrease in IAR is a slightly better predictor of relief and overall relief. That is, the decrease in IAR accounted for the most additional variance in overall relief and, in fact, was the only significant predictor of relief (six-item measure); whereas the decrease in EAR accounted for more additional variance in post-transition depressive symptoms and grief than did the decline in IAR. These findings extend Loucks-Atkinson's (2005) work on activity restriction domains to the context of transitions.

Several researchers (e.g., Bedini & Bilbro, 1991; Coleman & Iso-Ahola, 1993) have highlighted the benefits of leisure activity and engagement in dealing with stressful situations. My findings do not address leisure engagement, per se, but do address caregiver perceptions that their activity engagement has been restricted, as well as the ways in which decreases in restriction to different kinds of activities predict better caregiver well-being in the context of transitions that are thought to be stressful. Arguably, it is not whether caregivers are able to participate in leisure activities that contributes to caregiver well-being during this period, it is overcoming restrictions to activity engagement that is impactful. It is important to note that

caregivers' perceptions that they are better able to engage in activities that are functional in nature (i.e., instrumental activities), such as shopping or doing housework, may be more important for increasing positive emotional responses to care recipient death; whereas, caregivers' perceptions of being more able to engage in meaningful activities (i.e., expressive activities), such as working on hobbies or visiting with friends, may be more important for lessening negative emotional responses after care recipient death, a finding which was not expected.

The finding of the differing impact of decreases in EAR and IAR on caregiver well-being may have to do with other factors not examined in the scope of this research. One factor to consider is that the EAR scale items "visiting friends" or "maintaining friendships" may be related to perceptions of social support, which could be considered to be a predictor of subjective well-being. Social support is characterized by having someone (e.g., friends, family) to depend on when help is needed and is a major resource in coping with many forms of stress (e.g., Cohen & Wills, 1985; Fiore, Coppel, Becker, & Cox, 1986; House, Landis, & Umberson, 1988; Krause, Liang, & Yatomi, 1989), including the stress associated with care recipient loss (e.g., Aneshensel et al., 2004; Li, 2005; Robinson-Whelen, Tada, MacCallum, McGuire, & Kiecolt-Glaser, 2001; Schulz et al., 2003). It may be that activities are more restricted among individuals who perceive that they have less social support. Indeed, in cross-lagged analyses, Loucks-Atkinson (2005) found lower perceptions of social support availability to be a predictor of caregivers' perceived restrictions in expressive activities. In another study, Williamson (2000) showed that perceived social support explained significant additional variance in activity restriction among breast cancer patients when controlling for demographics, public self-consciousness, and illness severity. Williamson and colleagues (1994) also demonstrated that when limb amputees were

less satisfied with their social contacts they were more restricted in routine activities when controlling for demographics, amputation and prosthesis related factors (e.g., above knee amputation, hours using prosthesis), and pain. Others have identified, more generally, that in the presence of stressful life events social support facilitates the ability to conduct routine activities (e.g., Mutran, Reitzes, Mossey, & Fernandez, 1995; Oxman & Hull, 1997). Specifically in cross-sectional analyses, caregivers who perceive that they do not have access to social support as a result of care provision are likely to experience greater activity restriction, and perhaps most especially in the domain of expressive activities.

Study Limitations

In addition to the limitation of the specification of variables just noted, there were other limitations influencing the outcomes of this study. Change in activity restriction, including EAR and IAR, accounted for a modest amount of additional variance in post-transition outcomes, ranging from as little as 6% in depressive symptoms to 12% in overall relief. The focus on activity restriction in this study neglects other factors that may influence indicators of well-being among caregivers after care recipient death, such as social support or the quality of the relationship between caregiver and care recipient, which are thought to modify the impact of stressors on emotional well-being (e.g., Dooley, 2006; Pearlin et al., 1981; Williamson et al., 1998). Thus, the inclusion of additional salient predictors may increase the explanatory power of future studies examining the dynamics of caregiver role disengagement. That is not to say that results of this study are less applicable to our understanding of the role disengagement process, indeed, findings indicate that changes in activity restriction should be included in the grief-relief model of bereavement as an important predictor of caregiver adjustment.

One purpose of this study was to examine the importance of changes in caregiving status on activity restriction as a predictor of caregiver well-being. The longitudinal approach used to address this question, while affording some advantage for causal inference, has much room for improvement. For one thing, this study was limited to data collected from caregivers only before and after care recipient. Although this method is considerably more powerful than that of other studies (e.g., Kapari et al., 2010) using only retrospective reports at one time point following care recipient death, future researchers should aim to continue to obtain data from caregivers before the onset of caregiving as well as through the role acquisition period to provide baseline data on levels of activity restriction or depression. Without pre-caregiving baseline data it is impossible to know whether activity restriction rebounds to pre-caregiving level once caregiving ends. This could address, as Aneshensel and colleagues (1995) described, what exactly constitutes successful adaptation. That is, our view of what signifies caregiver adaptation should depend on where caregivers start and end. Thus, caregiver activity restriction following care recipient death must depend, not only on experiences during caregiving, but also on experiences *before* caregiving began. Determining when someone enters the caregiving role, however, is a complicated task because it can be such a gradual transition that the potential caregiver might not identify that it is occurring. Therefore, there must be stringent operationalization of what consists role acquisition (e.g., provision of care with one activity of daily living or two instrumental activities of daily living).

Additionally, all causes of caregiver role disengagement should be considered in order to fully understand caregivers' readjustment to life after caregiving. First, the experience one has in caregiving occurs on a continuum and is likely to influence subsequent life course experiences. For example, the perceptions or actual loss of ability to engage in routine activities may require

restructuring that cannot be understood in just one assessment following care recipient death; rather this would require multiple follow-up interviews over the course of months or years. Second, care recipient death is not the only cause of caregiving cessation and should be expanded to include other reasons such as care recipient institutionalization or relinquishing care to another family member since we do not know how activity restriction changes in the context of these transitions. The FRILL2 study addresses these other causes of role disengagement, but examination of these differences was outside the scope of this study. Similarly, the sequence of events leading up to care recipient death should be considered. Changes in activity restriction may be different than reported in this study had the death occurred after the care recipient had previously been institutionalized as opposed to the death occurring directly from the in-home care period.

Inherent to longitudinal studies of this nature, there is the question of whether the pre- and post-transition activity restriction measurements are equivalent. The measurement structure of the Activity Restriction Scale in the main study and in the follow-up study differ in their reference points (i.e., whether caregivers are restricted *since the start of caregiving* or whether caregivers are restricted *due to care recipient death*). Caregiver reports of activity restriction, then, may be viewed as a function of these reference points with the evaluation of restrictions provided based on attributions to either caregiving or care recipient death. However, in this study, pre-transition activity restriction was used as a control variable in the examination of the contribution of post-transition activity restriction on the dependent variable of interest in the series of hierarchical regressions. Thus, the *change* in activity restriction was only to be approximated by way of examining the change in R^2 . Only with more advanced analytic techniques, such as confirmatory factor analysis (CFA), can we directly test whether the activity

restriction scale has the same meaning to caregivers at pre- and post-transition interview occasions (see Vandenberg & Lance, 2000 for a review of measurement invariance and recommended practices). Although not the case in this study, in instances where research findings directly inform treatment plans or public policy, measurement invariance can be a serious issue (Pitts, West, & Tein, 1996). Still, future work should address this possibility using CFA to provide maximum interpretability of findings and address whether change over time from before to after care recipient death indicates change in the meaning of the underlying activity restriction construct.

Other possible influences that were not addressed in this study were differences, if any, between African American and White caregivers and between dementia and nondementia caregivers. In terms of caregiver race, African American caregivers have been found to experience lower levels of depression than White caregivers (e.g., Haley et al, 1995; Pinquart & Sörensen, 2005; Roth et al., 2001). These results, however, should not be attributed to race alone as there may be other factors associated with both race and psychological distress (e.g., Young & Kahana, 1995). Pinquart and Sörensen (2005), for example, suggested that racial differences in caregiver depression may be influenced by care recipient characteristics, such as illness severity. Additionally, in this study, as well as previous FRILL2 research (e.g., Christie et al., 2009), caregiver race was not associated with study variables and thus was not examined as a variable central in explaining caregiver subjective well-being.

Dementia status of the care recipient may have had implications for caregiver adjustment, especially when the transition is due to care recipient death. As shown in the bivariate analyses of this study, and in other research (e.g., Dooley, 2006; NAC/AARP, 2009; Ory et al., 2000), caregivers of individuals with dementia or other memory impairments are more likely to provide

more assistance with ADLs, perceive greater activity restriction, and experience more depression than caregivers of individuals without cognitive impairments. Caring for someone with an eventually fatal illness such as dementia is unique because of the individual's slow deterioration over a long period of time resulting in caregivers' prolonged preparation for care recipient death as the disease progresses (Butcher, Holkup, & Buckwalter, 2001; Gilbar & Ben-Zur, 2002). As a result, end-of-life care may have its own distinct characteristics. For example, dementia caregivers often begin grieving well before care recipient death as a result of their family member's cognitive-related decline and personality changes, while following the loss it is likely that they will feel more relieved and less depressed than their counterparts (e.g., Collins et al., 1993; Collins et al., 1994; Dooley, 2006; Jones & Martinson, 1992). Although a number of studies support these claims, other evidence suggests there is little difference in experiences of caregivers of family members with or without Alzheimer's disease (e.g., Montgomery, Kosloski, & Borgatta, 1990). Thus, for maximum distinction of the particular emotional difficulties or improvements facing dementia and nondementia caregivers, future work should continue to directly compare the caregiving and bereavement experiences of both groups.

Time since care recipient death, a variable unavailable for these analyses is another factor to consider when examining caregiver subjective well-being following care recipient death. The impact of length of bereavement on caregiver outcomes has been shown to be limited rather than widespread, affecting some variables more than others. Responses shown to be affected by time often are temporal in nature, such as emotional distress, particularly grief and depression (e.g., Aneshensel et al., 2004; Chentsova-Dutton et al., 2002; Mullan, 1992; Taylor et al., 2008) while positive emotional responses to care recipient death, such as relief, may be less affected by time since death (see Aneshensel et al., 1995 for a review of the impact of time since death on

caregiver emotional responses). Time between interviews was used in this study to approximate the amount of time caregivers had been bereaved. However, caregivers in this sample varied quite a bit in the amount of time between pre- and post-transition interviews, with the length of time between interview occasions ranging from three months to over two years. Although time between interviews may be a conservative estimate of time since death, because the precise measurement was not available for these analyses it is still unclear in what ways the amount of time since death impacts subjective well-being. Clearly, it should be critically examined in future research.

Study Implications and Future Directions

This study provides some insight into the processes behind the role disengagement transition and potential avenues for intervention. An implication of the findings of this study is that interventions should specifically be targeted at practical strategies to teach caregivers how to maintain activity engagement or overcome activity restriction with a focus on different kinds of activities for different types of caregivers before and after care recipient death. For example, intervention program goals can be refined to address expressive activities that hold personal meaning and meet creative or social needs, as well as how to overcome restrictions to instrumental activities that have more functional value that meet basic needs. Characteristically, intervention programs (e.g., respite programs) are utilized to alleviate difficulty with primary (i.e., care-related) caregiving stressors, such as care recipient dependency, provision of ADL care, or care recipient cognitive impairment. However, programs that address secondary stressors (e.g., activity restriction, limited social support) may be equally as effective in improving caregiver well-being. Aneshensel and colleagues (1995) emphasize that although some caregivers may be similar in the primary stressors they encounter, they probably vary quite

a bit in the secondary stressors they face. Thus, intervention programs encompassing secondary stressors should be helpful to caregivers' management of primary stressors in turn alleviating the consequences of caregiving stressors. And, in the context of transitions, when primary stressors are no longer present, intervention programs targeted at managing the longlasting effects of secondary caregiving stressors can help caregivers adjust to life after caregiving.

It should be noted that there are drawbacks to intervention programs in general, especially in terms of availability and accessibility. In fact, most caregivers utilize such services infrequently because they may be unaware of its availability, believe the services are inflexible (e.g., caregivers in rural areas who live outside the service area), or consider the programs to be more trouble than they are worth (e.g., too expensive, high staff turnover resulting in constant reorientation of service provider; Brodaty, Thomson, Thompson, & Fine, 2005). Adequate attention should be given, in future research, to the need for more comprehensive and flexible services. This study provides a potential avenue for intervention that could be implemented with consideration of the fact that restricted caregivers may be less likely to be willing to engage in additional activities when they feel they are unable to maintain routine activities, which will be a challenge.

Overall, this work supports the notion that that the role disengagement transition is an integral part of a caregiver's life (Aneshensel et al., 1995) and provides support for the influence of activity restriction on caregiving outcomes, as well as for social readjustment following care recipient death. This study additionally reinforces the idea that although role disengagement is unique, the meaning and consequences of care recipient death certainly are rooted in earlier stages of the caregiving experience. Finally, this work implicates activity restriction in the grief-relief model of bereavement and proposes potential additional avenues to better our

understanding of the conditions in which caregivers adapt to bereavement after a major life role ends. Future work should continue to address this period in the caregiving career to identify additional secondary stressors that have explanatory value while also expanding the use and validation of the ARMDA when examining the period following care recipient death.

REFERENCES

- Aneshensel, C. S., Botticello, A. L., & Yamamoto-Mitani, N. (2004). When caregiving ends: The course of depressive symptoms after bereavement. *Journal of Health and Social Behavior, 45*, 422–440. doi:10.1177/002214650404500405
- Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. J. (1995). *Profiles in caregiving: The unexpected career*. San Diego: Academic Press.
- Argimon, J. M., Limon, E., Vila, J., & Cabezas, C. (2004). Health-related quality of life in carers of patients with dementia. *Family Practice, 21*, 454–457. doi:10.1093/fampra/cmh418
- Barusch, A. S. (1988). Problems and coping strategies of elderly spouse caregivers. *Gerontologist, 28*, 677-685. doi:10.1093/geront/28.5.677
- Bass, D. M., & Bowman, K. (1990). The transition from caregiving to bereavement: The relationship of care-related strain and adjustment to death. *The Gerontologist, 30*, 35–42. doi:10.1093/geront/30.1.35
- Beach, S. R., Schulz, R., Yee, J. L., & Jackson, S. (2000). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the caregiver health effects study. *Psychology and Aging, 15*, 259–271. doi:10.1037/0882-7974.15.2.259
- Bédard, M., Kuzik, R., Chambers, L., Molloy, D. W., Dubois, S., & Lever, J. A. (2005). Understanding burden differences between men and women caregivers: The contribution of care-recipient problem behaviors. *International Psychogeriatrics, 17*, 99–118. doi:10.1017/S1041610204000857
- Bedini, L. A., & Bilbro, C. W. (1991). Caregivers, the hidden victims: Easing caregiver's burden

- through recreation and leisure services. *Annual in Therapeutic Recreation*, 2, 49-54.
- Bedini, L. A., & Guinan, D. M. (1996a). "If I could just be selfish...": Caregivers' perceptions of their entitlement to leisure. *Leisure Sciences*, 18, 227-239.
doi:10.1080/01490409609513284
- Bedini, L. A., & Guinan, D. M. (1996b). The leisure of caregivers of older adults: Implications for CTRS's in non-traditional settings. *Therapeutic Recreation Journal*, 30(4), 274-288.
- Bedini, L. A., & Phoenix, T. L. (1999). Addressing leisure barriers for caregivers of older adults: A model leisure wellness program. *Therapeutic Recreation Journal*, 33(3), 222-240.
- Bedini, L. A., & Phoenix, T. L. (2004). Perceptions of leisure by family caregivers: A profile. *Therapeutic Recreation Journal*, 38(4), 366-381.
- Bennett, K. M., & Vidal-Hall, S. (2000). Narratives of death: a qualitative study of widowhood in later life. *Ageing and Society*, 20, 413-428. doi:10.1017/S0144686X99007813
- Benyamini, Y., & Lomranz, J. (2004). The relationship of activity restriction and replacement with depressive symptoms among older adults. *Psychology of Aging*, 19, 362-366.
doi:10.1037/0882-7974.19.2.362
- Bernard, L. L., & Guarnaccia, C. A. (2002). Husband and adult-daughter caregivers' bereavement. *OMEGA: Journal of Death and Dying*, 45, 153-166. doi:10.2190/MXR9-MBEB-NKX6-5B83
- Bernard, L. L., & Guarnaccia, C. A. (2003). Two models of caregiver strain and bereavement adjustment: A comparison of husband and daughter caregivers of breast cancer hospice patients. *The Gerontologist*, 43, 808-816. doi:10.1093/geront/43.6.808
- Bodnar, J. C., & Kiecolt-Glaser, J. K. (1994). Caregiver depression after bereavement: Chronic

- stress isn't over when it's over. *Psychology of Aging*, 9, 372–380. doi:10.1037//0882-7974.9.3.372
- Boerner, K., Schulz, R., & Horowitz, A. (2004). Positive aspects of caregiving and adaptation to bereavement. *Psychology of Aging*, 19, 668–675. doi:10.1037/0882-7974.19.4.668
- Bonanno, G. A., Moskowitz, J. T., Papa, A., & Folkman, S. (2005). Resilience to loss in bereaved spouses, bereaved parents, and bereaved gay men. *Journal of Personality and Social Psychology*, 88, 827–843. doi:10.1037/0022-3514.88.5.827
- Bonanno, G. A., Wortman, C. B., Lehman, D. R., Tweed, R. G., Haring, M., Sonnega, J., ... Nesse, R. M. (2002). Resilience to loss and chronic grief: A prospective study from pre-loss to 18-months post-loss. *Journal of Personality and Social Psychology*, 83, 1150–1164. doi:10.1037/0022-3514.83.5.1150
- Bookwala, J., & Schulz, R. (2000). A comparison of primary stressors, secondary stressors, and depressive symptoms between elderly caregiving husbands and wives: The caregiver health effects study. *Psychology and Aging*, 15, 607–616. doi:10.1037/0882-7974.15.4.607
- Brodsky, H., Thomson, C., Thompson, C., & Fine, M. (2005). Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry*, 20, 537–546. doi:10.1002/gps.1322
- Burton, A. M., Haley, W. E., & Small, B. J. (2006). Bereavement after caregiving or unexpected death: Effects on elderly spouses. *Aging and Mental Health*, 10, 319–326. doi:10.1080/13607860500410045
- Butcher, H. K., Holkup, P. A., & Buckwalter, K. C. (2001). The experience of caring for a

- family member with Alzheimer's disease. *Western Journal of Nursing Research*, 23, 33–55. doi:10.1177/019394590102300104
- Chattillion, E. A., Ceglowski, J., Roepke, S. K., von Känel, R., Losada, A., Mills, P. J., ... Mausbach, B. T. (2012). Pleasant events, activity restriction, and blood pressure in dementia caregivers. *Health Psychology*, 42, 78-88. doi:10.1037/a0029412
- Chen, F., & Greenberg, J. S. (2004). A positive aspect of caregiving: The influence of social support on caregiving gains for family members of relatives with Schizophrenia. *Community Mental Health Journal*, 40, 423–435. doi:10.1023/B:COMH.0000040656.89143.82
- Chentsova-Dutton, Y., Shucter, S., Hutchin, S., Strause, L., Burns, K., Dunn, L., ... Zisook, S. (2002). Depression and grief reaction in hospice caregivers: From predeath to 1 year afterwards. *Journal of Affective Disorders*, 69, 53–60. doi:10.1016/S0165-0327(00)00368-2
- Christie, J., Smith, G. R., Williamson, G. M., Lance, C. E., Shovali, T. E., & Silva, L. C. (2009). Quality of informal care is multidimensional. *Rehabilitation Psychology*, 54, 173-181. doi:10.1037/a0015705
- Clipp, E. C., & George, L. K. (1990). Psychotropic drug use among caregivers of patients with dementia. *Journal of the American Geriatrics Society*, 38(3), 227–235.
- Cohen, J. (1992). A power primer. *Psychological Bulletin*, 112, 155–159. doi:10.1037/0033-2909.112.1.155
- Cohen, J., & Cohen, P. (Eds.). (1983). *Applied multiple regression/correlation analysis for the behavioral sciences* (2nd ed.). Mahwah, New Jersey: Erlbaum.
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis.

- Psychological Bulletin*, 98, 310-357. doi:10.1037/0033-2909.98.2.310
- Coleman, D., & Iso-Ahola, S. E. (1993). Leisure and health: The role of social support and self-determination. *Journal of Leisure Research*, 28(3), 169-187.
- Collins, C., Liken, M., King, S., & Kokinakis, C. (1993). Loss and grief among family caregivers of relatives with dementia. *Qualitative Health Research*, 3, 236–253.
doi:10.1177/104973239300300206
- Collins, C., Stommel, M., Wang, S., & Given, C. W. (1994). Caregiving transitions: Transitions in depression among family caregivers of relatives with dementia. *Nursing Research*, 43(4), 220–225.
- Csikszentmihalyi, M. (1993). *The evolving self: A psychology for the third millennium*. New York: HarperCollins.
- Dooley, W. K. (2006). *Caregiver adjustment to care recipient nursing home placement and death: Depressive symptoms, grief, and relief in context* (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses database.
- Dunn, N. J., & Strain, L. A. (2001). Caregivers at risk?: Changes in leisure participation. *Journal of Leisure Research*, 33(1), 32-55.
- Faul, F., Erdfelder, E., Buchner, A., & Lang, A. (2009). Statistical power analyses using G*Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods*, 41, 1149–1160. doi:10.3758/BRM.41.4.1149
- Feinberg, L., Reinhard, S. C., Houser, A., & Choula, R. (2011, July). *Valuing the invaluable: 2011 update* [Issue Brief]. Washington, DC: AARP Public Policy Institute.
- Ferrario, S. R., Cardillo, V., Vicario, R., Balzarini, E., & Zotti, A. M. (2004). Advanced cancer

- at home: Caregiving and bereavement. *Palliative Medicine*, 18, 129–136.
doi:10.3758/BRM.41.4.1149
- Fiore, J., Coppel, D. B., Becker, J., & Cox, G. B. (1986). Social support as a multifaceted concept: Examination of important dimensions for adjustment. *American Journal of Community Psychology*, 14, 93–111. doi:10.1007/BF00923252
- Fry, P. S. (2001). The unique contribution of key existential factors to the prediction of psychological well being of older adults following spousal loss. *The Gerontologist*, 47, 69–81. doi:10.1093/geront/41.1.69
- Gallagher-Thompson, D., Lovett, S., Rose, J., McKibbin, C., Coon, D., Futterman, A., & Thompson, L. W. (2000). Impact of psychoeducational interventions on distressed family caregivers. *Journal of Clinical Geropsychology*, 6(2), 91–110.
- Gallagher-Thompson, D., & Powers, D. V. (1997). Primary stressors and depressive symptoms in caregivers of dementia patients. *Aging and Mental Health*, 1, 248–255.
doi:10.1080/13607869757146
- George, L., & Gwyther, L. (1984). The dynamics of caregiving burden: Changes in caregiver well-being over time. *The Gerontologist*, 26, 253-269.
- Gilbar, O., & Ben-Zur, H. (2002). Bereavement of spouse caregivers of cancer patients. *American Journal of Orthopsychiatry*, 72, 422–432. doi:10.1037//0002-9432.72.3.422
- Gold, D. P., Reis, M. F., Markiewicz, D., & Andres, D. (1995). When home caregiving ends: A longitudinal study of outcomes for caregivers of relatives with dementia. *Journal of the American Geriatrics Society*, 43(1), 10–16.
- Graham, J. W. (2009). Missing data analysis: Making it work in the real world. *Annual Review of Psychology*, 60, 549-576. doi:10.1146/annurev.psych.58.110405.085530

- Grant, I., Adler, K. A., Patterson, T. L., Dimsdale, J. E., Ziegler, M. G., & Irwin, M. R. (2002). Health consequences of Alzheimer's caregiving transitions: Effects of placement and bereavement. *Psychosomatic Medicine, 64*(3), 477–486.
- Greenberg, S. (2007). *A profile of older Americans: 2007*. Washington, DC: Administration on Aging, U.S. Department of Health and Human Services.
- Haley, W. E., West, C. A. C., Wadley, V. G., Ford, G. R., White, F. A., Barrett, J. J., ... Roth, D. L. (1995). Psychological, social, and health impact of caregiving: A comparison of Black and White dementia family caregivers and noncaregivers. *Psychology and Aging, 10*, 540–552. doi:10.1037//0882-7974.10.4.540
- Hansson, R. O., & Stroebe, M. S. (2007). The nature of grief. In R. O. Hansson, & M. S. Stroebe (Eds.), *Bereavement in late life: Coping, adaptation, and developmental influences* (pp. 9–24). Washington, DC: American Psychological Association.
- Hertzog, C., Van Alstine, J., Usala, P. D., & Hultsch, D. F. (1990). Measurement properties of the Center for Epidemiologic Studies Depression Scale (CES–D) in older populations. *Psychological Assessment, 2*, 64–72. doi:10.1037//1040-3590.2.1.64
- House, J. S., Landis, K. R., & Umberson, D. (1988). Social relationships and health. *Science, 241*, 540–545. doi:10.1126/science.3399889
- Janke, M. C., Nimrod, G., & Kleiber, D. A. (2008). Leisure patterns and health among recently widowed adults. *Activities, Adaptation, and Aging, 32*, 19–39. doi:10.1080/01924780802039238
- Jones, P. S., & Martinson, I. M. (1992). The experience of bereavement in caregivers of family members with Alzheimer's disease. *IMAGE: Journal of Nursing Scholarship, 24*(3), 172–176.

- Kapari, M., Addington-Hall, J., & Hotopf, M. (2010). Risk factors for common mental disorder in caregiving and bereavement. *Journal of Pain and Symptom Management, 40*, 844–856. doi:10.1016/j.jpainsymman.2010.03.014
- Katz, S. (1983). Assessing self-maintenance: Activities of daily living, mobility, and instrumental activities of daily living. *Journal of the American Geriatrics Society, 31*(1), 721-727.
- Keene, J. R., & Prokos, A. H. (2008). Widowhood and the end of spousal care-giving: Relief or wear and tear? *Aging and Society, 28*, 551–570. doi:10.1017/S0144686X07006654
- Kelly, B., Edwards, P., Synott, R., Neil, C., Baillie, R., & Battistutta, D. (1999). Predictors of bereavement outcome for family carers of cancer patients. *Psycho-oncology, 8*, 237–249. doi:10.1002/(SICI)1099-1611(199905/06)8:3<237::AID-PON375>3.0.CO;2-C
- Kiecolt-Glaser, J. K., Dura, J. R., Speicher, C. E., Trask, J., & Glaser, R. (1991). Spousal caregivers of dementia victims: Longitudinal changes in immunity and health. *Psychosomatic Medicine, 53*(4), 345–362.
- Kiecolt-Glaser, J. K., Glaser, R., Shuttleworth, E. C., Dyer, C. S., Ogrocki, P., & Speicher, C. E. (1987). Chronic stress and immunity in family caregivers of Alzheimer's disease victims. *Psychosomatic Medicine, 49*(5), 523–535.
- Kleiber, D. A. (1999). *Leisure experiences and human development: A dialectical interpretation*. New York: Basic Books.
- Kleiber, D. A., Hutchinson, S. L., & Williams, R. (2002). Leisure as a resource in transcending negative life events: Self-protection, self-restoration, and personal transformation. *Leisure Sciences, 24*, 219-235. doi:10.1080/01490400252900167
- Kleiber, D. A., Walker, G. J., Mannell, R. C. (2011). *A social psychology of leisure (2nd ed.)*.

State College, PA: Venture.

- Krause, N., Liang, J., & Yatomi, N. (1989). Satisfaction with social support and depressive symptoms: A panel analysis. *Psychology and Aging, 4*, 88–97. doi:10.1037/0882-7974.4.1.88
- Lazarus, R. S., Kanner, A. D., & Folkman S. (1980). Emotions: A cognitive-phenomenological analysis. In R. Plutchik, H. Kellerman (Eds.), *Theories of emotion* (pp. 189–217). New York: Academic Press.
- Lee, S., Colditz, G. A., Berkman, L. F., Chapman Walsh, D., & Kawachi, I. (2003). Caregiving and risk of coronary heart disease in US women: A prospective study. *American Journal of Prevention Medicine, 24*, 113–119. doi:10.1016/S0749-3797(02)00582-2
- Lev, E., Munro, B. H., & McCorkle, R. (1993). A shortened version of an instrument measuring bereavement. *International Journal of Nursing Studies, 30*, 213–226. doi:10.1016/0020-7489(93)90032-P
- Li, L. W. (2005). From caregiving to bereavement: Trajectories of depressive symptoms among wife and daughter caregivers. *Journal of Gerontology, Series B: Psychological Sciences, 60*, P190–P198. doi:10.1093/geronb/60.4.P190
- Light, E., Niederehe, G., & Lebowitz, B. D. (1994). *Stress effects on family caregivers of Alzheimer's patients: research and interventions*. New York: Springer.
- Lopez, J., Lopez-Arrieta, J., & Crespo, M. (2005). Factors associated with the positive impact of caring for elderly and dependent relatives. *Archives of Gerontology and Geriatrics, 41*, 81–94. doi:10.1016/j.archger.2004.12.001

- Loucks-Atkinson, A. (2005). *The contribution of expressive versus instrumental activity restriction to the well-being of caregivers* (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses database.
- Loucks-Atkinson, A., Kleiber, D. A., & Williamson, G. M. (2006). Activity restriction and well-being in middle-aged and older caregivers. *Topics in Geriatric Rehabilitation, 22*(4), 269–282.
- Mancini, J., Baumstarck-Barrau, K., Simeoni, M. C., Grob, J. J., Michel, G., Tarpin, C., ... Auquier, P. (2010). Quality of life in a heterogeneous sample of caregivers of cancer patients: An in-depth interview study. *European Journal of Cancer Care, 20*, 483-492. doi:10.1111/j.1365-2354.2010.01227.x
- Marks, N. F., Lambert, J. D., & Choi, H. (2002). Transitions to caregiving, gender, and psychological well-being: A prospective U.S. national study. *Journal of Marriage and Family, 64*, 657–667. doi:10.1111/j.1741-3737.2002.00657.x
- Martwit, S. J., & Meuser, T. M. (2002). Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. *The Gerontologist, 42*, 751–765. doi:10.1093/geront/42.6.751
- Mausbach, B. T., Chattillion, E. A., Moore, R. C., Roepke, S. K., Depp, C. A., & Roesch, S. (2011). Activity restriction and depression in medical patients and their caregivers: A meta-analysis. *Clinical Psychology Review, 31*, 900-908. doi:10.1016/j.cpr.2011.04.004
- Mausbach, B. T., Harmell, A. L., Moore, R. C., Chattillion, E. A. (2011). Influence of caregiver burden on the association between daily fluctuations in pleasant activities and mood: A daily diary analysis. *Behaviour Research and Therapy, 49*, 74-79. doi:10.1016/j.brat.2010.11.004

- Mausbach, B. T., Patterson, T. L., & Grant, I. (2008). Is depression in Alzheimer's caregivers really due to activity restriction? A preliminary mediational test of the activity restriction. *Journal of Behavior Therapy and Experimental Psychiatry, 39*, 459-466.
doi:10.1016/j.jbtep.2007.12.001
- Mausbach, B. T., Patterson, T. L., Rabinowitz, Y. G., Grant, I., & Schulz, R. (2007). Depression and distress predict time to cardiovascular disease in dementia caregivers. *Health Psychology, 26*, 539-544. doi:10.1037/0278-6133.26.5.539
- Mausbach, B. T., Roepke, S. K., Depp, C. A., Moore, R., Patterson, T. L., & Grant, I. (2011). Integration of the pleasant events and activity restriction models: Development and validation of a "PEAR" model of negative outcomes in Alzheimer's caregivers. *Behavior Therapy, 42*, 78-88. doi:10.1016/j.beth.2009.11.006
- Mick, D. G. (1996). Are studies of dark side variables confounded by socially desirable responding? The case of materialism. *Journal of Consumer Research, 23*, 106-119.
doi:10.1086/209470
- Miller, B., & Cafasso, L. (1992). Gender differences in caregiving: Fact or artifact? *The Gerontologist, 32*, 498-507. doi:10.1093/geront/32.4.498
- Miller, B., & Montgomery, A. (1990). Family caregivers and limitations in social activities. *Research on Aging, 12*, 72-93. doi:10.1177/0164027590121004
- Montgomery, R. J., & Kosloski, K. (1994). A longitudinal analysis of nursing home placement for dependent elders cared for by spouses vs adult children. *Journal of Gerontology, Series B: Social Sciences, 49*, S62-S74. doi:10.1093/geronj/49.2.S62
- Montgomery, R. J., Kosloski, K., & Borgatta, E. (1990). Service use and the caregiving

- experience: Does Alzheimer's disease make a difference? In D. E. Biegel, & A. Blum (Eds.), *Aging and caregiving: Theory, research, and policy* (pp. 139-159). Newbury Park, CA: Sage.
- Moore, R. C., Harmell, A. L., Chattillion, E., Ancoli-Israel, S., Grant, I., & Mausbach, B. T. (2011). PEAR model and sleep outcomes in dementia caregivers: Influence of activity restriction and pleasant events on sleep disturbances. *International Psychogeriatrics*, *23*, 1462-1469. doi:10.1017/S1041610211000512
- Mullan, J. T. (1992). The bereaved caregiver: A prospective study of changes in well-being. *The Gerontologist*, *32*, 673-683. doi:10.1093/geront/32.5.673
- Mutran, E. J., Reitzes, D. C., Mossey, J., & Fernandez, M. E. (1995). Social support, depression, and recovery of walking ability following hip fracture surgery. *Journal of Gerontology*, *50*, 354-361. doi:10.1093/geronb/50B.6.S354
- National Alliance for Caregiving and AARP (2004). *Caregiving in the U.S.* Retrieved January 9, 2012, from <http://www.caregiving.org/data/04finalreport.pdf>
- National Alliance for Caregiving and AARP (2009). *Caregiving in the U.S.* Retrieved April 1, 2011, from http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf
- Nieboer, A. P., Schulz, R., Matthews, K. A., Scheier, M. F., Ormel, J., & Lindenberg, S. M. (1998). Spousal caregivers' activity restriction and depression: A model for changes over time. *Social Science and Medicine*, *47*, 1361-1371. doi:10.1016/S0277-9536(98)00214-7
- Norris, F. H., & Murrell, S. A., (1987). Older adult family stress and adaptation before and after bereavement. *Journal of Gerontology*, *42*, 606-612. doi:10.1093/geronj/42.6.606

- Ory, M. G., Hoffman, R. R., Yee, J. L., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *The Gerontologist, 39*, 177–185. doi:10.1093/geront/39.2.177
- Ory, M. G., Yee, J., Tennstedt, S., & Schulz, R. (2000). The extent and impact of dementia care: Unique challenges experienced by family caregivers. In R. Schulz (Ed.), *Handbook on dementia caregiving* (pp. 1–32). New York: Springer.
- Oxman, T. E., & Hull, J. G. (1997). Social support, depression, and activities of daily living in older heart surgery patients. *Journal of Gerontology, 52*, 1-14.
doi:10.1093/geronb/52B.1.P1
- Parks, S. H., & Pilisuk, M. (1991). Caregiver burden: Gender and the psychological costs of caregiving. *American Journal of Orthopsychiatry, 61*, 501–509. doi:10.1037/h0079290
- Partners for Livable Communities (2007). *A blueprint for action: Developing a livable community for all ages*. Retrieved from
http://www.aginginplaceinitiative.org/storage/aipi/documents/Blueprint_for_Action_web.pdf
- Patterson, I. (1996). Participation in leisure activities by older adults after a stressful life event: The loss of a spouse. *The International Journal of Aging and Human Development, 42*, 123-142. doi:10.2190/TG1M-75CB-PL27-R6G3
- Patterson, I., & Carpenter, G. (1994). Participation in leisure activities after the death of a spouse. *Leisure Sciences, 16*, 105–117. doi:10.1080/01490409409513223
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*, 583–594.
doi:10.1093/geront/30.5.583

- Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*, 250–267. doi:10.1037/0882-7974.18.2.250
- Pinquart, M., & Sörensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist, 45*, 90-106. doi: <http://dx.doi.org/10.1093/geront/45.1.90>
- Pinquart, M., & Sörensen, S. (2007). Correlates of physical health of informal caregivers: A meta-analysis. *Journal of Gerontology, Series B: Psychological Sciences, 62*, P126–P137. doi:10.1093/geronb/62.2.P126
- Pitts, S. C., West, S. G., & Tein, J. (1996). Longitudinal measurement models in evaluation research: Examining stability and change. *Evaluation and Program Planning, 19*, 333-350. doi: 10.1016/S0149-7189(96)00027-4
- Podsakoff, P. M., & Organ, D. W. (1986). Self-reports in organizational research: Problems and prospects. *Journal of Management, 12*, 531-544. doi:10.1177/014920638601200408
- Pritchard, R. S., Fisher, E. S., Teno, J. M., Sharp, S. M., Reding, D. J., Knaus, W. A., ... Lynn, J. (1998). Influence of patient preferences and local health system characteristics on the place of death. *Journal of the American Geriatrics Society, 46(10)*, 1242–1250.
- Pruchno, R. A., Moss, M. S., Burant, C. J., & Schinfeld, S. (1995). Death of an institutionalized parent: Predictors of bereavement. *OMEGA: Journal of Death and Dying, 31*, 99–119. doi:10.1080/13607860903046503
- Radloff, L. (1977). The CES–D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385–401. doi:10.1177/014662167700100306

- Richardson, V. E. (2010). Length of caregiving and well-being among older widowers: Implications for the dual process model of bereavement. *OMEGA: Journal Death and Dying*, 6, 333–356. doi:10.2190/OM.61.4.e
- Robinson-Whelen, S., Tada, Y., MacCullum, R. C., McGuire, L., & Kiecolt-Glaser, J. K. (2001). Long-term caregiving: What happens when it ends? *Journal of Abnormal Psychology*, 110, 573-584. doi:10.1037/0021-843X.110.4.573
- Rogers, N. B. (1999). Family obligation, caregiving, and loss of leisure: The experience of three caregivers. *Activities, Adaptation, & Aging*, 24, 35-49. doi:10.1300/J016v24n02_03
- Rosenthal, C. J., & Dawson, P. (1991). Wives of institutionalized elderly men: The first stage of the transition to quasi-widowhood. *Journal of Aging and Health*, 3, 315–334. doi:10.1177/089826439100300301
- Roth, D. L., Haley, W. E., Owen, J. E., Clay, O. J., & Goode, K. T. (2001). Latent growth models of the longitudinal effects of dementia caregiving: A comparison of African American and White family caregivers. *Psychology and Aging*, 16, 427–436. doi:10.1037/0882-7974.16.3.427
- Roth, P. L., Switzer, F. S., & Switzer, D. M. (1999). Missing data in multiple item scales: A Monte Carlo analysis of missing data techniques. *Organizational Research Methods*, 2, 211-232. doi:10.1177/109442819923001
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *Journal of the American Medical Association*, 282, 2215–2219. doi:10.1001/jama.282.23.2215
- Schulz, R., Beach, S. R., Lind, B., Martire, L. M., Zdaniuk, L. M., Hirsch, C., ... Burton, L. (2001). Involvement in caregiving and adjustment to death of a spouse:

- Findings from the caregiver health effects study. *Journal of the American Medical Association*, 285, 3123–3129. doi:10.1001/jama.285.24.3123
- Schulz, R., Boerner, K., Shear, K., Zhang, S., & Gitlin, L. N. (2006). Predictors of complicated grief among dementia caregivers: A prospective study of bereavement. *The American Journal of Geriatric Psychiatry*, 14, 650–658. doi:10.1097/01.JGP.0000203178.44894.db
- Schulz, R., Mendelsohn, A. B., Haley, W. E., Mahoney, D., Allen, R. S., Zhang, S., ... Belle, S. H. (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *New England Journal of Medicine*, 349, 1936–1942. doi:10.1056/NEJMsa035373
- Schulz, R., Newsom, J. T., Fleissner, K., Decamp, A., R., & Nieboer, A. P. (1997). The effects of bereavement after family caregiving. *Aging and Mental Health*, 1, 269–282. doi:10.1080/13607869757173
- Schulz, R., Newsom, J. T., Mittelmark, M., Burton, L., Hirsch, C., & Jackson, S. (1997). Health effects of caregiving: The caregiver health effects study: An ancillary study of the Cardiovascular Health Study. *Annals of Behavioral Medicine*, 19, 110–116. doi:10.1007/BF02883327
- Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist*, 35, 771–791. doi:10.1093/geront/35.6.771
- Schulz, R., & Williamson, G. M. (1991). A 2-year longitudinal study of depression among Alzheimer's caregivers. *Psychology and Aging*, 6, 569–578. doi:10.1037//0882-7974.6.4.569
- Selzter, M. M., & Li, L. W. (2000). The dynamics of caregiving: Transitions during a three-year

- prospective study. *The Gerontologist*, 40(2), 165–178. doi:10.1093/geront/40.2.165
- Skaff, M. M., & Pearlin, L. I. (1992). Caregiving: Role engulfment and the loss of self. *The Gerontologist*, 32, 656–664. doi:10.1093/geront/32.5.656
- Skaff, M. M., Pearlin, L. I., & Mullan, J. T. (1996). Transitions in the caregiving career: Effects on sense of mastery. *Psychology and Aging*, 11, 247–257. doi:10.1093/geront/32.5.656
- Smith, G. R. (2010). *Increases in informal caregiver psychological distress and physical health symptoms lead to poor quality of care over time* (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses database.
- Smith, G. R., Williamson, G. M., Miller, L. S., & Schulz, R. (2011). Depression and quality of informal care: A longitudinal investigation of caregiving stressors. *Psychology and Aging*, 26, 584–591. doi:10.1037/a0022263
- Steiger, J. H. (1980). Tests for comparing elements of a correlation matrix. *Psychological Bulletin*, 87, 245–251. doi:10.1037/0033-2909.87.2.245
- Stevens, A. B., Coon, D., Wisniewski, S., Vance, D., Arguelles, S., Belle, S.,...Haley, W. (2004). Measurement of leisure time satisfaction in family caregivers. *Aging & Mental Health*, 8, 450–459. doi:10.1080/13607860410001709737
- Taylor, D. H., Kuchibhatla, M., Østbye, T., Plassman, B. L., & Clipp, E. C. (2008). The effect of spousal caregiving and bereavement on depressive symptoms. *Aging and Mental Health*, 12, 100–107. doi:10.1080/13607860801936631
- Thompson, L. (2000, November). *Long-term care: Support for family caregivers* [Issue Brief]. Washington, DC: U.S. Agency for Healthcare Research and Quality.
- Thompson, L. (2004, March). *Long-term care: Support for family caregivers* [Issue Brief]. Washington, DC: Georgetown University, Long-Term Care Financing Project.

- Thompson, L. W., Gallagher-Thompson, D., Futterman, A., Gilewski, M. J., & Peterson, J. (1991). The effects of late-life spousal bereavement over a 30-month interval. *Psychology and Aging, 6*, 434–441. doi:10.1037/0882-7974.6.3.434
- Vandenberg, R. J., & Lance, C. E. (2000). A review and synthesis of the measurement invariance literature: Suggestions, practices, and recommendations for organizational research. *Organizational Research Methods, 3*, 4-70. doi:10.1177/109442810031002
- Vitaliano, P. P., Zhang, J., & Scanlon, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin, 129*, 946–972. doi:10.1037/0033-2909.129.6.946
- Walters, A. S., & Williamson, G. M. (1999). The role of activity restriction in the association between pain and depression: A study of pediatric patients with chronic pain. *Children's Health Care, 28*, 33-50. doi:10.1207/s15326888chc2801_3
- Waterman, A. S. (1990). Personal experiences: Philosophical and psychological foundations. *Journal of Mind and Behavior, 11(1)*, 47-74.
- Wheaton, B. (1990). Life transitions, role histories, and mental health. *American Sociological Review, 55*, 209–223. doi:10.2307/2095627
- White-Means, S. I., & Chang, C. F. (1994). Informal caregivers' leisure time and stress. *Journal of Family and Economic Issues, 15*, 117-136. doi:10.1007/BF02353636
- Wijngaards-de-Meij, L., Stroebe, M., Schut, H., Stroebe, W., van den Bout, J., van der Heijden, P., & Dijkstra, I. (2005). Couples at risk following the death of their child: Predictors of grief versus depression. *Journal of Consulting and Clinical Psychology, 73*, 617–623. doi:10.1037/0022-006X.73.4.617
- Williamson, G. M. (1995). Restrictions of normal activities among older adult amputees: The

- role of public self-consciousness. *Journal of Clinical Geropsychology*, *1*(3), 229-242.
- Williamson, G. M. (1998). The central role of restricted normal activities in adjustment to illness and disability: A model of depressed affect. *Rehabilitation Psychology*, *43*, 327–347.
doi:10.1037/0090-5550.43.4.327
- Williamson, G. M. (2000). Extending the activity restriction model of depressed affect: Evidence from a sample of breast cancer patients. *Health Psychology*, *19*, 339-347.
doi:10.1037/0278-6133.19.4.339
- Williamson, G. M., & Schulz, R. (1992a). Physical illness and symptoms of depression among elderly outpatients. *Psychology and Aging*, *7*, 343–351. doi:10.1037//0882-7974.7.3.343
- Williamson, G. M., & Schulz, R. (1992b). Pain, activity restriction, and symptoms of depression among community-residing elderly adults. *Journal of Gerontology*, *47*, P367–P372.
doi:10.1093/geronj/47.6.P367
- Williamson, G. M., & Schulz, R. (1995). Activity restriction mediates the association between pain and depressed affect: A study of younger and older adult cancer patients. *Psychology and Aging*, *10*, 369-378. doi:10.1037//0882-7974.10.3.369
- Williamson, G. M., Schulz, R., Bridges, M. W., & Behan, A. M. (1994). Social and psychological factors in adjustment to limb amputation. *Journal of Social Behavior & Personality*, *9*(5), 249–268.
- Williamson, G. M., & Shaffer, D. R. (2000). The Activity Restriction Model of Depressed Affect: Antecedents and consequences of restricted activities. In G. M. Williamson, D. R. Shaffer, & P. A. Parmelee (Eds.), *Physical illness and depression in older adults: A handbook of theory, research, and practice* (pp. 173–200). Dordrecht, Netherlands: Kluwer Academic Publishers.

- Williamson, G. M., Shaffer, D. R., & Schulz, R. (1998). Activity restriction and prior relationship history as contributors to mental health outcomes among middle-aged and older spousal caregivers. *Health Psychology, 17*, 152–162. doi:10.1037//0278-6133.17.2.152
- Wortman, C. B., Silver, R. C., & Kessler, R. C. (1993). The meaning of loss and adjustment to bereavement. In M. S. Stroebe, W. Stroebe, & R. O. Hansson (Eds.), *Handbook of bereavement: Theory, research and intervention* (pp. 349-366). New York: Cambridge University Press.
- Yee, J. L., & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: A review and analysis. *The Gerontologist, 40*, 147–164. doi:10.1093/geront/40.2.147
- Young, R. F., & Kahana, E. (1995). The context of caregiving and well-being outcomes among African and Caucasian Americans. *The Gerontologist, 35*, 225–232. doi:10.1093/geront/35.2.225
- Zarit, S. H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist, 20*, 649-655. doi:10.1093/geront/20.6.649
- Zarit, S. H., & Whitlatch, C. J. (1993). The effects of placement in nursing homes on family caregivers: Short and long term consequences. *Irish Journal of Psychology, 14*, 25–37. doi:10.1080/03033910.1993.10557912

APPENDIX A

MEASURE OF ACTIVITY RESTRICTION

Activity Restriction Scale

Now, I'd like to ask you some questions about the ways in which taking care of (care recipient) may have caused changes in your activities. Using the following responses, please tell me, in general, how much providing care has restricted your activities in each of the following areas since onset of (care recipient's) illness.²

0. Never or seldom did this
1. Not restricted at all
2. Slightly restricted
3. Moderately restricted
4. Greatly restricted

1. Caring for yourself^a
2. Caring for or helping other people^a
3. Doing household chores^a
4. Going shopping^a
5. Visiting friends^b
6. Working on hobbies^b
7. Sports and recreation^b
8. Going to work³
9. Maintaining friendships^b

²This prompt was used for the T1 (baseline) interviews. For interviews after care recipient death, the following prompt was used: Now, I'd like to ask you some questions about the ways in which (care recipient's) death may have caused changes in your activities. Using the following responses, please tell me, in general, how much your activities have been restricted in each of the following areas since (care recipient) passed away.

^aRepresents the instrumental domain of activity restriction as specified by Loucks-Atkinson (2005).

^bRepresents the expressive domain of activity restriction as specified by Loucks-Atkinson (2005).

³The item "going to work" was not appropriately classified as an instrumental activity as theorized by Loucks-Atkinson (2005) and was excluded in the final composite measure of instrumental activity restriction. The cross-validation of the factor structure conducted in a sample of older cancer patients with the item did not adequately fit the data as it did in a sample of caregivers (see Loucks-Atkinson, 2005)

APPENDIX B

MEASURE OF DEPRESSION

Center for Epidemiological Studies Depression (CES-D) Scale

Now I'd like to ask some questions about how you've felt more recently. Please indicate the response for each statement, describing about how often you have felt that way during the past WEEK.

0. Rarely or none of the time (less than 1 day)
1. Some or a little of the time (1-2 days)
2. Occasionally or a moderate amount of the time (3-4 days)
3. Most or almost all the time (5-7 days)

1. I was bothered by things that usually don't bother me.
2. I did not feel like eating, my appetite was poor.
3. I felt that I could not shake off the blues, even with help from family and friends.
4. I felt that I was just as good as other people.
5. I had trouble keeping my mind on what I was doing.
6. I felt depressed.
7. I felt that everything I did was an effort.
8. I felt hopeful about the future.
9. I thought my life had been a failure.
10. I felt fearful.
11. My sleep was restless.
12. I was happy.
13. I talked less than usual.
14. I felt lonely.
15. People were unfriendly.
16. I enjoyed life.
17. I had crying spells.
18. I felt sad.
19. I felt that people disliked me.
20. I could not "get going."

APPENDIX C

MEASURE OF GRIEF/BEREAVEMENT

For each statement that I read, tell me which of the following responses is most appropriate to your situation.

0. Strongly disagree
1. Disagree
2. Neither agree or disagree
3. Agree
4. Strongly agree

1. (Care recipient's) death is the most difficult problem I have ever faced.
2. It is easy to feel overwhelmed in a situation like this.
3. I can understand why some people lose the will to go on in situations like this.
4. I didn't expect that I would have as hard a time adjusting to (care recipient's) death as I did.
5. Life has lost its meaning.
6. Life seems empty and barren.
7. I feel like I am just "going through the motions."
8. I feel lost without (care recipient) around.
9. My personal problems are too much to handle.
10. I am frequently in a negative mood.
11. I have feelings of guilt because I was spared and (care recipient) died.
12. I cry when I think of (care recipient).
13. Since (care recipient's) death, I don't have enough energy to get things done.
14. Since (care recipient's) death, I have trouble controlling my grief.
15. Since (care recipient's) death, I have trouble getting good advice or suggestions on how to manage this situation.
16. Since (care recipient's) death, my physical or emotional health has changed for the worse.

APPENDIX D

MEASURES OF RELIEF

The next statements represent feelings that some caregivers experience after the death of a relative or close friend. For each statement, please give the response that reflects your true feelings best.

1. Strongly disagree
2. Disagree
3. Neither agree or disagree
4. Agree
5. Strongly agree

1. I feel as though a weight has been lifted from my shoulders.
2. I feel like I have regained a part of my life that was lost.
3. I feel relieved that I no longer have primary responsibility for (care recipient's) well being.
4. I feel like (care recipient) is better off now.
5. I feel like I am better off now.
6. I feel as though my life is getting back to normal now.

Please answer the following question with one of these responses.

1. Very troubled
2. Somewhat troubled
3. Somewhat relieved
4. Very relieved

7. How do you generally feel about (care recipient's) death?