

CAREGIVER ADJUSTMENT TO CARE RECIPIENT NURSING HOME PLACEMENT AND
DEATH: DEPRESSIVE SYMPTOMS, GRIEF, AND RELIEF IN CONTEXT

by

WILLIAM KEITH DOOLEY

(Under the Direction of Gail M. Williamson)

ABSTRACT

Research on informal caregiving in late life has only recently addressed complexities involved in the shift from in-home care provision to cessation of the caregiver role. Existing models of caregiver adjustment to caregiving transitions suggest complex relations among life-span development, care-related factors, and post-caregiving outcomes. This study examined depressive symptoms, grief, and relief among informal caregivers following care recipient (CR) nursing home placement and CR death. A sample of 132 caregivers completed face-to-face surveys before and after a transition; 624 caregivers who continued to provide in-home care during the study provided data for baseline comparisons. Participants provided information on demographic and other background characteristics, quality of their past relationship with the CR, care-related stress, pre-transition depressive symptoms, and post-transition depressive symptoms, grief, and relief. Continuing caregivers, caregivers who experienced CR nursing home placement, and caregivers who experienced CR death did not differ with respect to pre-transition depressive symptoms. There were mean-level increases in depressive symptoms after a transition, which differed by transition type and CR cognitive impairment status. Regression analyses indicated that less time providing in-home care, poor caregiver health, higher care-

related stress, and more pre-transition depressive symptoms predicted more post-transition depressive symptoms. Male caregivers, those who co-resided with a CR and who reported poorer health, better historical relationship with the CR, less care-related stress, and more pre-transition depressive symptoms experienced stronger post-transition grief. Poorer historical relationship quality with the CR, more care-related stress, and more pre-transition depressive symptoms predicted more post-transition relief. Type of transition moderated relations between duration of in-home care provision and post-transition depressive symptoms; care-related stress and post-transition relief; and pre-transition depressive symptoms and post-transition relief. Results support existing models of stress accumulation and depletion of coping resources following a caregiving transition. However, the co-existence of negative (depressive symptoms, grief), and positive (relief) outcomes indicates that transitions produce ambiguous emotional responses, and individual differences across the lifespan contribute to post-caregiving adjustment. This research should inform mental health professionals designing targeted caregiver interventions following CR institutionalization and death and raises new questions concerning the effects of mixed emotional reactions on long-term adjustment in former caregivers.

INDEX WORDS: Caregiver, Transition, Care recipient, Nursing home placement, Death, Grief, Relief, Depression

CAREGIVER ADJUSTMENT TO CARE RECIPIENT NURSING HOME PLACEMENT AND
DEATH: DEPRESSIVE SYMPTOMS, GRIEF, AND RELIEF IN CONTEXT

by

WILLIAM KEITH DOOLEY

Bachelor of Arts, University of Mississippi, 1993

Master of Education, University of Mississippi, 1996

Master of Science, University of Georgia, 2000

A Dissertation Submitted to the Graduate Faculty of The University of Georgia in Partial

Fulfillment of the Requirements for the Degree

DOCTOR OF PHILOSOPHY

ATHENS, GEORGIA

2006

© 2006

William Keith Dooley

All Rights Reserved

CAREGIVER ADJUSTMENT TO CARE RECIPIENT NURSING HOME PLACEMENT AND
DEATH: DEPRESSION, GRIEF, AND RELIEF IN CONTEXT

by

WILLIAM KEITH DOOLEY

Major Professor: Gail M. Williamson

Committee: Charles Lance
David R. Shaffer

Electronic Version Approved:

Maureen Grasso
Dean of the Graduate School
The University of Georgia
August 2006

DEDICATION

This research is dedicated to the caregivers who generously gave of their time and wisdom so that I could better understand their experiences in the face of major life change. Also, I am forever dedicated to my wife, Melissa, whose unending support and encouragement have allowed me to accomplish both my academic and personal goals.

ACKNOWLEDGEMENTS

This research was supported by National Institute on Aging Grant R-01-AG15321 (Gail Williamson, Principal Investigator, W. Keith Dooley, Co-Investigator).

TABLE OF CONTENTS

	Page
ACKNOWLEDGEMENTS	v
LIST OF TABLES	viii
LIST OF FIGURES	ix
CHAPTER	
1 INTRODUCTION	1
2 BRIEF REVIEW OF IN-HOME FAMILY CAREGIVING	10
3 REVIEW OF THE CAREGIVING TRANSITIONS LITERATURE	14
Caregiver Depressive Symptoms Following CR Nursing Home Placement	16
Correlates of Caregiver Depressive Symptoms Following CR Nursing Home Placement	19
Caregiver Depressive Symptoms Following CR Death	21
Correlates of Caregiver Depressive Symptoms Following CR Death	24
Comparison of In-Home Care and Caregiving Transitions.....	26
Caregiver Grief Following CR Nursing Home Placement or CR Death	28
Correlates of Caregiver Grief Following CR Nursing Home Placement or CR Death	30
Caregiver Relief Following CR Nursing Home Placement or CR Death	32
4 RESEARCH QUESTIONS AND HYPOTHESES	34
5 METHOD	37

Design and Participants	37
Measures	39
6 RESULTS	44
Preliminary Analyses	44
Pre- to Post-Transition Differences in Caregiver Depressive Symptoms	51
Regression Models of Post-Transition Depressive Symptoms, Grief, and Relief ..	52
7 DISCUSSION	67
Do Pre-Transition Depressive Symptoms Differ Among Caregivers Who Continue to Provide In-Home Care and Those Who Experience a Transition?	68
Do Informal Caregivers' Depressive Symptoms Change After CR Nursing Home Placement or CR Death?	69
How Are Caregiver and CR Background Characteristics, Pre-Illness Relationship Quality, Care-Related Stress, and Pre-Transition Mental Health Related to Post-Transition Caregiver Depressive Symptoms, Grief, and Relief?	72
Limitations and Future Directions.....	79
REFERENCES	83
APPENDIX SCALES EMPLOYED IN THE STUDY	96

LIST OF TABLES

	Page
Table 1: Characteristics of the Sample	46
Table 2: Intercorrelations among Study Variables	48
Table 3: Repeated Measures Analysis of Variance Results for Caregiver Depressive Symptoms (CES-D) Using Type of Transition and Time of Assessment, with Care Recipient Dementia Diagnosis as Covariate	53
Table 4: Means and Standard Deviations for Pre- and Post-Transition Depressive Symptoms (CES-D) as a Function of Type of Transition and Care Recipient Dementia Diagnosis	54
Table 5: Summary of Hierarchical Regression Analysis for Variables Predicting Post-Transition Caregiver Depressive Symptoms (CES-D).....	57
Table 6: Summary of Hierarchical Regression Analysis for Variables Predicting Post-Transition Caregiver Grief	60
Table 7: Summary of Hierarchical Regression Analysis for Variables Predicting Post-Transition Caregiver Relief.....	62
Table 8: Summary of Hierarchical Regression Analysis for Variables Predicting Post-Transition Caregiver Overall Relief.....	65

LIST OF FIGURES

	Page
Figure 1: Interaction Effect of Type of Transition and Time in Caregiver Role on Post-Transition Caregiver Depressive Symptoms	58
Figure 2: Interaction Effect of Type of Transition and Pre-Transition Activity Restriction on Post-Transition Caregiver Relief.....	63
Figure 3: Interaction Effect of Type of Transition and Pre-Transition Depressive Symptoms (CES-D) on Post-Transition Caregiver Overall Relief.....	66

CHAPTER 1

INTRODUCTION

This is a study of the short-term effects of cessation of in-home elder care on informal caregivers' emotional well-being. As the U.S. population ages, more and more family members will find themselves in the role of primary caregiver for a chronically ill or disabled aged relative. The Baby Boomer generation will begin to reach traditional retirement age (i.e., 65) in 2011, signaling the "graying" of society (U.S. Census Bureau, 2001). These individuals may require large amounts of professional, financial, social, and physical resources in order to age gracefully, and the strain this may place on the U.S. economy and political structure could be tremendous. During the past half century, there has been an intensive focus on the processes and effects of aging in industrialized societies such as the United States; more recently, an equally intensive focus has concentrated on caring for the aging individual. Together, government and private nursing homes provide long-term care for only a small proportion of elderly people; for example, it is estimated that only five percent of the 35 million persons over age 65 reside in nursing homes (U.S. Census Bureau, 2001). More often, the responsibility for elder care falls on the family. As a result, informal caregivers have become one of if not the most important health care resources in our country.

An abundant literature documents the impact of caring for an ill or disabled elderly relative. It is well-established that caregivers are at risk for increased psychological morbidity (e.g., Biegel, Sales, & Schulz, 1991; Bookwala & Schulz, 2000; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Schulz, Visintainer, & Williamson, 1990). Compelling evidence also exists that

caregiving places strains on caregiver physical health and immune system functioning (e.g., Beach, Schulz, Yee, & Jackson, 2000; Kiecolt-Glaser, Bodnar, & Glaser, 1994; Kiecolt-Glaser, Dura, Speicher, et al., 1991; Schulz & Beach, 1999; Schulz et al., 1997; Vitaliano, Zhang, & Scanlan, 2003; Vitaliano, 1997). The effects of adopting the caregiver role reach many areas of life. For example, the onset of chronic illness or permanent cognitive decline in a relative or close friend often introduces considerable psychological stress and worry into the family. Researchers recognize that care provision impacts career stability, financial security, and interpersonal relationships (e.g., Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Grafstrom, Fratiglioni, Sandman, & Winblad, 1992; Haley, Levine, Brown, et al., 1987). In general, results suggest that caregivers are at higher risk for difficulty in these areas than their age-matched, non-caregiving peers. By its nature, the caregiving relationship does not last indefinitely, but the stress generated by this life event may have considerable long-term consequences.

While considerable variability exists in the course and duration of informal care, care provision will almost certainly end in one of two ways: care recipient (CR) nursing home placement or death. Nursing home placement occurs in a small minority of families (Montgomery & Kosloski, 1994; Pruchno, Michaels, & Potashnik, 1990; Scott, Edwards, Davis, Cornman, & Macera, 1997), whereas bereavement is more common and represents the endpoint of actual care provision. However, neither of these transitions occurs without considerable psychosocial impact on the family, particularly caregivers who were responsible for the primary care of their relatives. Researchers have only recently begun to question what happens to caregivers after the placement or death of their elderly CRs.

The emerging literature draws upon two theoretical perspectives to investigate the impact of CR nursing home placement and death on family caregivers. Elder (1994) developed the concept of the “life course,” consisting of multiple developmental pathways (e.g., social, career, marriage, parenthood) that are (a) sensitive to earlier life events and (b) reciprocally related to one another throughout the lifespan. A major theme of this model is “linked lives,” described as “the interaction between the individual’s social worlds over the lifespan...” (p. 6). As applied to informal caregiving in general, the model suggests that perceptions and attitudes about quality of the family relationship are determined long before the need for care arises. When a spouse or adult child transitions into the role of caregiver, the relationship becomes strained, and in some cases (e.g., Alzheimer’s disease caregiving), care provision virtually envelopes the caregiver’s life. Earlier relationships with CRs and significant others will influence caregiver reactions to the responsibilities and stresses of providing care. The link between prior relationship quality and caregiver well-being is documented in recent studies (e.g., Williamson & Schulz, 1990, 1995; Williamson & Shaffer, 1996; Williamson, Shaffer, & Schulz, 1998; Williamson, Shaffer, & The Family Relationships in Late Life Project, 2001).

Elder’s emphasis on the relatedness of events though the life course suggests how caregivers might react to CR nursing home placement or death, although relatively little empirical research has been conducted in this area. For example, adult children caring for parents may view nursing home placement as a stark reminder of their own mortality. In contrast, spousal caregivers may already have come to grips with the current state and future course of their lives; as a result, they may view nursing home placement as beneficial to both their CR and themselves. To summarize, the life course perspective leads to the expectation that caregiving

transitions will have different emotional consequences for caregivers with different background characteristics and life experiences.

The second theoretical model particularly suitable for examining caregiving transitions is provided by Pearlin and colleagues (e.g., Aneshensel et al., 1995; Pearlin, Mullan, Semple, & Skaff, 1990), whose research produced the Stress Process Model of caregiving. These researchers view caregiving as a career, marked by transitions through stages – i.e., acquisition of the caregiver role, engagement in care at home and possibly in the nursing home, and disengagement following CR death. Throughout the caregiving “career,” there is an interchange between background characteristics, care-related stressors, mediating factors (such as social support and coping resources), and caregiver outcomes. The Stress Process Model provides additional evidence that background and contextual factors contribute to individual differences in how caregivers adapt to events throughout the caregiving career, including nursing home placement and bereavement. For example, caregivers who experienced more role strain and social isolation during in-home care provision are better adjusted after nursing home placement and bereavement (e.g., Aneshensel et al., 1995; Bass & Bowman, 1990; Collins, Liken, King, & Kokinakis, 1993; Norris & Murrell, 1990). While it was developed based on systematic assessment of dementia caregivers, the Stress Process Model is derived from a general stress and coping paradigm (Lazarus & Folkman, 1984).

Research guided by the stress and coping paradigm in the area of caregiver bereavement following CR death has resulted in two competing models (Bass & Bowman, 1990). One model, referred to as the Depletion Model or the Complicated Grief Model, predicts that greater strain during the provision of care will compromise caregiver well-being following CR death. Because in-home care provision is often highly stressful and depletes personal and social resources, when

faced with additional stressors (i.e., the end-stages of disease and CR death), the depletion of resources caused by stress accumulation leaves caregivers unable to cope and results in poorer psychological adjustment. In contrast, the second model, referred to as the Relief Model, predicts that caregivers who experience greater strain during care provision will experience more relief after CR death. According to this model, cessation of care allows caregivers to recoup physically, socially, and emotionally, resulting in better overall psychological adjustment. Independent empirical studies have found support for both the Depletion and Relief models.

Thus, the caregiving transitions literature provides evidence that cessation of in-home care can have both beneficial and harmful consequences for informal caregivers. However, there are important questions that have not been addressed. For example, the majority of studies have focused on caregiver adjustment following CR death, but the Depletion and Relief models should be equally applicable to the transition from in-home care to nursing home placement. Little research has been conducted to test alternative models of post-nursing home placement adjustment. Additionally, the majority of existing studies focuses on negative mental health outcomes associated with caregiving transitions (e.g., depressive symptoms, anxiety, and grief), but there is good reason to apply these models to examine caregiver mental health benefits (e.g., feelings of relief) in the caregiver population. Research suggests that many stressful life transitions (e.g., divorce, job loss) can have beneficial effects on mental health, particularly if they are preceded by periods of stress (see Aldwin, 1994, for a review; Wheaton, 1990). In fact, rather than either the Depletion Model or the Relief Model being fully supported, it is more likely that cessation of in-home care provision is related to better outcomes in some caregivers, worse outcomes in others, and quite possibly, a combination of positive and negative mental health effects in the same individuals.

In short, evidence at this time is too inconsistent to rule out or confirm either the Depletion Model or the Relief Model of cessation of care. A critical condition for the development of a comprehensive model of informal care will be the integration of findings from studies of life-long family relationships, caregiving, and caregiving transitions. In the tradition of previous studies of the caregiving career (Aneshensel et al., 1995), models of informal care should incorporate information about the relationship that existed before the need for care; additionally, models of caregiving transitions should include information about the family's history and the impact of in-home care provision.

Fortunately, the literature on caregiving transitions is growing. Researchers have documented considerable variability in adaptation to nursing home placement and bereavement; however, much less information is available about specific factors that account for this variability. Many early studies employed informative, but less than ideal, cross-sectional or retrospective research designs, often failing to include potentially critical pre-transition factors that may influence post-transition outcomes. Existing longitudinal studies, some extending beyond single pre- and post-transition data collection points, provide important information about change over time, but many focus on average (i.e., group-level) change and provide little information about individual differences correlated with pre- to post-transition change.

Other shortcomings remain in this area of research. Variability in outcomes across studies may be due in part to differences in sample composition. Most of the extant literature focuses on caregivers of persons with Alzheimer's disease (AD) or other forms of dementia; in fact, the Pearlin et al. (1990) Stress Process Model is a model of AD caregiving stress. While AD caregiving places significant demands on family caregivers, it is estimated that only one in five informal caregivers provide care to someone with AD (National Alliance for Caregiving and

AARP, 1997). Results of studies focusing on AD care may not generalize to the larger population of informal caregivers. For example, cognitive impairment associated with dementia typically does not occur in illnesses such as cancer (Bernard & Guarnaccia, 2003). With few exceptions (e.g., Canadian Study of Health & Aging Working Group [CSHAWG], 2002; Williamson, Martin-Cook, Weiner, et al., 2005), researchers have made little effort to compare mental health outcomes between caregivers of dementia patients versus those with other illnesses or disabilities. In addition, variables that have yet to receive enough attention include living with the CR (versus living in a separate household), instrumental social support, and quality of the pre-illness relationship between caregiver and CR (but see, e.g., Williamson, Shaffer et al., 2000, 2001, for exceptions).

Moreover, as mentioned before, there is a dearth of literature investigating the potential mental health *benefits* of nursing home placement and CR death, particularly with respect to caregiver feelings of relief (e.g., positive feelings about no longer providing care or the end of CR suffering). While there is indirect evidence of improvements in caregiver well-being following a transition – for example, decreases in depressive symptoms over the long-term (e.g., Mullan, 1992; Pot, Deeg, & VanDyck, 1997) – it still is not entirely clear how pre-transition (or pre-caregiving) factors contribute to such changes; for example, it is unknown how historical relationship quality influences following CR death. Nor have researchers adequately described the co-occurrence of feelings of relief with negative outcomes (e.g., depressive symptoms or grief) following a caregiving transition.

The purpose of this study was threefold. First, I examined change in depressive symptoms among caregivers who initially provided care at home but who, during the course of the study, experienced CR nursing home placement or CR death. Second, guided by the Life

Course and Caregiver Stress Process Models, I examined the effects of caregiver and CR background characteristics, pre-illness relationship quality, objective and subjective care-related stress, and pre-transition depressive symptoms on post-transition depressive symptoms, grief, and relief. Third, I examined associations among the type of transition (CR nursing home placement versus CR death), pre-transition factors, and these caregiver outcomes.

The need for more empirical research in this area is evident if one considers the number of individuals who may be faced with caring for an impaired relative in the future and the impact this will have on the family. Estimates suggest that by the year 2007, as many as 39 million households, representing more than one of every four families in the U.S., will be involved in caring for a person over age 50 (National Alliance for Caregiving & AARP, 1997). It is widely accepted that providing primary care to an elder can place considerable physical, psychosocial, and relationship strain on families (e.g., Biegel, Sales, & Schulz, 1991; Kriegsman, Penninx, & van Eijk, 1994; Schulz, O'Brien, Bookwala, & Fleissner, 1995; and Schulz, Visintainer, & Williamson, 1990). Depending, among other things, on the amount of strain experienced, care provision can result in severe mental and physical health consequences, including increased risk for mortality (e.g., Schulz & Beach, 1999).

Moreover, it remains far from clear how informal caregivers respond to nursing home placement and bereavement. Erroneous assumptions about what constitutes “normal” versus “problematic” adjustment can lead to unrealistic societal expectations from family members and friends and may contribute additional social and emotional stress to caregivers already coping with a difficult stressor. A better understanding of individual differences in adjustment to CR nursing home placement and death could allow earlier detection of risk factors for both physical

and psychological morbidity and, therefore, provide avenues for early intervention to prevent problematic caregiver outcomes following both of these transitions.

CHAPTER 2

BRIEF REVIEW OF IN-HOME FAMILY CAREGIVING

The family caregiving literature documents the deleterious effects of providing in-home care, including high rates of depression (e.g., Alspaugh, Stephens, Townsend, et al., 1999; Cohen & Eisdorfer, 1988; Schulz, Newsom, Mittlenmark, et al., 1997; Schulz, O'Brien, Bookwala, & Fleissner, 1995), activity restriction (e.g., Deimling, Bass, Townsend, & Noelker, 1989; Williamson, Shaffer, & Schulz, 1998), declines in physical health or immune system function (e.g., Esterling, Kiecolt-Glaser et al., 1994; Kiecolt-Glaser et al., 1991), and health risk behavior (e.g., Beach et al., 2000; Gallant & Connell, 1998; Schulz, Newsom, Mittlenmark, et al., 1997; Vitaliano, Russo, Scanlan, & Greeno, 1996). Studies also document higher rates of depression, anxiety, and hostility among caregivers when compared to age-matched population norms or non-caregiving control groups (Anthony-Bergstone, Zarit, & Gatz, 1988; Dura, Stukenberg, & Kiecolt-Glaser, 1990; Pinquart & Sorensen, 2003; Russo, Vitaliano, Brewer et al., 1995; Schulz et al., 1997). Schulz and Beach (1999) found a higher risk for mortality among strained (versus unstrained) caregivers; after controlling for demographics, other stressful life events, and physical health status, caregivers who felt strained were 63% more likely to die in a four-year period than were caregivers who did not feel strained.

Personal, contextual, and social factors shown to predict higher psychological and physical morbidity in family caregivers include, but are not limited to, female gender, more CR problem behavior, increases in CR impairment, high caregiver burden, restriction of caregiver activities, decreases in social and emotional support, emotion-focused coping strategies, and poor

quality of the caregiver-CR relationship (e.g., Beach et al., 2000; Beery, Prigerson, Bierhals, et al., 1997; Draper, Poulos, Poulos, & Ehrlich, 1996; Levesque, Cossette, & Lachance, 1998; Li, Seltzer, & Greenberg, 1999; McLendon & Smith, 2002; Redinbaugh, MacCallum, & Kiecolt-Glaser, 1995; Schulz et al., 1995; Schulz et al., 1997; Williamson, Shaffer, & Schulz, 1998). This body of literature, as a whole, provides compelling evidence for the deleterious effects of providing care. While results have not been entirely consistent across all studies, more recent systematic studies of in-home caregivers do provide compelling findings about the nature, trajectory, and correlates of negative outcomes.

For example, a series of studies of spousal caregiving by Schulz and colleagues addressed, in four specific ways, some methodological shortcomings believed to account for inconsistencies in prior research on the mental and physical health effects of informal care. First, they used population-based sampling in order to include caregivers and non-caregiving controls with a wide range of backgrounds and experiences (i.e., not just caregivers who were self-identified as highly involved and distressed by their caregiving role). Second, they used measurement and analytic strategies that distinguished between amount of care provided and caregiving strain; for example, they prospectively assessed not only changes in level of involvement in care provision but also analogous changes in health-related outcomes including depressive symptoms, health-promoting behavior, and mortality (Beach, Schulz, Yee, & Jackson, 2000; Burton, Zdaniuk, Schulz, et al., 2003; Schulz & Beach, 2001; Schulz, Newsom, Mittelmark, et al., 1997). Third, they extended their longitudinal analyses to include examination of adjustment to nursing home placement and death of a spouse (Burton et al. 2003; Schulz, Beach, Lind, et al., 2001). Finally, to address the need for both objective and subjective assessment of the health effects of caregiving, these studies incorporated a range of outcome

measures assessing multiple domains of caregiver functioning (e.g., self-rated physical health, health risk behavior, anxiety, and depressive symptoms).

Results clearly illustrate the complex nature of informal care. In cross-sectional analyses, caregivers who experienced strain as a result of their roles reported more anxiety and depressive symptoms and poorer perceived health than those experiencing no strain or non-caregiving controls (Schulz et al., 1997). Despite providing a similar amount of assistance, caregiving wives fared significantly worse than husbands with regard to restriction of normal activities, marital relationship strain, and depression (Bookwala & Schulz, 2000). Predictors of negative health outcomes were slightly different for husbands and wives, but both primary stressors (e.g., amount of care provided) and secondary stressors (e.g., financial strain resulting from care provision) were associated with poor mental health outcomes in both genders. Longitudinal results were consistent with cross-sectional results, in that care-related strain, rather than overall amount of care provided, was associated with caregiver well-being.

Beach et al. (2000) found both improvements and declines in depressive symptoms, symptoms of anxiety, perceived health, and health risk behavior in spousal caregivers over the course of one year. Increased CR functional impairment (i.e., more ADL and IADL needs) was associated with poorer physical health outcomes; in contrast, more ADL/IADL assistance was associated with decreased caregiver anxiety and depressive symptoms. Increased caregiver strain predicted declines in all outcome measures, further supporting how caregiver perceptions of strain, rather than amount of care provided, place caregivers at risk (Beach et al., 2000). Taken together, the longitudinal studies by Schulz and colleagues provide compelling evidence that both personal and contextual factors, including kinship and perceptions of strain, influence

caregiver mental and physical health. Researchers have begun to incorporate these and other factors into studies of caregiving transitions, but findings in this area to date are mixed.

CHAPTER 3

REVIEW OF THE CAREGIVING TRANSITIONS LITERATURE

The majority of caregiving transition studies have as the primary outcome variable one or more indicator of post-transition caregiver mental health (e.g., Aneshensel et al., 1995; Brody, Dempsey, & Pruchno, 1990; Collins, Stommel, Wang, & Given, 1994; CSHAWG, 1992; Gaugler et al., 1999; Grant, Adler, Patterson, Dimsdale, Zeigler, & Irwin, 1992; Kaplan & Boss, 1999; King, Collins, Given, & Vredevoogd, 1991; Kramer, 2000; Lieberman & Fisher, 2001; Pot, Deeg, & Van Dyke, 1997; RIS MRC CFAS, 2000; Rosenthal & Dawson, 1991; Seltzer & Wi, 2000; Stull et al., 1997; Whitlatch, Feinberg, & Stevens, 1999; Wright, 1994; Zarit & Whitlatch, 1992; Whitlatch et al., 2001). These studies focus primarily on depression, but anxiety, anger, and generalized psychological distress are also represented. Most researchers have chosen well-established scales to measure caregiver mental health, but the same measures have not been used consistently across all studies. Although the use of a variety of measures makes thorough comparison of findings across studies more difficult, the general agreement of results increases confidence in the validity of findings overall.

The most commonly utilized measure of caregiver depressive symptoms, the Center for Epidemiological Studies Depression scale (CES-D; Radloff, 1977) has been used extensively in general caregiving (e.g., Schulz et al., 1990, 1995) and caregiving transition studies (e.g., Brody et al., 1990; Collins et al., 1994; Kaplan & Boss, 1999; King et al., 1991; Kramer, 2000; Rosenthal & Dawson, 1991; Stull et al., 1997; Whitlatch et al., 2001). Other studies have employed scales that assess depression concurrently with anxiety, anger, and/or positive affect

(e.g., Barber, 1993; Gaugler et al, 1999; Lieberman & Fisher, 2001; Rudd et al., 1999; Stephens, Kinney, & Ogrocki, 1991; Stephens, Ogrocki, & Kinney, 1991); examples include the Hopkins Symptoms Checklist (HSC; Derogatis, 1974), the Symptom Check List (SCL-90-R; Derogatis, 1983), and the Affect Balance Scale (ABS; Bradburn, 1969). Throughout this review of the literature, “depression” and “depressive symptoms” are used interchangeably to refer to any score, as described above, assessing the construct of depressed affect. In all other cases, the terms chosen by the researchers to represent the construct of interest (e.g., negative affect) are used.

The concept of grief has received a great deal of attention in psychological research, and several influential theories of the grief process have emerged in past decades (Bowlby & Parkes, 1970; Kubler-Ross, 1969; Rando, 1984). Researchers have questioned the validity of these and other stage theories of grief (e.g., Lund, Caserta, & Dimond, 1986; Wortman & Silver, 1989) for describing a universal, “normal” grieving process. This study will not attempt to weigh in on the ongoing debate over what constitutes normative versus pathological grief; rather, the purpose of assessing grief here is to examine caregiver emotional reactions specific to CR nursing home placement and death. Depressive symptoms will be assessed both before and after these transitions. However, grief is distinguished from depressive symptoms in a number of important ways, including symptom onset, severity, and duration. Grief may evolve into a major depressive episode, but it is typically characterized by thoughts and feelings associated with a specific loss (e.g., death of a loved one) and, therefore, should capture additional variability in caregiver reactions to these experiences beyond general depressive symptoms (Rando, 1984; Wolfelt, 1992). For example, a family caregiver may experience grief after nursing home placement or death (e.g., feelings of being lost without the CR around, frequent crying when thinking of the

CR) without experiencing depressive symptoms (e.g., loss of appetite, pervasive negative mood, chronic physical complaints) or being diagnosed with a depressive disorder. Likewise, a caregiver with symptoms of depression prior to CR death may or may not experience grief reactions (e.g., auditory hallucinations of the deceased person, feelings of guilt) after a loss. In short, it cannot be said that grief and depressive symptoms are mutually exclusive; in fact, it is more likely that their symptoms overlap. Furthermore, within the context of caregiving, it is possible that each phenomenon has distinct pre- and post- transition correlates. The proposed study will address these issues.

Caregiver Depressive Symptoms Following CR Nursing Home Placement

Many older adults have long-term care needs, often due to a chronic condition, illness, or disability that limits their capacity to carry out basic self-care tasks. The vast majority remains at home or in a community setting (Agency for Healthcare Research & Quality, 2000) and relies on family members for their daily care. Relatively few receive additional help from formal service providers or someone paid privately (Liu, Manton, & Aragon, 2000). As recently as 1997, only a small proportion (roughly 4%) of elderly persons needing long-term care resided in nursing homes (Gabriel, 2000; Montgomery & Kosloski, 1994; Scott, Edwards, Davis, et al., 1997), defined here as a residential facility for people who require extensive medical care or supervision. Even though relatively few families experience nursing home placement, the transition from in-home care to full-time nursing home care is so significant for family caregivers as to have a wide range of psychosocial consequences. Nursing home placement may relieve informal caregivers of some of the burdens of providing care, but there is considerable evidence that stress continues to influence well-being and that new stressors are substituted for those that are alleviated (e.g., Seltzer & Li, 2000).

Caregiver CES-D scores indicate that after CR nursing home placement, depressive symptoms fall below levels indicative of clinical depression in the general population. In studies where scores were actually reported, mean CES-D scores ranged from less than 1.0 (King et al., 1991) to 18.2 (Collins et al., 1994) out of a possible score of 60. However, in some samples as many as 20% of caregivers scored at or above 16, the score generally agreed to represent being at risk for clinical depression (e.g., Kaplan & Boss, 1999; Rosenthal & Dawson, 1991; Whitlatch et al., 2001). Two possible reasons for the wide range of CES-D scores across studies are related to sample size and composition. First, sample sizes varied across studies. The study with the lowest mean CES-D scores (King et al., 1991) contained less than 40 subjects. The other studies were based on samples of at least 75 subjects, and variability in those studies was slightly higher, suggesting that sample size may have reduced variability in King et al. Second, studies with samples composed exclusively of spouse caregivers (Collins et al., 1994; Kaplan & Boss, 1999; Kramer, 2000; Rosenthal & Dawson, 1991) indicate slightly higher mean CES-D scores than those containing spouses and children or children only (Brody et al., 1990; King et al., 1991; Whitlatch et al., 2001). King and colleagues tested the effect of kinship on post-placement caregiver depressive symptoms and found that spouses scored significantly higher than non-spouses on the CES-D. These findings underscore the importance of interpreting results in light of sample size and composition as well as designing studies to include potentially influential background characteristics.

Despite inconsistencies in study design, results generally reveal that (a) depressive symptoms, while not at the level considered to place caregivers at risk for a clinical diagnosis, persist after nursing home placement, and (b) post-placement caregivers experience levels of depressive symptoms similar to their in-home caregiving peers. For example, some studies

indicate no difference between in-home and nursing home caregivers, albeit on different measures of depressive symptoms (Barber, 1993; Stephens, Kinney, & Ogrocki, 1991). In a content analysis of open-ended responses, post-placement caregivers reported higher levels of sadness, anger, and guilt than in-home caregivers; however, when the same caregivers responded to a standardized measure of mental health, only sadness was significantly higher in the post-placement group (Rudd et al., 1999).

When the same caregivers were measured before and after placement, depressive symptoms remained stable over time, with no differences between pre- and post-placement levels of depression (King et al., 1991; Lieberman & Fisher, 2001; Stull et al., 1997). Similar results emerged when in-home and post-placement caregiver groups were compared over time. For example, after controlling for several background variables (caregiver gender, education, use of professional services, kinship to elder, and severity of elder impairment), neither initial level nor trajectory of change in depressive symptoms differed among these groups (Aneshensel et al., 1995; Lieberman & Fisher, 2001).

In other studies, researchers compared patterns of change in caregivers who eventually transitioned from in-home to nursing home care with those who continued to provide in-home care. Regardless of the nature of the initial sample or the measure of mental health, there were no significant differences between in-home and post-placement caregivers over time (Collins et al., 1994; Kramer, 2000; Buck et al., 2000; Zarit & Whitlatch, 1992). Kramer (2000) observed trend-level effects toward decreased depressive symptoms among in-home caregivers and increased depressive symptoms among post-placement caregivers. However, this sample was composed entirely of husbands caring for wives, and the post-placement caregiver group consisted of only 14 caregivers. Despite the evidence for stability of caregiver depressive symptoms through the

nursing home placement transition, in one sample, depressive symptoms declined among both male and female caregivers after placement (Pot, Deeg, & Van Dyck, 1997). Thus, there is no universal pattern of caregiver emotional status following CR nursing home placement but, rather, a pattern of (non-conclusive) results across studies that suggests that other factors are involved.

Correlates of Caregiver Depressive Symptoms Following CR Nursing Home Placement

The literature generally supports stability or, at best, slight improvement in caregiver mental health following CR nursing home placement; however, group-level mean differences in pre- and post-placement depression scores do not adequately reflect the variability that exists across individuals in response to this stressful life event. It is important to study why some caregivers adapt well to the placement of their relatives while others do not. In other words, attempts should be made to identify which characteristics promote and which characteristics impede or prevent adjustment.

Researchers have identified several predictors of post-placement caregiver depressive symptoms. While CR characteristics are, in general, poor predictors of caregiver adaptation, there is some evidence that the nature and severity of CR illness are associated with post-placement caregiver mental health. For example, CR problem behavior and cognitive declines after nursing home admission have been shown to predict caregiver depressive symptoms (Brody et al., 1990; Whitlatch et al., 2001). More recent onset of behavioral and cognitive problems also predicted depressive symptoms among caregiving wives and daughters, but not husbands (Gaugler et al., 1999), suggesting that sudden changes in behavior are harder to cope with than long-term problem behavior. Thus, it appears that caregivers adjust poorly to behavioral and cognitive decline, particularly when the decline occurs at the time of or immediately following placement.

As one might expect, pre-placement caregiver depression is a robust predictor of post-placement depression (e.g., Gaugler et al., 1999). Other caregiver characteristics shown to predict caregiver mental health after CR placement include gender, kinship, and perceived health. Spouses and daughters experienced more negative emotional reactions to placement than sons (Riddick et al., 1992), while spouses scored higher than non-spouses on measures of depression (King et al., 1991). Caregivers who reported poorer physical health also reported poorer mental health outcomes, regardless of gender or kinship to the CR (Grau et al., 1993). Other important caregiver characteristics include negative or ambiguous thoughts about the placement process, but the causal nature of these relations is, as yet, unclear. For example, caregivers who had a harder time adjusting to their relatives' placement reported more depressive symptoms (Whitlatch et al., 2001). Ambiguity about the nature of the marital relationship and spousal roles after placement predicted higher depression scores among caregiving spouses (Kaplan & Boss, 1999).

Finally, caregiver strain related to post-placement care provision, but not continued provision of care itself, predicts poor caregiver adjustment after nursing home placement. For example, caregivers who helped *less* often with IADLs after nursing home placement experienced *more* depressive symptoms; in other words, providing less care was associated with poorer caregiver emotional well-being (Brody et al., 1990). However, when caregivers perceived that their continued assistance with ADLs after placement disrupted their normal lives or was a hassle, more assistance predicted more depressive symptoms (Riddick et al., 1992; Stephens, Ogrocki, & Kinney, 1991). These studies did not control for pre-admission levels of caregiver strain or depression; therefore, it cannot be ruled out that the association between strain and depressive symptoms simply carried over from the pre-placement caregiving relationship and is

not unique to the transition itself. Nevertheless, consistent with the studies of in-home caregiving by Schulz and colleagues (e.g., Beach et al., 2000; Schulz et al., 1997), it appears that burden or strain before placement are associated with caregiver mental health after placement. In another study, caregivers who helped *less* often with IADLs after nursing home placement experienced *more* depressive symptoms, suggesting that not providing care was associated with poorer caregiver emotional well-being (Brody et al., 1990). These results suggest that when caregivers desire to continue providing care after nursing home placement but are unable to do so, their emotional well-being may be at risk.

Caregiver Depressive Symptoms Following CR Death

While nursing home placement is experienced by relatively few families, most caregivers will eventually experience the death of the person to whom they have dedicated so much of their time and effort. CR death probably brings about the most extensive changes in the lives of surviving caregivers (Aneshensel et al., 1995); nevertheless, as with nursing home placement, the impact of in-home care provision does not come to an end after the CR's death. There currently is no consensus regarding the prevalence, duration, or severity of post-bereavement caregiver depressive symptoms. Furthermore, caregivers vary considerably in their responses to CR death, but the pre- and post-death factors that contribute to this variability are not well known. As with other transitions, bereaved caregivers face a time of adjustment, and many factors may contribute to that adjustment.

Results of research investigating caregiver depressive symptoms following CR death are mixed, but taken together, generally support a non-linear trajectory. That is, a number of studies suggest that death may have negative short-term effects, but over time, depression declines to pre-death levels or even lower. For example, when caregiver depression was measured

immediately before and up to five times after bereavement, symptoms increased significantly at the time of death, decreased to pre-death levels within four months, and reached their lowest levels after 65 months (Schulz et al., 2003). In the same study, depression scores remained significantly lower than pre-death levels one year after bereavement, and the proportion of caregivers scoring at a level indicative of being at risk for clinical depression fell from 43% to 30%. Robinson-Whelen, Tada, MacCallum, et al. (2001) found that widowed caregivers experienced only slight decreases in depressive symptoms after three years; however, these widows reported significant increases in positive affect and significant decreases in negative affect in the first year following bereavement. In another population-based study spanning five years, after controlling for age and pre-death CR health status, bereaved caregivers' risk for depressive symptoms increased significantly with more recent CR death (CSHAWG, 2002). Studies of shorter duration also suggest a non-linear trend in caregiver depressive symptoms. At the aggregate level, caregiver depressive symptoms increased or, at best, remained stable in the first six months following CR death. However, symptoms declined significantly after roughly one year (Chentzova-Dutton et al., 2002; Grant et al., 2002; Mullan, 1992).

While the majority of studies support immediate increases in caregiver depressive symptoms after bereavement, followed by gradual declines over time, there is some evidence of continued long-term difficulties with depression and negative affect. For example, caregiver depressive symptoms did not change over time in a two-year, pre- to post-transition study (Wright, 1994); however, this study did not control for time since death at the post-transition interview. When time since death was controlled in other studies, continuing and bereaved caregivers did not differ in their self-reported depressive symptoms or in the likelihood of meeting clinical criteria for a depressive disorder three years following bereavement (Bodnar &

Kiecolt-Glaser, 1994). Other studies without in-home caregiver comparison groups suggest that some caregivers continued to struggle with symptoms of depression two (Pot et al, 1987; Seltzer & Wi, 2000) and three years (Collins et al., 1994) after bereavement.

Schulz et al. (2001) compared changes over time in depressive symptoms of non-caregiving spouses, spouse caregivers who reported strain while providing care, and spouse caregivers who reported no strain. Following bereavement, depressive symptoms increased among non-caregivers and non-strained caregivers, but there was no change in the symptoms of previously strained caregivers. Furthermore, time since bereavement, which ranged from one to four years, was not associated with severity of depressive symptoms. These findings suggest that CR death, while reducing burden, may not completely alleviate the stress associated with providing care (which is entirely consistent with established models of caregiver stress – c.f. Aneshensel et al., 1995). This study also demonstrates how individual differences in pre-death factors (i.e., perceptions of strain before and after CR death) may contribute to both the magnitude and duration of negative affect after bereavement.

Finally, there is some evidence that providing more care before a spouse's death may actually reduce the emotional impact of bereavement. In one cross-sectional comparison of depressive symptoms among caregivers, recently widowed caregivers, and recently widowed non-caregivers, widowed *non*-caregivers were twice as likely to be depressed as widowed caregivers, suggesting that providing care may act as a buffer for adjusting to the death of a spouse (Wells & Kendig, 1997).

In summary, the extant literature on caregiver psychological adjustment to CR death, vis à vis depressive symptoms, generally supports a risk of somewhat more depressed affect immediately after death (i.e., in the first several weeks) followed by a gradual decline in

symptoms over the course of the next one to two years. While research exists that does not support this curvilinear pattern of adjustment, with few exceptions (e.g., Pot et al., 1987) these studies did not examine caregiver outcomes immediately following CR death. Instead, conclusions were based on two- to three-year follow-up assessments – intervals that may not have detected short-term, non-linear changes described above. In order to accurately assess the trajectory of change, studies are needed in which caregivers are assessed on multiple occasions (i.e., ≥ 3 months) and at smaller (e.g., 3-month) intervals (see Li, 2005, for a similar design). Such studies would enable researchers to more accurately describe patterns of adjustment. Furthermore, inclusion of potential predictor variables is necessary to answer important questions about individual differences in successful and unsuccessful transitions. For example, how do specific pre-death stressors contribute to caregiver adjustment? This question has been addressed in some, but not all, studies of caregiving transitions. Furthermore, several potentially important factors have not been addressed adequately.

Correlates of Caregiver Depressive Symptoms Following CR Death

The general bereavement literature documents individual variability in reactions to death (e.g., Sanders, 1993; Wortman & Silver, 1989, 2001). Not surprisingly, some of the same personal, contextual, and social factors associated with bereavement in the general population (e.g., kinship, age, gender, and coresidence) appear to influence caregiver adaptation to bereavement. Other potentially important predictors of post-bereavement caregiver adjustment, such as pre-illness relationship history and pre-death physical health, have not been thoroughly studied but will be addressed by this research.

Although the general public might assume that spouse caregivers would have more difficulty adapting emotionally than adult children or other relatives, results in this area are

mixed. Some studies suggest that caring for a spouse creates more complications following CR death (e.g., Bass & Bowman, 1990; Bernard & Guarnaccia, 2003), but other researchers have not found differences in depressive symptoms over time between spouses and other relatives (e.g., Aneshensel et al., 1995; Bodnar & Keicolt-Glaser, 1994; Chentzova-Dutton et al., 2002; Schulz et al., 2003). There is some evidence that husbands, but not wives, may become slightly more depressed than daughters (Mullan, 1992). Socioeconomic status (as measured by both education and income) is frequently included as a covariate in longitudinal analyses, but results suggest no association with post-bereavement depression (Chentzova-Dutton et al., 2002; Mullan, 1992; Schulz et al., 2001) or trajectory of change in depressive symptoms (Schulz et al., 2003). In one study, bereaved caregivers with higher pre-death incomes received more socioemotional support; however, neither income nor socioemotional support were associated with post-death depressive symptoms (Aneshensel et al., 1995). With regard to caregiver age, older caregivers appear to be at higher risk for depression after the CR's death than younger caregivers (Bernard & Guarnaccia, 2003; Gilbar & Ben-Zur, 2002).

With regard to caregiver gender, female caregivers were more likely than their male counterparts to experience depressive symptoms in the first year following a CR's death (Bodnar & Kieicolt-Glaser, 1994; Gilbar & Ben-Zur, 2002; Kelly, Edwards, Synott et al., 1999). Collins et al. (1994) did not specifically test for gender differences in post-bereavement depressive symptoms, but there were different patterns of results in separate analyses of males and females. Among male caregivers, depressive symptoms increased initially before declining to pre-death levels, whereas among female caregivers, depressive symptoms declined initially and continued to decline over time.

No study was identified that directly examined the effect of coresidence on caregiver adjustment to CR death. Although coresidence is implicit in studies of caregiving spouses, researchers examining both spouse and nonspouse caregivers have not attempted to examine how sharing the same household with the CR may influence either immediate or long-term depressive symptoms among non-spouses. This could be accomplished by including coresidence while controlling for the effects of related factors (i.e., kinship and caregiver age).

Comparisons of In-Home Care and Caregiving Transitions

Few researchers have incorporated data from continuing in-home caregivers, post-nursing home placement caregivers, and bereaved caregivers into the same analyses, probably due to the inherent difficulties in recruiting and retaining subjects for long periods of time through such stressful life experiences. Nevertheless, it is worthwhile to review those studies that have successfully compared outcomes among these caregiver groups (Collins et al. 1994; Gold et al., 1995; Grasel, 2002; Pot et al., 1997). These studies provide valuable information about the relative impact of the two transitions by using the same instruments, thus, ostensibly measuring the same theoretical constructs in both transition groups. A few researchers also incorporated non-caregiving control subjects into their designs (Grant et al., 2000; Seltzer & Wi, 2000), allowing for more detailed hypothesis testing and interpretation of results.

Collins et al. (1994) examined depressive symptoms among continuing, nursing home, and bereaved AD caregivers. The transition groups were interviewed before the transition and again 15 and 30 months after the transition. At the aggregate level, depressive symptoms remained stable over time, and there were no group differences in the trajectory of depressive symptoms. However, results varied according to caregiver gender: males who were still involved with their CRs (continuing and nursing home groups) were less depressed than their

female counterparts over time, whereas bereaved females were slightly less depressed than bereaved males. Thus, there were different effects for type of transition on depressive symptoms for men and women.

Grant et al. (2002) compared change over time in depressive symptoms among in-home caregivers, nursing home caregivers, bereaved caregivers, and non-caregiving controls. Controlling for dementia severity and duration of caregiving, symptoms were reduced after in-home care ended. Nursing home caregivers' depressive symptoms declined 6 months after placement and continued to decline after 12 months, whereas bereaved caregivers' depressive symptoms declined after 12 months. Neither severity of CR dementia nor duration of care was related to caregiver adjustment. In short, while the trajectory of change differed by transition type, after one year, both groups showed significant improvements in mental health relative to continuing caregivers.

Gold et al. (1995) assessed differences in overall mental health between continuing, bereaved, and nursing home caregivers before and two years following the transition. There were no differences in overall mental health by caregiver group at baseline, but bereaved caregivers reported feeling significantly better at follow-up (i.e., after the transition) than continuing or nursing home placement groups. Although it was not clear whether the authors controlled for time since transition in their analyses, their results suggest positive outcomes for transitioned caregivers compared to continuing care providers and possible mental health benefits for bereaved caregivers compared to those who transition to nursing home placement. In another longitudinal study comparing psychological well-being among continuing care, nursing home placement, and bereaved caregiver groups over a three-year period, continuing caregivers exhibited overall linear declines in psychological well-being, bereaved caregivers exhibited no

change, and nursing home caregivers exhibited overall linear increases in psychological well-being (Pot et al., 1997). Seltzer and Wi (2000) compared depressive symptoms of new or continuing in-home caregivers with nursing home placement and bereaved caregivers during a two-wave, three-year longitudinal study and found very few differences in the experiences of these groups. This study, while limited to female caregivers, was one of few not limited to dementia caregivers.

To summarize, findings from studies comparing in-home, nursing home, and bereaved caregivers are not entirely consistent, and there is some disagreement about whether nursing home placement or bereavement is the more difficult transition. However, regardless of the type of transition, it appears that, in general, transitioned caregivers are no *worse* off over time than if they had continued to provide care. Finally, a few background factors, namely kinship and gender, may influence post-transition caregiver depressive symptoms, and their influence may differ according to the type of transition experienced.

Caregiver Grief Following CR Nursing Home Placement or CR Death

Early studies of older adults' reactions to death and loss suggest that depression and grief are unique forms of emotional distress defined by different symptoms (e.g., Breckenridge, Gallagher, Thompson, & Peterson, 1986; Gallagher, Breckenridge, Thompson, Dessonville, & Amaral, 1982) with different long-term trajectories (Thompson, Gallagher-Thompson, Futterman, Gilewski, & Peterson, 1991). Grief and depression, particularly clinical depression, are by and large treated as separate, but related, phenomena in the general bereavement literature. For example, traumatic, or complicated, grief was shown to be distinct from bereavement-related depression (Prigerson, Kasl, Reynolds, et al., 1995) and to predict poor long-term mental and physical health outcomes, including depression (Prigerson, Bierhals, Kasl,

et al., 1996). Grief has been characterized as a depressive syndrome (i.e., a set of symptoms much milder than those found in a major depressive disorder) associated with a specific loss event such as the death of a spouse (Zisook & Shuchter, 1993). There continues to be a considerable amount of inconsistency and overlap in the measurement of grief and depression, but standardized measures of grief (e.g., the Grief Experience Inventory; Sanders & Mauger, 1979) and empirically derived, psychometrically sound grief scales (e.g., Bernard & Guarnaccia, 2003) are available. Although grief is now conventionally recognized and assessed distinctly from depression, operational definitions of grief vary from study to study.

In the caregiving literature, grief has been described as an emotional response to a traumatic event marked by a great sense of loss (Schuchter & Zisook, 1993). Researchers also have defined grief as the emotional and psychosocial difficulties associated with adjusting to a relative's death (Bass & Bowman, 1990; Bass, Bowman, & Noelker, 1991), with well over half of caregivers reporting that a loved one's death is one of the most difficult experiences ever faced (Bass & Bowman, 1990; Pruchno, Moss, Burant, & Schinfeld, 1995). Some caregivers have reported feelings of preoccupation and longing for the deceased, painful emotions, dissociation with the world around them, and, less frequently, sensory illusions of the deceased's presence (Aneshensel et al., 1995). Grief responses were most intense immediately following the loss and declined slowly but steadily the first year after CR death (Aneshensel et al., 1995; Chentzova-Dutton et al., 2002).

No studies were identified that used the label "grief" with respect to nursing home placement, but it has been suggested that caregiver responses to this transition are a form of grief or, at minimum, anticipatory reactions to CR death (Aneshensel et al., 1995; Rosenthal & Dawson, 1991). Therefore, in order to make comparisons between the grief experiences of

nursing home placement and bereavement, the same conceptual measures, worded differently according to transition circumstances, will be employed in the present study.

In sum, there is adequate empirical evidence to support examining caregiver grief and depression following nursing home placement or bereavement as separate, but related, phenomena. Further examination of these emotional outcomes in informal caregivers is needed, particularly following CR nursing home placement. It is possible that caregivers experience considerable grief following either of these transitions without evidence of excessive depressive symptomology; at the same time, greater grief reactions may predict more depressive symptoms. Therefore, these outcomes will be examined separately.

Correlates of Caregiver Grief Following CR Nursing Home Placement or CR Death

Researchers have identified specific factors associated with caregiver grief, and these factors are similar to those associated with caregiver depressive symptoms. For example, caregivers who expressed more problems related to in-home care provision and more family difficulties arising from caregiving also expressed more problems coping with a relative's death (Bass & Bowman, 1990). More care-related strain and less time elapsed since bereavement were associated with more preoccupation and longing, more care-related strain was associated with more painful emotions and dissociation from reality, and more pre-bereavement depression were associated with more frequent sensory illusions of the deceased's presence (Aneshensel et al., 1995). Interestingly, difficulties in the past relationship with the CR predicted fewer of these symptoms (suggesting a sense of relief, discussed below). More pre-death depressive symptoms predicted more frequent post-death sensory illusions (i.e., feeling that the deceased was present). Bernard and Guarnaccia (2003) observed stronger grief reactions among husbands who reported more pre-bereavement anxiety, depression, emotional strain, and physical strain. More

problematic grief has been associated with older caregivers in some studies (e.g., Bernard & Guarnaccia, 2003) and with younger caregivers in others (e.g., Gilbar & Ben-Zur, 2002). Coresidence with a parent prior to death predicted more grief among daughters (Bernard & Guarnaccia, 2002). Gender impacts caregiver grief as well: daughters expressed more feelings of emotional loss and recurrent thoughts of the deceased parent than sons (Pruchno et al., 1995), and wives experienced more grief than husbands (Gilbar & Ben-Zur, 2002). Taken together, these results support individual variability in caregiver grief reactions to CR death. Moreover, results are consistent with models of caregiver stress and coping (e.g., Lazarus & Folkman, 1984; Pearlin et al., 1990) suggesting that both individual factors (e.g., gender) and care-related experiences influence caregiver grief reactions.

The literature on caregiver adjustment to CR nursing home placement provides little information regarding correlates, or predictors, of grief. It is unclear whether they might be expected to react similar to bereaved caregivers. On one hand, CR death may be sudden and predictable, whereas nursing home placement is frequently preceded by a period of extreme strain or crisis, introducing the possibility that this adjustment may be more emotionally draining. On the other hand, unlike nursing home placement, bereavement entails permanent separation from the deceased and may create unique emotional reactions. Both types of transition are likely to trigger similar feelings (e.g., guilt, loss) and require role adjustments, leading to the possibility that caregiver reactions will be similar. This research represents one of the first attempts to measure and compare grief reactions and correlates of grief in these two transition groups.

Caregiver Relief Following CR Nursing Home Placement or CR Death

There has been very little effort to define or measure caregiver relief following either nursing home placement or death. In the literature, relief is often inferred by decreases in negative outcomes. For example, Aneshensel et al. (1995) concluded that caregivers experience similar levels of relief following nursing home placement and CR death as indicated by decreases in scores on their measure of role overload from pre- to post-transition. However, other researchers have begun to examine relief as a unique construct. In qualitative analyses, for example, Rosenthal and Dawson (1991) described how some wives stated explicitly that they felt relief over relinquishing responsibility for care following their husbands' nursing home placement; however, these feelings occurred simultaneously with negative feelings about the experience, resulting in emotional ambivalence. Roughly 70% of caregivers interviewed by Nolan and Dellasega (1999) reported feelings of relief and ambivalence after a CR's nursing home placement. In a sample of dementia caregivers, over 72% of respondents reported feeling that the CR's death was somewhat or very much a relief (Schulz et al., 2003). In another sample, relief was the most common reaction immediately following death (experienced by 51% of caregivers), but relief frequently co-occurred with feelings of grief. Types of relief reported included feeling glad for the deceased (in this study, dementia patients), feeling relieved to be released from the responsibility of providing care, and feeling relieved that the death occurred before caregiver resources were depleted and made nursing home placement necessary (Collins et al., 1993).

Few researchers have examined correlates of caregiver relief following nursing home placement or death, but in one study of adult children, being younger and caring for a parent with more cognitive impairment predicted stronger feelings of relief after bereavement (Pruchno et

al., 1995). Negative emotional experiences prior to death were associated with more relief, but this association was contingent upon a strong social support structure both before and after the death (Collins et al., 1993). Among a sample of non-caregiving adult daughters, quality of the mother-daughter relationship was associated with reaction to the mother's death (Popek & Scharlach, 1991). For example, women in close relationships with their mothers experienced less complicated grief than those with ambivalent relationships (i.e., close but conflictual) and those with distant or negative relationships. Taken together, these findings suggest that relief occupies a unique place in caregiver emotional reactions to CR nursing home placement and death. Reports of ambivalence following these transitions support the idea that grief and relief occur in the same individuals; what remains to be seen is how the co-occurrence of grief and relief differs among caregivers with unique background characteristics or caregiving experiences. Likewise, it is worthwhile to examine how grief and relief, as reactions to a specific caregiving event (i.e., a transition experience) relate to long-term, overall caregiver psychological well-being (e.g., depressive symptoms).

CHAPTER 4

RESEARCH QUESTIONS AND HYPOTHESES

This research addressed three questions.

First, do pre-transition depressive symptoms differ among caregivers who continue to provide in-home care and those who experience a transition? Factors such as gender (Collins et al., 1994), kinship (Seltzer & Wi., 2000), and time since placement or death (Grant et al., 2002) may influence pre- to post-transition changes in depressive symptoms. Thus, after controlling for these and other socio-demographic variables that could influence this association, I expected to find no difference between continuing and transitioned caregivers' depressive symptoms at baseline (i.e., that period in which all participants were providing in-home care).

Second, do informal caregivers' depressive symptoms change after CR nursing home placement or CR death? Competing models suggest either successful adaptation (i.e., relief) or complicated grief in response to care recipient death (Bass & Bowman, 1990); however, these models have not been tested in the context of adaptation to nursing home placement. The empirical literature tends to support stability in depressive symptoms following nursing home placement (e.g., Aneshensel et al., 1995; King et al., 1991; Lieberman & Fisher, 2001; Stull et al., 1997), and, with a few exceptions (e.g., Bodnar & Kiecolt-Glaser, 1994; Seltzer & Wi, 2000), a curvilinear pattern in depressive symptoms following bereavement -- i.e., an immediate increase followed by a gradual decrease to pre-death or lower levels over time (e.g., Chentzova-Dutton et al., 2002; CSHAWG, 2002; Schulz et al., 2003). The present sample was limited to caregivers whose post-transition interviews took place several months or more following a transition, and

data are available for only one pre- and one post-transition interview. Given these constraints, I expected to find, at the aggregate level, a slight decrease in depressive symptoms following a transition.

Third, how are caregiver and CR background characteristics, pre-illness relationship quality, care-related stress, and pre-transition mental health related to post-transition caregiver depressive symptoms, grief, and relief? Based on previous findings in the caregiving transitions literature, I hypothesized that caregivers who were female, spouses of the CR, and who reported more pre-transition depressive symptoms would exhibit more depressive symptoms after a transition. I also expected caregivers who experienced CR death to exhibit more depressive symptoms than those who experienced CR nursing home placement. Consistent with the relief model of coping with bereavement (Bass & Bowman, 1990), caregivers who experience greater strain during care provision should exhibit higher overall depressive symptoms after bereavement than non-caregivers and non-strained caregivers (Schulz et al., 2001). However, post-transition adjustment in these strained caregivers should be much more successful than for non-caregivers and non-strained caregivers – i.e., there should be no change or a slight reduction in symptoms, compared with increased depressive symptoms in the other groups. Schulz and colleagues suggest that the death of a severely disabled CR often is (a) anticipated, (b) grieved in advance by the caregiver, (c) ends CR suffering, and (d) reduces caregiver physical strain, the cumulative effect of which promotes more adaptive functioning following bereavement. However, this hypothesis has not been tested in the context of nursing home placement. Therefore, while these analyses were exploratory in nature, I expected that caregivers who reported less strain before a transition (i.e., those who experienced less care recipient problem behavior and who felt that providing care placed less restriction on their normal activities) would

exhibit greater increases in depressive symptoms following the transition and would be equally or more symptomatic than those who experienced greater pre-transition strain.

With respect to predictors of post-transition caregiver grief, I expected to replicate previous findings. Specifically, I hypothesized that female caregivers, those who co-resided with their CRs prior to the transition, and those who reported more pre-transition depressive symptoms would report higher levels of grief. Likewise, I expected stronger grief reactions among bereaved caregivers compared to those who experienced CR nursing home placement. Although only a few researchers have tested hypotheses about post-transition relief, findings from these studies led me to expect that caregivers who are younger, those who provided care to cognitively impaired (versus physically impaired) CRs, and those who reported more pre-transition care-related stress and depressive symptoms would report feeling more relieved after a caregiving transition (Collins et al., 1993; Pruchno et al., 1995; Schulz et al., 2003).

There is not enough existing evidence to specify hypotheses for associations between pre-illness relationship quality and post-transition depressive symptoms, grief, and relief. However, based on the theory of communal relationships (e.g., Clark & Mills, 1979, 1993), as well as results from previous studies of informal caregivers (e.g., Williamson, Shaffer, & FRILL, 2000, 2001) and non-caregivers (e.g., Popek & Scarlach, 1991), it was reasonable to expect that, because of the long-term mutual respect and lack of conflict associated with this type of relationship, caregivers whose relationships with their CRs historically were characterized by frequent mutually communal behavior would experience more depressive symptoms and more grief. In contrast, it was expected that a poorer quality relationship, reflected by less frequent mutually communal behavior, would result in more relief following a transition out of the caregiver role.

CHAPTER 5

METHOD

Design and Participants

Participants for this study were drawn from the Family Relationships in Late Life (FRILL) research project, a longitudinal study of informal elder care. The FRILL study took place in two phases. In the first phase (FRILL1), participants were recruited using various techniques (e.g., media advertisements, voter registration lists, word-of-mouth communication with community agencies and medical facilities) from the Athens, GA, Pittsburgh, PA, and Dallas, TX areas ($N = 312$ caregiver-CR dyads). In the second phase (FRILL2), data were collected primarily using random digit dialing and word-of-mouth recruiting, and participants were recruited from the Athens, GA, Pittsburgh, PA, and Tuscaloosa, AL areas ($N = 444$ caregiver-CR dyads). For both phases of the FRILL project, a caregiver was defined as the individual primarily responsible for the care of an impaired relative aged 60 years or older. Caregivers were eligible to participate if they provided assistance with at least one basic activity of daily living (ADL, e.g., bathing, dressing, eating) or at least two instrumental activities of daily living (IADL, e.g., shopping, light housework, driving to appointments). In FRILL1, CRs must have been residing in the community, either in their own home or with the caregiver; in FRILL2, participants consisted only of dyads who resided in the same household.

Upon determination of eligibility, structured interviews were carried out in person by a pair of carefully trained research assistants. Interviews most often took place in the participants' homes. Interviewers obtained written informed consent before each interview. Interviews lasted,

on average, one to two hours, and each participant was paid \$20 per interview (\$25 per interview during FRILL2). Data collection proceeded in waves, with each caregiver-CR dyad expected to complete three pre-transition interviews at 12-month intervals (18-month intervals during FRILL2). During each interview, caregivers and CRs were asked a series of questions about their background, their relationship with one another, the caregiving situation, and the quality of care provided. Mental health (e.g., depressive symptoms) was assessed in caregivers but not CRs. Raw data were visually screened for interviewer errors before being converted to electronic format; data verified as accurate were analyzed using SPSS version 12.0.2 for Windows.

The sample consisted of 550 women and 206 men, 679 (90%) of which were residing in the same household as the CR at the time of the baseline interview. Participants ranged in age from 22 to 91 years ($M = 61.38$, $SD = 14.52$). Caregivers were providing care to a spouse (50%), parent or parent-in-law (37%), or another relative (13%). Less than half (41%) were currently employed. The sample was well-educated (53% completed high school, 29% completed college) and had a median household income of \$20,000 to \$29,999 (range = less than \$5,000 – \$100,000 or more). Additionally, 65% of caregivers identified themselves as White and 32% identified their ethnicity as African American. Caregivers rated their overall health on a 5-point Likert-type scale ranging from 1 (*poor*) to 5 (*excellent*). Average ratings indicated that participants viewed their overall health as good to very good ($M = 3.11$, $SD = .99$). CRs ranged in age from 60 to 102 ($M = 76.54$, $SD = 9.62$), and 54% were women.

If at any point during the study, it was determined (typically through routine follow-up telephone contact with participants) that a CR had been admitted to a nursing home or died since the last interview, the caregiver was asked to take part in a follow-up interview designed to examine the impact the transition had on her/him. Informed consent, data collection, and data

entry procedures for the post-transition interviews were identical to those described above. During the course of FRILL1, 54 caregivers (17%) who experienced CR death and 16 caregivers (5%) who experienced CR nursing home placement consented to participate in post-transition interviews. During FRILL2, 52 caregivers who experienced CR death and 10 caregivers who experienced CR nursing home placement continued in the study. Thus, for the present study, a synthetic cohort consisting of 132 caregivers who experienced a transition, regardless of the timing of that transition during the course of the FRILL project, was constructed and used for analyses.

Missing data were addressed at the scale-level. I first identified all cases where missing data occurred and ensured that data were not missing due to an error during data entry or verification. All data was assumed to be “missing at random” (see Little & Rubin, 1987, for a discussion of types of missing data) and were replaced using the expectation-maximization (EM) algorithm method of multiple imputation (Schaffer, 1999) in PRELIS8.54 software (Joreskog & Sorbom, 1993). The multiple imputation procedure has been shown to provide highly accurate replacement values (Schaffer, 1999), allowing for use of all available data and minimal reduction in reliability of results.

Measures

Background characteristics. Background characteristics known to be linked with adjustment to CR nursing home placement and death include age, gender, kinship to CR (here limited to spouses and non-spouses), annual household income, and time elapsed from the transition to the post-transition interview (time since transition). In addition, race (White vs. Other), marital status, education, employment status, CR age, CR gender, co-residence (i.e., whether the caregiver and CR resided in the same household), caregiver self-rated health (a

single-item rating from 1 = *poor* to 5 = *excellent*), and duration of the caregiving relationship at baseline (time in caregiver role) were assessed.

Pre-illness relationship quality. The 10-item Mutual Communal Behavior Scale (MCBS; e.g., Williamson & Schulz, 1995) was used to measure quality of the interpersonal relationship between caregiver and CR prior to illness/disability onset. The MCBS assesses frequency of behavioral expressions of communal feelings between caregiver and CR *before the caregiving relationship existed*. Respondents indicate the frequency (1 = *never occurred*, 4 = *always occurred*) of behavior exhibited by caregivers toward CRs (e.g., “If he/she was feeling bad, I tried to cheer him/her up”) as well as behavior exhibited by CRs toward caregivers (e.g., “He/she did things just to please me”). Internal consistency of this instrument has been acceptable in numerous studies (e.g., Williamson & Schulz, 1995; Williamson et al., 1998, 2001), and mean pre-transition coefficient α for the present sample was .90.

Care-related stress. This group of variables included measures of both objective and subjective stress. Objective stress was assessed with two measures: formal diagnosis of dementia or other condition(s) that cause memory problems in the CR (single question, 0 = *no*, 1 = *yes*, answered by the caregiver), and amount of caregiving assistance provided. As in prior studies (e.g., Williamson & Schulz, 1990; Williamson et al., 1998, 2000, 2001), I used an 18-item (e.g., personal grooming, taking care of personal business) assessment adapted from the ADL instrument (Duke University, Older American Resources & Services, 1978) to assess amount of caregiving assistance provided. Due to slight differences in the measurement of ADL assistance in the FRILL1 and FRILL2 phases, these items were scored as dichotomous responses (i.e., “no” if the caregiver did not provide help with an activity, “yes” if the caregiver had provided any

amount of help). Coefficient α (averaged over the three pre-transition interview occasions for the full FRILL sample) was .93 (range = .89-.96).

Because objective measures of functional status (e.g., ADLs) typically do not capture specific behavioral problems exhibited by disabled or otherwise dependent older adults, I also assessed the frequency of common types of CR controlling behavior. Using a 14-item scale developed by Steinmetz (1988), caregivers indicated on a scale of 0 (*never*) to 4 (*always*) how often each behavior (e.g., refused to eat, manipulated family members) occurred within the past month. Higher scores on this subjective measure represent more frequent CR controlling behavior. Pre-transition coefficient α for the sample was .88 (range = .87-.89).

Because of consistent findings that perceptions of strain related to care provision, rather than the amount of care provision itself, can have negative consequences for caregivers, subjective stress also was measured using the Activity Restriction Scale (ARS; e.g., Williamson & Schulz, 1992), which assesses how much (0 = *never or seldom did this*, 1 = *not restricted at all*, 4 = *greatly restricted*) nine activities related to self-care, recreation, and social activity have been restricted since the onset of the CR's illness or disability. Higher scores represent more care-related activity restriction. Previous research has shown the ARS to have high internal consistency in samples of caregivers (e.g., Williamson & Schulz, 1992; Williamson, Shaffer, & Schulz, 1998). The mean coefficient α for the sample was .86 (range = .84-.87).

Depressive symptoms. The Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977) was used to assess caregiver depressive symptoms. The CES-D is a 20-item scale designed to identify persons at risk for clinical depression. Participants respond to statements such as "I felt depressed" and "I was happy" (reverse scored) with reference to their feelings during the past week. Individual items are scored on a 4-point scale (0 = *rarely or none of the*

time, 3 = *most of the time*); the 20 items are summed such that higher scores indicate more frequent depressive symptoms during the previous week. Scores of 16 or higher are generally believed to indicate that individuals are “at risk” for clinical depression. The CES-D is preferred for use with older populations because it places less emphasis on somatic symptoms of depression that are often found among non-depressed older persons (e.g., Schulz, Tompkins, & Rau, 1988). The CES-D has high internal consistency, test-retest reliability, and validity (e.g., Herzog et al., 1990; Radloff, 1977) and has been used extensively in studies of caregivers (e.g., Williamson & Schulz, 1990, 1995; Williamson et al., 1998, 2001). In the present sample, mean pre-transition coefficient α was .90 (range = .90-.91), while the α s for post-transition depression were .93 and .92 for the CR nursing home placement and CR deceased caregiver groups, respectively.

Caregiver grief. Sixteen questions about caregivers’ grief experiences after CR nursing home placement or death were included in the post-transition interview. Seven items were selected from the Revised Grief Experience Inventory (Lev, Munro, & McCorkle, 1993), a shortened version of a measure shown to be appropriate for measuring grief in non-death loss situations (Zinner, Ball, Stutts, & Mikulka, 1991). The remaining items, adapted from work by Bass and Bowman (1990) and Pruchno et al. (1995), were selected to assess caregiver appraisals of difficulty adapting to the transition (e.g., “CR’s placement/death is the most difficult problem I have ever faced”) as well as negative individual consequences associated with the experience (e.g., “I feel lost without CR around”). Two forms of this scale were developed with items worded to reflect caregiver reactions to CR nursing home placement or death. All items were scored on the same 5-point response scale (0 = *strongly disagree*, 4 = *strongly agree*), with

higher scores indicating a stronger grief experience. In this sample, coefficient α s were .93 for the CR nursing home placement group and .96 for the CR deceased group.

Caregiver relief. The measure of post-transition caregiver relief was developed after a review of studies that examined this phenomenon either qualitatively or quantitatively (Collins et al., 1993; Pruchno et al., 1995; Rosenthal & Dawson, 1991). Transitioned caregivers were asked to respond to six statements describing feelings related to CR nursing home placement or death (i.e., “I feel as though a weight has been lifted from my shoulders;” “I have regained a part of my life that was lost;” “I am relieved that I no longer have responsibility for CR’s well being;” “CR is better off now;” “I am better off now;” “my life is getting back to normal now”). Parallel versions were administered with wording changed to match the type of transition. Caregivers selected from four response choices (1 = *definitely false*, 4 = *definitely true*), and higher scores reflected greater relief. Coefficient α s for caregiver relief were .88 and .78 for the CR nursing home placement and CR death groups, respectively. An additional item assessing overall relief asked caregivers, “How do you generally feel about CR’s death/placement?” (1 = *very troubled*, 2 = *somewhat troubled*, 3 = *somewhat relieved*, 4 = *very relieved*) This item was included for the purpose of examining whether this single item would correlate highly with predictors of the summary score and perhaps serve as a more parsimonious assessment of relief.

CHAPTER 6

RESULTS

For all analyses, statistical significance was defined at the conventional 95% level ($\alpha = .05$, two-tailed). In multivariate analyses, measures of effect size (e.g., η^2 for ANOVA and adjusted R^2 for multiple regression) were used to describe the proportion of variance accounted for in each dependent/criterion variable by the independent/predictor variable(s).

Preliminary Analyses

Characteristics of the participants by caregiver group. Descriptive data on background characteristics, pre-illness relationship history, care-related stress, and caregiver mental health measures for each caregiver group (continuing caregivers, CR nursing home placement, and CR death,) are provided in Table 1. To determine if any factors should be controlled in subsequent analyses, a multivariate analysis of variance (ANOVA) and chi-square tests were conducted to determine whether significant differences existed on any of the pre-transition variables between (a) the continuing caregiver group and the combined caregiver transition groups and (b) the two caregiver transition groups. At baseline, transitioned caregivers were caring for older CRs, provided more ADL assistance, and reported more activity restriction than continuing caregivers, Wilks's $\lambda = .91$, multivariate $F(11,721) = 6.64$, $p < .001$. Transitioned caregivers also were more likely than continuing caregivers to have provided care for a CR diagnosed with dementia (50.8% and 29.3%, respectively, $\chi^2(1) = 22.63$, $p < .001$). The transition groups (CR placed vs. CR deceased) did not differ in age, education, income, self-rated health, time in caregiver role, CR age, amount of pre-transition ADL assistance provided, CR controlling behavior, activity

restriction, pre- illness mutual communal behavior, or pre-transition depressive symptoms, Wilks's $\lambda = .96$, multivariate $F(11,120) = .43$, *n.s.*, although the difference in caregiver age approached significance ($p = .06$) with caregivers of deceased recipients ($M = 64.11$, $SD = 13.79$) being, on average, older than caregivers of placed recipients ($M = 58.38$, $SD = 14.54$). There also were no significant differences between the transition groups on gender, race, kinship, marital status, employment status, co-residence, or CR gender, all $\chi^2(1) < 2.21$, *n.s.* However, significantly more caregivers in the CR placement group (76.9%) than in the CR death group (44.3%) reported caring for someone diagnosed with a condition that causes memory problems, such as Alzheimer's disease or dementia, $\chi^2(1) = 8.90$, $p < .01$.

Bivariate correlations among study variables. Correlations among background characteristics, pre-illness relationship quality, care-related stress, pre-transition depressive symptoms, and post-transition caregiver depressive symptoms, grief, and relief are reported in Table 2. These correlations were analyzed to determine whether any variables were related to any of the outcome measures such that they should be included in subsequent multivariate analyses. Only those background characteristics correlated to any post-transition outcome variable at $p < .05$ were retained for subsequent analysis. This resulted in the exclusion of caregiver age, race, marital status, employment status, CR age, and CR gender.

At the bivariate level, more post-transition depressive symptoms were associated with higher pre-transition depressive symptoms, supporting my hypothesis and suggesting reliability of measurement across these transitions. As expected, caregivers with more post-transition depressive symptoms reported, at pre-transition assessment, lower income, lower self-rated

Table 1

Characteristics of the Sample

Variable	Continuing Care (<i>n</i> = 624)		CR Deceased (<i>n</i> = 106)		CR Placed (<i>n</i> = 26)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
<u>Background Characteristics</u>						
Age	61.04	15.60	64.11	13.79	58.38	14.54
Female, %	71		78		85	
Caucasian, %	64		75		62	
Relationship to CR						
Spouse, %	51		45		35	
Child, %	35		51		54	
Other Relative, %	14		4		12	
Married, %	67		73		58	
Employed, %	41		37		46	
Education						
HS Graduate, %	54		52		42	
College Graduate, %	28		33		42	
Annual Household Income (Mdn)	\$25k	\$10k	\$25k	\$10k	\$37k	\$10k
CR Age	75.47	9.46	81.64	8.90	81.27	8.38
CR Female, %	54		55		50	
CR Diagnosed with Dementia, %	29		44		77	
Co-Resided with CR, %	90		89		85	
Self-Related Health	3.11	0.98	3.13	1.05	3.08	0.86
Time in Role (months)	82.55	98.83	82.1	70.71	83.15	64.36
Time Since Transition (months)	n/a	n/a	8.40	7.92	9.35	7.72
<u>Pre-Illness Relationship History</u>						
MCBS	32.61	6.41	32.24	6.32	31.11	6.01
<u>Care-Related Stress</u>						
Pre-Transition ADL Assistance	3.90	5.80	6.21	6.93	6.96	6.24
Pre-Transition Control Scale	5.91	7.27	7.19	7.73	7.23	6.78
Pre-Transition ARS	13.94	6.59	17.33	6.91	16.88	6.70
<u>Pre- and Post-Transition Mental Health</u>						
Pre-Transition CES-D	10.72	9.35	11.60	10.02	11.77	9.25
Post-Transition CES-D	n/a	n/a	15.28	12.19	14.96	12.30
Post-Transition Caregiver Grief	n/a	n/a	35.44	16.90	30.27	13.43
Post-Transition Caregiver Relief	n/a	n/a	16.66	4.41	18.31	4.68
Post-Transition Overall Relief	n/a	n/a	2.50	0.93	3.15	0.97

Note. CR = Care Recipient; MCBS = Mutual Communal Behavior Scale; ADL = Activities of Daily Living; ARS = Activity Restriction Scale; CES-D = Center for Epidemiological Studies Depression Scale.

health, more CR controlling behavior, and greater activity restriction. The hypothesized associations between gender, relationship to CR, pre-illness relationship quality, and post-transition depressive symptoms were not statistically significant.

In terms of caregiver grief, providing care to a spouse, less education, lower income, and lower self-rated health were related to higher caregiver grief. As hypothesized, caregivers who co-resided with the CR before a transition exhibited stronger grief reactions; however, male caregivers, rather than females as hypothesized, reported more post-transition grief. Consistent with the literature, shorter time since transition was related to higher grief score, meaning that caregivers who experienced either CR nursing home placement or death more recently also experienced stronger grief reactions. Additionally, as hypothesized, caregivers who reported a better pre-illness relationship with the CR reported more post-transition grief. One indicator of care-related stress – amount of ADL assistance – was related to grief such that less assistance predicted more grief. As hypothesized, caregivers with higher pre-transition depressive symptoms reported stronger grief following a transition.

Consistent with my hypotheses about post-transition relief, caring for an individual diagnosed with a condition that causes memory problems, such as Alzheimer's disease or dementia, was associated with greater caregiver relief, as were higher income and higher self-rated health. The pattern of bivariate correlations among predictors and the single-item measure of overall relief was somewhat different from that of the six-item relief scale. More relieved caregivers had been providing care for a non-spouse; almost 75% of non-spouse caregivers were CRs' children, which indirectly supported the hypothesis that younger caregivers adapt better to transitions. More relieved caregivers also were female and had more education, higher income,

Table 2

Intercorrelations Among Study Variables

Variable	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.
1. Age	—											
2. Gender	.14	—										
3. Race	-.30***	-.15	—									
4. Relationship to CR	-.64***	-.21*	.26**	—								
5. Marital Status	-.37***	-.21*	.29***	.53***	—							
6. Employment Status	.25**	.17*	.05	-.05	.08	—						
7. Education	-.16	-.01	-.18*	.29***	.05	.05	—					
8. Annual Income	-.03	.02	-.41***	.03	-.32***	-.23**	.43***	—				
9. CR Age	.10	-.16	.03	.48***	.32***	.14	.26**	.05	—			
10. CR Gender	.17*	-.17	-.07	-.50***	-.35***	-.17	-.24**	.02	-.36***	—		
11. Co-Resides with CR	.25*	.02	.03	-.18*	.04	.09	-.26**	-.08	.05	.02	—	
12. Self-Rated Health	.04	.02	-.23**	.04	-.01	-.10	.22*	.26**	.09	-.08	-.06	—
13. Time In Role	.06	-.09	.01	-.09	-.05	-.19*	-.16	.00	-.09	.06	.07	-.06
14. Time Since Trans.	.06	.03	-.05	-.06	-.03	.08	-.08	-.03	-.07	.13	-.12	.07
15. CR Dementia Status	-.03	-.03	.04	.04	.09	.15	.03	.05	-.07	-.09	-.09	-.12
16. Pre-Trans. ADL	.03	-.06	-.17	-.03	-.13	-.00	.21*	.29***	-.07	.00	-.19*	-.09
17. Pre-Trans. Control	-.01	.02	.07	.05	.13	-.04	.13	-.06	.04	-.04	-.28***	-.19*
18. Pre-Trans. ARS	.07	-.04	-.00	-.03	-.07	.04	.15	.03	.15	-.00	.03	-.28***
19. Pre-Illness MCBS	.10	.12	-.01	-.12	-.01	.10	-.23**	-.11	-.01	-.23**	-.37***	.03
20. Pre-Trans. CES-D	-.06	.06	.18	-.09	.04	.06	.01	-.07	.01	.01	-.04	-.37***
21. Trans. Status	-.16	-.06	.12	.12	.13	-.08	.08	.04	-.02	.04	-.04	-.04
22. Post-Trans. CES-D	-.03	.10	.06	-.09	.08	.05	-.08	-.17*	-.12	.08	-.43***	-.43***
23. Post-Trans. Grief	.01	.23**	.15	-.23**	.06	.15	-.33***	-.34***	-.12	-.03	-.26**	-.26**
24. Post-Trans. Relief	.06	-.12	-.15	.05	.05	-.17	.15	.20**	.05	.08	.21*	.21*
25. Overall Relief	-.04	-.18*	-.11	.21*	.12	-.14	.25**	.20**	.17*	.03	.28***	.28***

* $p < .05$. ** $p < .01$. * $p < .001$. CR = Care Recipient; ADL = Activities of Daily Living; ARS = Activity Restriction Scale; MCBS = Mutual Communal Behavior Scale; CES-D = Center for Epidemiological Studies Depression Scale.

Table 2 (cont.)

Variable	13.	14.	15.	16.	17.	18.	19.	20.	21.	22.	23.	24.
1. Age												
2. Gender												
3. Race												
4. Relationship to CR												
5. Marital Status												
6. Employment Status												
7. Education												
8. Annual Income												
9. CR Age												
10. CR Gender												
11. Co-Resided with CR												
12. Self-Rated Health												
13. Time In Role	—											
14. Time Since Trans.	.03	—										
15. CR Dementia Status	-.12*	.11	—									
16. Pre-Trans. ADL	.18*	.42***	.25**	—								
17. Pre-Trans. Control	.10	.01	.19*	.24**	—							
18. Pre-Trans. ARS	.12	-.08	.29***	.23**	.28***	—						
19. Pre-Illness MCBS	.02	-.03	.03	-.22*	-.38***	-.02	—					
20. Pre-Trans. CES-D	.02	-.02	.23**	.17*	.35***	.40***	-.09	—				
21. Trans. Status	.01	.05	.26**	.04	.00	-.03	-.07	.01	—			
22. Post-Trans. CES-D	.02	.02	.01	.10	.45***	.35***	-.10	.49***	-.01	—		
23. Post-Trans. Grief	-.01	-.27**	-.10	-.46***	.02	.12	.32***	.25**	-.13	.46***	—	
24. Post-Trans. Relief	-.01	-.15	.18*	-.12	-.09	.02	-.17	-.16	.15	-.26**	-.28***	—
25. Overall Relief	-.07	-.06	.01	.01	-.05	-.17	-.21*	-.28***	.27**	-.40***	-.44***	.47***

* $p < .05$. ** $p < .01$. *** $p < .001$. CR = Care Recipient; ADL = Activities of Daily Living; ARS = Activity Restriction Scale; MCBS = Mutual Communal Behavior Scale; CES-D = Center for Epidemiological Studies Depression Scale.

higher self-rated health, lower quality pre-illness mutually communal relationships with the CR, and fewer pre-transition depressive symptoms.

The post-transition outcome measures were moderately correlated in the expected directions. Specifically, more depressive symptoms were correlated with higher scores on the grief scale, lower scores on the relief measure, and less overall relief. A stronger grief reaction was associated with lower scores on the relief scale and lower overall relief. Finally, as would be expected, higher score on the relief scale was associated with higher score on the overall relief item.

Assessment of baseline differences in depressive symptoms among continuing and transitioned caregivers. To determine if depressive symptoms differed among continuing caregivers and transitioned caregivers prior to a transition, the transition groups – CR nursing home placement ($n = 106$) and CR death ($n = 26$) – were combined and compared with a control group of caregivers who continued to provide care in the community ($n = 624$). For continuing caregivers, data from the first FRILL interview were used for comparison with the final pre-transition interview conducted with transitioned caregivers. An ANCOVA was conducted with caregiver group as the between-subjects factor. Because of previous research findings that female and spouse caregivers are at higher risk for depressive symptoms, these variables were included as covariates along with those variables that were shown to differ significantly at baseline (i.e., CR age, CR dementia diagnosis, amount of ADL assistance, and activity restriction). The ANCOVA revealed no significant differences between continuing and transitioned caregivers on depressive symptoms, $F_s < 2.39$, *n.s.* Simple contrasts between each caregiver transition group and the continuing caregiver group were not significant, supporting the hypotheses that no differences would exist among the caregiver groups at baseline.

Pre- to Post-Transition Differences in Caregiver Depressive Symptoms.

The prospective nature of the FRILL study allowed me to compare pre- and post-transition caregiver depressive symptoms among transitioned caregivers. Data collected at the interview immediately preceding the transition served as a baseline for comparison with post-transition scores. When the CR nursing home placement and death groups were examined together in a repeated measures ANOVA, CES-D scores increased from pre-transition ($M = 11.64$, $SD = 9.84$) to post-transition ($M = 15.22$, $SD = 12.16$). Contrary to my hypothesis that depressive symptoms would remain stable or decrease slightly after a transition, at the aggregate level, the increase was significant, $F(1,131) = 13.98$, $p < .001$, partial eta squared = .09.

I then split the sample to determine if type of transition influences change in depressive symptoms from pre- to post-transition. A second repeated measures ANOVA of caregiver depressive symptoms was conducted with time of interview (i.e., pre- or post-transition) as the within-subjects factor, transition group as the between-subjects factor, and, because of the significant difference between the transition groups at baseline, CR dementia status as a covariate. Results of the repeated measures ANOVA are provided in Table 3, which shows a significant Time X Type of Transition interaction when CR dementia diagnosis was controlled. Means and standard deviations on the CES-D for each caregiver group by type of transition and CR dementia diagnosis are provided in Table 4. After CR death, depressive symptoms remained stable in dementia caregivers but increased sharply among non-dementia caregivers. One explanation for this finding is that dementia caregivers' depressive symptoms are already relatively high ($M = 14.55$) during care provision, and death is not an entirely unexpected or unwelcome occurrence; in contrast, for non-dementia caregivers, whose pre-death CES-D scores were much lower ($M = 9.25$), CR death is unexpected or less anticipated.

Conversely, after CR nursing home placement, depressive symptoms remained stable in non-dementia caregivers but increased appreciably in dementia caregivers. It is possible that non-dementia caregivers are in a more favorable position to discuss the placement well in advance and seek CR agreement with the placement decision, which may in turn reduce caregivers' burden and increase their ability to cope, whereas dementia caregivers consider themselves to be forcing, or "committing," CRs into skilled care. These dementia caregivers also may be more likely to experience resistance or actual combativeness during the placement. In short, while the type of transition itself may not influence change in caregiver depressive symptoms, factors such as the nature of pre-transition illness condition and CR behavior before, during, or (in the case of nursing home placement) after a transition may affect caregiver mental health. In order to determine whether individual differences in caregiver or CR factors predict mental adjustment to a caregiving transition, I next conducted multiple regression analyses to examine the influence of several potential predictor variables on depressive symptoms, grief, and relief.

Regression Models of Post-Transition Depressive Symptoms, Grief, and Relief

Hierarchical multiple regression was used to examine the hypotheses that background characteristics, pre-illness relationship quality, care-related stress, and pre-transition caregiver mental health contribute to variance in post-transition depressive symptoms, grief, and relief. Separate regression equations were constructed for scores on each outcome variable. Based on previous findings and to examine the independent contribution of specific variables, the regressions proceeded in the following steps: (1) background characteristics (caregiver gender, kinship, education, income, co-residence, self-rated health, time in caregiver role, type of transition, time since transition); (2) pre-illness relationship quality (MCBS); (3) pre-transition

Table 3

Repeated Measures Analysis of Variance Results for Caregiver Depressive Symptoms (CES-D)

Using Type of Transition and Time of Assessment, with CR Dementia Diagnosis as Covariate

Variable	<i>df</i>	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>p</i>	η^2
Between subjects						
Intercept	1	5619.96	5619.96	30.83	.00	.19
Type of Transition	1	45.69	45.69	.25	.30	.00
Type of Transition X CR Diagnosis	2	443.59	221.79	1.22	.62	.02
Error	128	23331.29	182.28			
Within subjects						
Time	1	118.17	118.17	1.94	.17	.02
Time X Type of Transition	1	95.46	95.46	1.56	.21	.01
Time X Type of Transition X CR Diagnosis	2	473.02	236.51	3.88	.02	.06
Error	128	7810.54	61.02			

Note. CES-D = Center for Epidemiological Studies Depression Scale; CR = Care Recipient.

Table 4

Means and Standard Deviations for Pre- and Post-Transition Depressive Symptoms (CES-D) as a Function of Type of Transition and CR Dementia Diagnosis

Source	<u>Pre-Transition</u>		<u>Post-Transition</u>	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
CR Deceased				
Dementia Diagnosis	14.55	10.68	15.00	11.13
No Dementia Diagnosis	9.25	8.86	15.51	13.06
CR Nursing Home Placement				
Dementia Diagnosis	12.25	9.56	16.30	12.28
No Dementia Diagnosis	10.17	8.73	10.50	12.34

Note. CES-D = Center for Epidemiological Studies Depression Scale; CR = Care Recipient.

care-related stress (CR dementia diagnosis, ADL Assistance, CR controlling behavior, activity restriction); and (4) pre-transition depressive symptoms (CES-D).

To examine the possible contribution of type of transition beyond main effects, I tested interactions between type of transition and each predictor variable in a fifth and final step. Given the sample size, to reduce the chance of Type 1 error I entered each interaction term independently. For each outcome variable, significant interaction terms are included in the model summary. Examination of variance inflation factor (VIF) statistics for predictor variables in each model suggested that multicollinearity was not sufficient to produce unstable estimates of regression coefficients.

Caregiver depressive symptoms. Table 5 summarizes the hierarchical regression model for post-transition depressive symptoms (CES-D). Background characteristics accounted for 24% of the variance in depressive symptoms ($p < .001$). Not surprisingly, lower self-rated health predicted more depressive symptoms. The relation between physical health and psychological health is well-documented in the caregiving literature. Pre-illness relationship quality (MCBS), entered in the second step, was not a significant predictor of post-transition depressive symptoms, accounting for only 1% of additional variance. As a group, pre-transition care-related stress accounted for a significant additional 9% of variance ($p < .01$). Among this block of variables, the important predictors of more depressive symptoms were providing care for a CR with no diagnosis of dementia, more CR controlling behavior, and greater activity restriction. These predictors remained significant after controlling for pre-transition depressive symptoms, which, as hypothesized, was also a significant predictor of post-transition depressive symptoms and accounted for an additional 6% of the variance in the model ($p < .001$). Among the 15 two-way

interactions tested, only Type of Transition X Time in Caregiver Role was significant, accounting for an additional 2% of variance in depressive symptoms ($p < .05$).

This interaction is illustrated in Figure 1, with CES-D score plotted at low, medium, and high values of time in caregiver role (computed using the mean as the medium value, one standard deviation above the mean as the high value, and one standard deviation below the mean as the low value) for each transition group. The effect of time in caregiver role on post-transition depressive symptoms in the CR death group was not significant (simple slope = $-.01$, $t(128) = -1.16$, *n.s.*); in other words, depressive symptoms remained stable regardless of how long care was provided before CR death.

In contrast, there was a rather dramatic decrease in post-transition depressive symptoms as time in role increased in the CR nursing home placement group (simple slope = $-.09$, $t(128) = -2.25$, $p < .05$); this slope suggests that caregivers who provided care for briefer periods of time prior to CR death experienced more depressive symptoms than those who provided care for longer periods of time. This pattern of depressive symptoms provides partial support for the hypothesis that caregivers who experienced CR death would exhibit more depressive symptoms than those who experienced CR nursing home placement; only among caregivers who have spent the least amount of time in role does nursing home placement appear to have the same mental health impact as bereavement. In total, the full model (main effects and interaction) accounted for an adjusted 35% of the variance in caregiver depressive symptoms, $F(16,115) = 5.45$, $p < .001$.

Table 5

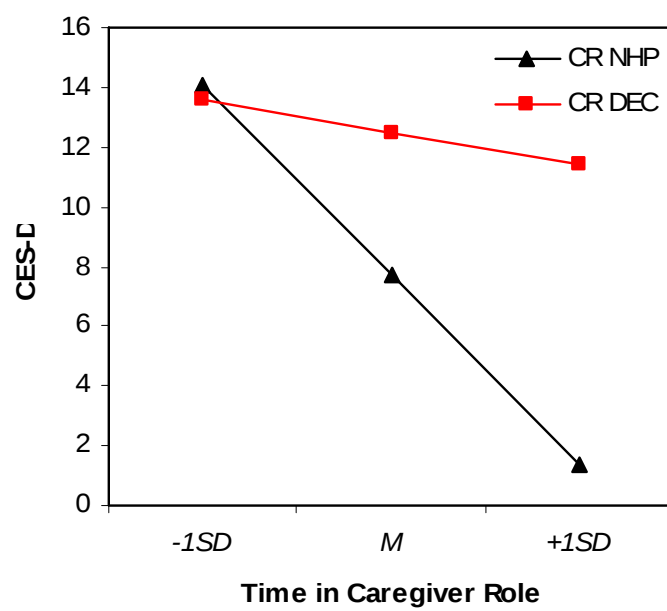
*Summary of Hierarchical Regression Analysis for Variables Predicting Post-Transition**Caregiver Depressive Symptoms (N = 132)*

Step	Variable	<i>B</i>	<i>SE B</i>	β	R^2	ΔR^2
1	Gender	1.79	2.23	.06	.24	.24***
	Relationship to CR	-.95	1.92	-.04		
	Education	-.31	.65	-.05		
	Annual Household Income	-.28	.40	-.06		
	Co-Resided with CR	4.92	2.98	.13		
	Self-Rated Health	-3.03	1.02	-.25**		
	Time in Caregiver Role	-.02	.01	-.09		
	Type of Transition	1.47	2.29	.05		
	Time Since Transition	.10	.13	.06		
2	Pre-Illness Relationship History (MCBS)	-.07	.16	-.04	.26	.01
3	CR Diagnosed with Dementia	-4.78	2.03	-.20*	.35	.09**
	Pre-Transition ADL Assistance	.10	.17	.06		
	Pre-Transition Control Scale	.28	.14	.17*		
	Pre-Transition Activity Restriction (ARS)	.31	.15	.17*		
4	Pre-Transition Depressive Symptoms (CES-D)	.40	.11	.32***	.41	.06***
5	Type of Transition X Time in Caregiver Role	-.08	.04	-.16*	.43	.02*

Note. Total adjusted $R^2 = .35$. CR = Care Recipient; MCBS = Mutual Communal Behavior Scale; ADL = Activities of Daily Living; ARS = Activity Restriction Scale; CES-D = Center for Epidemiological Studies Depression Scale.

Figure 1

*Interaction Effect of Type of Transition and Time in Caregiver Role on Post-Transition
Caregiver Depressive Symptoms*



Note. CR = Care Recipient; NHP = Nursing Home Placement; DEC = Deceased.

Caregiver grief. Table 6 provides a summary of the hierarchical regression model predicting post-transition caregiver grief. Background characteristics accounted for a significant 39% of variance ($p < .001$). Caregiver gender was a significant predictor of grief; contrary to my hypothesis, men experienced a stronger grief reaction. Co-residing with the CR and lower self-rated health also predicted a stronger grief reaction. As hypothesized, in the second step, a more mutually communal, or higher quality, pre-illness relationship predicted more grief, alone accounting for a significant 4% of the total variance ($p < .01$). In the third step, care-related stress variables contributed an additional 9% of the variance in caregiver grief ($p < .001$), among which less pre-transition ADL assistance was the only significant predictor. As hypothesized, caregivers who provided help with fewer basic or instrumental ADLs reported more grief after the transition. The bivariate correlation between pre-transition depressive symptoms and grief remained in the multivariate analysis, with more depressive symptoms predicting a stronger grief reaction and accounting for 3% of additional variance in the model ($p < .01$). None of the interactions between type of transition and the other variables predicted grief. Overall, the model accounted for an adjusted 49% of the variance in post-transition caregiver grief, $F(15,116) = 9.28, p < .001$.

Caregiver relief. The hierarchical regression model predicting post-transition caregiver relief is summarized in Table 7. Although no individual background characteristic was a significant predictor, the block of variables accounted for 13% of the total variance in relief, which was statistically significant ($p < .05$). In the second step, less mutually communal pre-illness relationship predicted significantly greater relief after a transition; this relationship was in the hypothesized direction but accounted for only an additional 2% of the total variance in relief ($p = .10, n.s.$).

Table 6

*Summary of Hierarchical Regression Analysis for Variables Predicting Post-Transition**Caregiver Grief (N = 132)*

Step	Variable	<i>B</i>	<i>SE B</i>	β	R^2	ΔR^2
1	Gender	5.76	2.65	.14*	.39	.39***
	Relationship to CR	-3.66	2.28	-.11		
	Education	-.62	.77	-.07		
	Annual Household Income	-.71	.48	-.11		
	Co-Resided with CR	8.22	3.56	.17*		
	Self-Rated Health	-2.56	1.22	-.16*		
	Time in Caregiver Role	.00	.02	.00		
	Type of Transition	-1.57	2.73	-.04		
	Time Since Transition	-.16	.16	-.08		
2	Pre-Illness Relationship History (MCBS)	.57	.19	.22**	.43	.04**
3	CR Diagnosed with Dementia	-2.27	2.41	-.07	.52	.09***
	Pre-Transition ADL Assistance	-.87	.20	-.36***		
	Pre-Transition Control Scale	.21	.17	.09		
	Pre-Transition Activity Restriction (ARS)	.15	.18	.06		
4	Pre-Transition Depressive Symptoms (CES-D)	.33	.13	.20**	.55	.03**

Note. Total adjusted $R^2 = .49$. CR = Care Recipient; MCBS = Mutual Communal Behavior Scale; ADL = Activities of Daily Living; ARS = Activity Restriction Scale; CES-D = Center for Epidemiological Studies Depression Scale.

In step 3, care-related stress variables accounted for a significant additional 9% of the total variance ($p < .01$). As hypothesized, providing care for an individual diagnosed with dementia predicted greater relief after relinquishing the caregiver role. Contrary to my hypothesis that caregivers who exhibited more depressive symptoms would experience greater relief following a transition, this variable was not significantly associated with relief after controlling for the other predictors in the model. There was a significant Type of Transition X Pre-Transition Activity Restriction interaction effect on caregiver relief, which accounted for an additional 3% of variance in the final model ($p < .05$). This interaction is illustrated in Figure 2 with relief score plotted at low, medium, and high values of activity restriction for each caregiver transition group.

In the CR death group, feelings of relief were stable regardless of the amount of activity restriction before CR death (simple slope = .06, $t(128) = .86$, *n.s.*). In the CR nursing home placement group, caregivers who experienced higher activity restriction before placement felt greater relief after placement (simple slope = .35, $t(128) = 2.33$, $p < .05$). The model accounted for an adjusted 18% of variance in post-transition caregiver relief, $F(16,115) = 2.77$, $p < .001$.

In terms of overall relief, the results of the hierarchical regression of the single-item relief measure are provided in Table 8. This was the only model in which the main effect for type of transition reached statistical significance, with the nursing home placement group reporting higher relief. Driven by the predictive power of type of transition, the background characteristics accounted for a significant 24% of the variance in overall relief. The association between pre-illness mutually communal behavior and overall relief was in the hypothesized direction (i.e., less mutually communal behavior was associated with greater overall relief), but the

Table 7

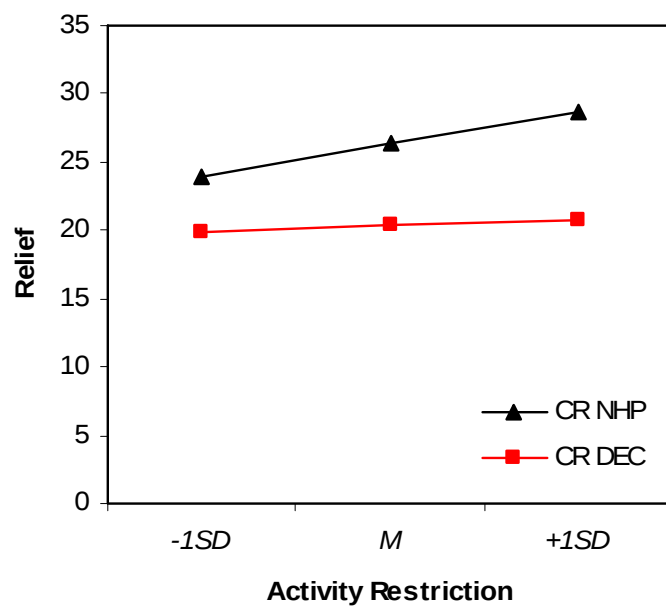
*Summary of Hierarchical Regression Analysis for Variables Predicting Post-Transition**Caregiver Relief (N = 132)*

Step	Variable	<i>B</i>	<i>SE B</i>	β	R^2	ΔR^2
1	Gender	-1.00	.93	-.09	.13	.13*
	Relationship to CR	-.39	.79	-.04		
	Education	.13	.27	.05		
	Annual Household Income	.26	.17	.15		
	Co-Resided with CR	-.29	1.24	-.02		
	Self-Rated Health	.67	.43	.15		
	Time in Caregiver Role	.00	.01	.06		
	Type of Transition	.84	.95	.07		
	Time Since Transition	-.07	.06	-.12		
2	Pre-Illness Relationship History (MCBS)	-.17	.07	-.24**	.15	.02
3	CR Diagnosed with Dementia	2.56	.84	.29**	.24	.09**
	Pre-Transition ADL Assistance	-.16	.07	-.24*		
	Pre-Transition Control Scale	-.05	.06	-.09		
	Pre-Transition Activity Restriction (ARS)	.06	.06	.08		
4	Pre-Transition Depressive Symptoms (CES-D)	-.06	.04	-.12	.25	.01
5	Type of Transition X Pre-Transition ARS	.30	.14	.18*	.28	.03*

Note. Total adjusted $R^2 = .18$. CR = Care Recipient; MCBS = Mutual Communal Behavior Scale; ADL = Activities of Daily Living; ARS = Activity Restriction Scale; CES-D = Center for Epidemiological Studies Depression Scale.

Figure 2

Interaction Effect of Type of Transition and Pre-Transition Activity Restriction on Post-Transition Caregiver Relief



Note. CR = Care Recipient; NHP = Nursing Home Placement; DEC = Deceased.

standardized coefficient fell just short of significance ($p = .06$) and the variable alone contributed only 2% additional variance to the model ($p = .09$). None of the pre-transition care-related stress variables contributed individually or collectively to the total variance in overall relief. Higher pre-transition CES-D score was associated with less overall relief; however, this relationship was moderated by type of transition. The significant Type of Transition X Pre-Transition Depressive Symptoms interaction is illustrated in Figure 3. Among caregivers in the CR nursing home placement group, more pre-transition depressive symptoms were associated with higher overall relief. In contrast, among caregivers in the CR death group, more pre-transition depressive symptoms were associated with lower overall relief. Neither simple slope in the interaction was statistically significant (both $ts < .45$, *n.s.*). However, the interaction accounted for a significant additional 3% of variance in overall relief ($p < .05$). None of the other variables in the model interacted with type of transition to influence overall relief (all $\beta < .001$, all $p < .001$). The final model accounted for an adjusted 23% of variance in overall relief, $F(16,115) = 3.50$, $p < .001$.

Table 8

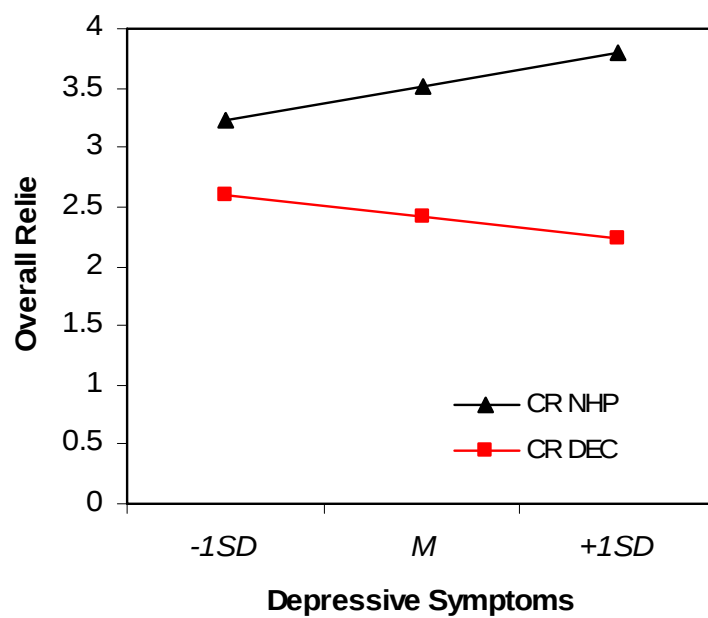
*Summary of Hierarchical Regression Analysis for Variables Predicting Post-Transition**Caregiver Overall Relief (N = 132)*

Step	Variable	<i>B</i>	<i>SE B</i>	β	R^2	ΔR^2
1	Gender	-.29	.19	-.12	.24	.24***
	Relationship to CR	.10	.17	.05		
	Education	.07	.06	.13		
	Annual Household Income	.03	.04	.08		
	Co-Resided with CR	-.22	.26	-.07		
	Self-Rated Health	.16	.09	.16		
	Time in Caregiver Role	-.00	.00	-.05		
	Type of Transition	.55	.20	.23**		
	Time Since Transition	-.01	.01	-.08		
2	Pre-Illness Relationship History (MCBS)	-.03	.01	-.17	.26	.02
3	CR Diagnosed with Dementia	.10	.17	.05	.27	.01
	Pre-Transition ADL Assistance	-.01	.02	-.07		
	Pre-Transition Control Scale	.00	.01	.00		
	Pre-Transition Activity Restriction (ARS)	-.01	.01	-.04		
4	Pre-Transition Depressive Symptoms (CES-D)	-.02	.01	-.18*	.30	.03*
5	Type of Transition X Pre-Transition CES-D	.05	.02	.18*	.33	.03*

Note. Total adjusted $R^2 = .23$. CR = Care Recipient; MCBS = Mutual Communal Behavior Scale; ADL = Activities of Daily Living; ARS = Activity Restriction Scale; CES-D = Center for Epidemiological Studies Depression Scale.

Figure 3

Interaction Effect of Type of Transition and Pre-Transition Depressive Symptoms (CES-D) on Post-Transition Caregiver Overall Relief



Note. CR = Care Recipient; NHP = Nursing Home Placement; DEC = Deceased.

CHAPTER 7

DISCUSSION

This study examined depressive symptoms, grief, and relief in a sample of informal caregivers who experienced either nursing home placement or death of an elder care recipient. These transitions are quite common among informal caregivers, and I investigated the impact of these events by (a) testing pre- to post-transition mean-level change in depressive symptoms and (b) investigating individual differences in post-transition depressive symptoms, grief, and relief. The findings indicate that, at the aggregate level, depressive symptoms increase following the cessation of in-home care, but the degree of change depends on which transition occurs and the cognitive impairment status of the CR before the transition. Another important finding is that although many caregivers experience depressive symptoms and grief after CR institutionalization or death, there also are considerable feelings of both general and context-specific relief. Relief could result from cumulative effects of being freed from the intense stress of informal care provision, from relinquishing a role that was not highly valued or rewarding, and from a return to normalcy in other areas (e.g., social, recreational) of life. Moreover, it is evident that while depressive symptoms, grief, and relief are correlated and share common associations with predisposing factors, the correlations among these constructs are far from perfect and each outcome is predicted by a unique combination of pre-transition factors.

The sample of caregivers in the present study was functioning moderately well from a mental health standpoint, despite some having experienced nursing home placement or death as

recently as one month prior to assessment. Approximately 30% of caregivers reported pre-transition depressive symptoms at levels widely recognized as placing an individual at risk for clinical depression (i.e., CES-D scores of 16 or more); following a transition, the prevalence rate approached 40%. Thus, the sample included caregivers with a wide range of pre-existing and transition-related mental health strain. The sample was quite similar to estimates of the national caregiving population in terms of age, marital status, and socioeconomic status (e.g., National Alliance for Caregiving and the American Association of Retired Persons, 1997; Select Committee on Aging, 1987), but, in a number of ways, this sample is more heterogeneous than those found in other studies of caregiving transitions. For example, the sample contained roughly equal numbers of spouses and adult child caregivers, one third reported their ethnicity as African American or another minority, and caregivers provided care to both cognitively impaired and cognitively intact elderly CRs. In short, the sample represents a diverse set of caregivers; nevertheless, because participation was voluntary, the results should be generalized with caution.

Do Pre-Transition Depressive Symptoms Differ Among Caregivers Who Continue to Provide In-Home Care and Those Who Experience a Transition?

It should be noted that at baseline (i.e., pre-transition) assessment, depressive symptoms of caregivers who would experience a transition during the course of the study did not differ from a control group of continuing caregivers drawn from the same study. This finding indicates that transitioned caregivers were no more depressed than the general informal caregiving group that continued to provide in-home care. It might be argued that those caregivers who would eventually experience a transition had reached a peak level of CR illness and care-related stress at the time of pre-transition assessment; indeed, these caregivers reported significantly more ADL assistance and activity restriction at baseline. However, these differences did not influence

depressive symptoms when controlled in analysis of covariance. Furthermore, the finding of no difference in pre-transition depression strengthens the argument for an association between experiencing a transition and declining mental health, which I found in subsequent analyses.

Do Informal Caregivers' Depressive Symptoms Change After CR Nursing Home Placement or CR Death?

Previous studies demonstrate a non-linear pattern of caregiver depression following the death of an elder CR, with symptoms reaching their highest point in the first few months of bereavement, then declining to pre-death levels and continuing to decline after one to two years (e.g., Chentzova-Dutton et al., 2002; CSHAWG, 2002; Grant et al., 2002; Schulz et al., 2003). My results reflect this pattern, as demonstrated by the significant increase in mean depressive symptoms for all transitioned caregivers from pre- to post-placement assessment. My initial hypothesis (that, at the aggregate level, depressive symptoms would decrease slightly over this time period) was based on assumptions concerning data collection procedures. Specifically, in the FRILL1 sub-sample, transition data collection began in the third year of the 3-year study, and many caregivers were not approached to participate immediately following the transition. I expected this to create a positively skewed sample (i.e., one in which most participants had transitioned anywhere from 12 to 24 months before being interviewed). However, participation by transitioned FRILL2 caregivers (who, as part of the study protocol, were tracked at 3-month intervals to maintain updated records of their status) was higher than I expected. The result was a sample whose distribution of time since transition was actually negatively skewed. In this regard, a finding of a significant increase in mean depressive symptoms is not surprising and, indeed, what I would expect to find in other samples of similar structure. To summarize, there was a

significant short-term increase in post-transition caregiver depressive symptoms when the CR nursing home placement and CR death caregiver groups were examined together.

This study allowed for mean-level comparisons between caregivers who experienced CR nursing home placement and those who experienced CR death. Baseline (pre-transition) comparisons revealed significant differences between these groups on one key study variable: Caregivers who sought nursing home placement for their CR were more likely than bereaved caregivers to have been providing care for someone diagnosed with a disorder that causes memory problems such as AD or other dementia. When I examined pre- to post-transition differences across the two caregiver groups, CR dementia status moderated the change in depressive symptoms. Specifically, among caregivers of deceased CRs, depressive symptoms increased only if the CR was not diagnosed with dementia, whereas among caregivers of institutionalized CRs, symptoms increased only if the CR was diagnosed with dementia. I expect that this interaction occurred because, regardless of the type of transition that ensues, at baseline, dementia caregivers were more susceptible than non-dementia caregivers to increasing care-related stress as the disease progresses. Prior research on caregiver well-being strongly suggests that cognitive and behavioral problems associated with AD and dementia are especially troublesome and may be a deciding factor in nursing home placement and end-of-life decisions (e.g., Cohen, Gold, Shulman, et al., 1993; Kasper, Steinbach, & Andrews, 1994).

For dementia caregivers, death may not be entirely unexpected, or even unwelcome, if the disease is advanced. However, institutionalization of a demented CR may create additional stressors (e.g., caregivers consider themselves to be “committing” or giving up on CRs, or they may face considerable resistance from the CR during placement) and lead to a depletion of mental health resources as suggested by Bass and Bowman (1990) in their model of bereaved

caregivers. For non-dementia caregivers, CR death not be as predictable or may not be given full prior consideration; thus, the death creates a stronger disturbance in the social environment and in caregiver mental health. Furthermore, it is possible that non-dementia caregivers are in a more favorable position to seek CR consent for placement and allow a degree of CR autonomy during the placement process. In turn, this mutual decision-making may alleviate some of the stress and the associated negative mental health effects during and after institutionalization. In short, while the type of transition, in and of itself, may not influence change in caregiver depressive symptoms, factors such as the nature of pre-transition illness condition and associated CR reactions through the transition process may influence caregiver mental health. This reinforces Elder's (1994) concept of life course development, whereby adjustment to stress throughout the lifespan is sensitive to earlier life events that occur in multiple life settings. Within the context of family caregiving, it is important to view a transition on the family as linked to experiences that preceded the transition.

The results of this study also suggest that adaptation to nursing home placement and death of a care recipient are more similar than previously imagined. This is not to say that there are no differences in caregiver reactions to these two events. The competing models of caregiver adaptation proposed by Bass and Bowman (1990) were conceptualized as models of caregiver bereavement. To my knowledge, this research is the first to examine these models in the context of CR nursing home placement. However, the same measures were utilized to gather data from both caregiver groups, and, in many cases, there were no differences in caregiver responses based on the type of transition experienced. Some exceptions to this finding are discussed below, but there is sufficient evidence to suggest that similar methods and measurement instruments can be used to examine both transitions. The impact of CR nursing home placement on caregiver

well-being is not well-studied, perhaps because of the small proportion of elders who currently receive long-term skilled nursing care. However, population trends in aging and family structure suggest that a broad range of informal and formal care will be needed in the future.

How Are Caregiver and CR Background Characteristics, Pre-Illness Relationship Quality, Care-Related Stress, and Pre-Transition Mental Health Related to Post-Transition Caregiver Depressive Symptoms, Grief, and Relief?

Caregiver depressive symptoms. With regard to depressive symptoms, caregivers who reported poorer pre-transition physical health reported more post-transition depressive symptoms. The relation between physical and mental health is well-established in the caregiving and mental health literature, and my results suggest that pre-existing physical illness taxes both pre- and post-transition ability to cope. I expected spouses to express more depressive symptoms than non-spouses, and the association between these variables was in the predicted direction but was not significant. I also expected female caregivers to express more depressive symptoms than males, but the bivariate relationship suggested that males may have more difficulty adjusting. As expected, caregivers with higher pre-transition depressive symptoms report higher post-transition depressive symptoms, confirming the repeated measures analysis done here and thus the assertion that cessation of care does not automatically eliminate negative effects of the experience and that new stressors may take the place of stressors eliminated by the end of in-home care provision (e.g., Seltzer & Li, 2000).

My expectation that caregivers who experienced CR death would exhibit more depressive symptoms than those who experienced CR nursing home placement was partially supported. Type of transition interacted with CR dementia diagnosis such that bereaved caregivers of CRs without a diagnosis of dementia experienced the largest mean increase in depressive symptoms

over time. Based on previous research by Schulz and colleagues (2001), I expected caregivers who felt more strain (i.e., from ADL assistance, CR controlling behavior, and activity restriction) to be less, or at least no more, depressed after a transition. However, it was caregivers who reported more CR controlling behavior and more activity restriction who had more depressive symptoms after a transition. Schulz and colleagues categorized caregivers into strained and non-strained groups based on minimum cutoffs for amount of ADL assistance and presence or absence of physical and emotional strain as a result of ADL assistance; in contrast, I used continuous, interval-level measures of more diverse aspects of care-related stress, which could partially explain the difference in findings. It is important to note that these relations remained even after accounting for pre-existing depressive symptoms. Research based on the Caregiver Stress Process Model suggests that caregivers who experience more role strain and social isolation during in-home care adapt better after a caregiving transitions (e.g., Aneshensel et al., 1995; Collins, Liken, King, & Kokinakis, 1993; Norris & Murrell, 1990), but this was not the case in the present study. Instead, my results suggest an accumulation of stress through the transition and depletion of caregiver resources to protect themselves from further mental health difficulties (Bass & Bowman, 1990). Future studies will include multiple interviews with transitioned caregivers over a two-year period, which should allow more thorough examination of patterns of change in depressive symptoms over time.

The hypothesis that caregivers who reported a more mutually communal relationship with the CR (specifically in long-term interactions before taking on the caregiver role) would report more depressive symptoms following a transition was not supported; in fact, the bivariate correlation between these variables was in the opposite direction I expected. Finally, the significant interaction effect of type of transition with time in caregiver role on post-transition

symptoms of depression suggests that caregivers who are relatively “new” in their roles may experience the most mental health disruption following nursing home placement. This is not the case for bereaved caregivers, who have more difficulty adjusting to CR death regardless of the amount of time spent providing in-home care. The implication for this finding is that in terms of nursing home placement, caregivers who transition more rapidly through the entire caregiving career – i.e., role acquisition, role performance, and disengagement via institutionalization – may be more susceptible to negative mental health outcomes. Efforts should be made to identify and target these “rapid transitioners” for proactive mental health intervention.

Caregiver grief. The hypothesized model of post-transition caregiver grief accounted for nearly half of the variance in my sample. I hypothesized that females would experience more grief following either transition, but in fact males appear to have a more difficult time adjusting. Furthermore, over a third of the male caregivers were non-spouses, limiting the likelihood of complete confounding with kinship that one might expect (i.e., that male spouses were driving the relationship between gender and grief). This finding has substantial implications for interventions planning with end-of-life caregivers. Males clearly do not respond in the same manner as females to CR nursing home placement or death; therefore, the professional community should address their unique needs in terms of social support, anticipatory grief, post-bereavement counseling grief therapy, and post-transition adaptation.

As hypothesized, caregivers who resided with the CR prior to a transition and those with poorer self-rated health had stronger grief reactions. The relationship between pre-illness health and post-transition grief was similar to (but not as strong as) the relationship between health and depressive symptoms, supporting the argument for a link between physical health and susceptibility to negative reactions to stressful life events. Frequency of mutually communal

behavior between caregiver and CR, which I included to represent the overall historical quality of the relationship, was a significant predictor of caregiver grief. Caregivers who reported a history of “behaviors that are responsive to (or indicative of a desire to respond to) a partner’s needs (Williamson & Schulz, 1995)” responded more negatively to CR nursing home placement and death. In addition, more pre-transition depressive symptoms was a significant predictor of a stronger grief reaction. Depressive symptoms and grief were moderately correlated in this sample ($r = .46$). While these constructs undoubtedly share similar characteristics, it is clear from earlier research as well as from the present study that their relationship is a far from perfect and their associations with other care-related variables are quite dissimilar.

For example, caregivers in this sample who reported more challenging CR behavior and more restriction of normal activities experienced more depressive symptoms, but the only care-related stress variable associated with grief was in the opposite direction: *less* ADL assistance was associated with more caregiver grief. These results suggest that being less involved in assistance with daily care – whether because of geographical distance, relationship conflict, physical stamina, or some other, unknown reason – leaves former caregivers with feelings of guilt, regret, and/or dissatisfaction with how the caregiving relationship ended. Of course, another plausible explanation that cannot be ruled out is that assistance with ADLs does not adequately represent care-related stress, but this measure was significantly and positively correlated with the other care-related stress measures in the study. An important direction for future research is to examine similarities and differences between grief and depression in the context of caregiving transitions and to tease apart their immediate and long-term effects on one another. With that said, the present study is, to my knowledge, one of the first in the caregiving transitions literature to address this relationship between sub-clinical depression and grief.

Caregiver relief. Another important topic addressed in this study is the role of relief in adjustment to CR nursing home placement and death. Several studies have alluded to caregiver feelings of relief following a transition (Collins et al., 1993; Pruchno et al., 1995; Rosenthal & Dawson, 1991), but few have attempted to relate relief to pre-existing socio-demographic, care-related, or mental health factors. The relief scale used in this study examines caregiver perceptions of their own well-being and the well-being of the CR following a transition. The data confirmed my hypothesis that dementia caregivers experience a greater sense of relief after relinquishing care than non-dementia caregivers. A diagnosis of dementia was the strongest predictor of post-transition relief, reflecting the difficulties not only of providing care to a relative with this class of disorder, but also of watching the inevitable decline into profound mental impairment and inevitable death. Interestingly, caregivers who provided *less* assistance with ADLs feel a greater sense of relief following a transition. It is possible that the less involved caregivers are with the provision of care, the less invested they are in the relationship as a whole, and thus the more relieved they feel at relinquishing their role.

Another explanation for the relationship between less pre-transition ADL assistance and more post-transition relief emerges in the examination of the alternative measure of relief used in this study. This single item asks caregivers to rate their overall relief as a result of CR nursing home placement or death. The single-item measure and the relief scale were moderately but significantly correlated ($r = .47$), and I included the single-item measure in my analysis with hopes of gaining more insight into caregivers' global feelings of relief (i.e., feelings tied not to a specific aspect of the caregiving experience or a specific emotional reaction, but rather to the overall experience). Interestingly, the correlations of depressive symptoms and grief with the relief scale were noticeably lower than their correlations with the single item assessing overall

relief. I expect this was due to the content of the six-item scale, on which caregivers were asked to address specific aspects of relief; there might have been a tendency toward positive response bias on specific items (i.e., caregivers may not have been willing to admit that they felt relieved about not having primary responsibility for CR well-being). The single-item relief measure confirmed additional hypotheses and sheds light on the relationship between relief and grief, particularly at the bivariate level.

For example, as reflected in simple correlations, male caregivers expressed stronger grief reactions, but female caregivers expressed stronger overall relief. As with gender differences in grief, this suggests that although both males and females experience relief, gender differences exist in perceptions of personal well-being after a transition. Additionally, spouses reported stronger feelings of grief, whereas non-spouses and caregivers who did not live with the CR reported more relief. Also, caregivers with less education and lower income expressed more grief, whereas more highly educated and more financially affluent caregivers expressed more relief. Finally, caregivers who reported a more mutually communal pre-illness relationship with the CR reported more grief, whereas those with less frequent mutually communal relationships reported more relief. The relationship between mutually communal behavior and more overall relief was substantial but failed to reach significance in multivariate analysis ($p = .06$).

Nevertheless, the pattern that emerges from this data clearly illustrates how socioeconomic factors and investment in the relationship affect post-transition outcomes. Adult children – particularly those who are younger, better educated and more financially affluent – are less likely to live with the CR, more likely to be involved in time-consuming careers and child rearing, and likely to be less directly involved with the daily care of an elder CR. This level of involvement may or may not be intentional, but the correlations found in this study suggest that, at minimum,

there is a stronger feeling of relief among this more independent “sandwich generation” after relinquishing the role of primary caregiver.

Interestingly, overall relief was the only outcome that was directly influenced by which type of transition occurred; however, this effect was qualified by its interaction with pre-transition depressive symptoms (which also had a significant main effect on overall relief). The two caregiver groups respond differently depending on their pre-transition levels of depressive symptoms. In the CR nursing home placement group, more pre-transition depressive symptoms were associated with greater overall relief, whereas in the caregiver death group, more pre-transition depressive symptoms was associated with less overall relief. Although the magnitude of this interaction was relatively small, it was nonetheless significant and suggests that caregiver reactions to CR placement and CR death are moderated by prior level of depressive symptoms. This finding is not surprising when considered in light of Pearlin and colleagues’ (1990) Caregiver Stress Process Model, which asserts that the caregiving career involves an interchange between background characteristics, care-related stressors, mediating or moderating factors such as coping resources, and caregiver outcomes. In the case of overall relief, it is evident that predisposing factors and prior experiences interact with specific care related stressors (i.e., placement or death), to influence caregiver adaptation.

To summarize, the analyses of caregiver relief in this study breaks new ground by establishing the magnitude of relief following a transition, examining relations between grief and relief, and determining specific correlates of post-transition relief. The measures employed in the study produced similar, but not identical, results. Responses on the relief scale suggest caregivers with generally lower quality relationships with the CR feel relieved at relinquishing responsibility for CR well-being and regaining their pre-caregiving lives. Responses to the

single-item measure of overall relief suggest that relief is related to caregiver mental health, particularly depressive symptoms, and that CR death may heap further stress on caregivers whereas CR nursing home placement may eliminate some of the feelings of being overwhelmed and helplessness associated with a depressive disorder. It is clear that further studies should incorporate both types of measure in order to clarify the nature of post-transition relief. The similarities and differences between these measures is undoubtedly a topic to address in future research.

Limitations and Future Directions

Unfortunately, the current structure of the data precluded testing longitudinal hypotheses across continuing and transitioned caregivers. Even when considering only the caregiver transition groups, a two time-point model precluded any causal inferences regarding changes in or prediction of individual differences in depressive symptoms, grief, and relief. Future research should incorporate multiple assessment points, including pre- and post- transition data, in order to examine trends in caregiver outcomes over time and test non-linear models of change. These types of analyses will provide more detailed insight into how changes in predictor variables (e.g., employment status, physical health, activity restriction) relate to changes in mental health and emotional outcomes in former caregivers.

Another limitation is the number of caregivers ($n = 26$) who experienced CR nursing home placement. There have been very few studies of the emotional and mental health effects of institutionalization, or of pre-transition factors that contribute to individual differences in post-placement caregiver outcomes. As the rate of CR nursing home placement increases over the course of the FRILL2 study, it will be interesting to learn the extent to which the current regression models of depressive symptoms, grief, and relief can be replicated in a larger sample

with a more equal distribution across the two caregiver transition groups. If possible, models for each caregiver transition group will be tested separately to confirm the patterns of adjustment evidenced in the current sample.

An important line of future research will involve systematic examination of the similarities and differences between each of the outcomes studied here. Depression, a more global mental health syndrome, and grief, an emotional reaction to a specific life stressor have commonalities, but their underlying meaning has traditionally been interpreted quite differently (e.g., Rando, 1984; Wolfelt, 1992). Factor analyses of the grief scale and further comparisons with the CES-D are necessary in order to confirm the unique characteristics of these measures and to examine the relationship between these constructs at the latent variable level. Systematic examination of underlying constructs also is needed to clarify the relation between grief and relief. It is evident from this study that grief and relief are negatively correlated, but there still is much to be learned about the impact that such emotional ambiguity has on long-term caregiver well-being. For example, it is not clear whether feelings of relief buffer or exacerbate the emotional and physical effects of grief. Understanding the circumstances and implications of simultaneously feeling grief and relief following a caregiving transition should be useful in applied clinical and counseling settings in terms of emotional conflict resolution and during post-bereavement recovery.

Population trends strongly suggest that responsibility for end of life care will increasingly fall upon family members, and it is important that the experiences of informal caregivers be studied in context. Services and housing options for older adults suggest that in-home caregivers are likely to go through several care-related transitions, eventually culminating in CR death. The present study was limited to examining caregivers after CR placement in skilled nursing care and

CR death, but more research is needed to assess adjustment to various levels of formal care services (i.e., in-home nursing care, assisted living, specialized dementia care, and hospice).

The growing body of research on the caregiving career strongly suggests that both positive and negative outcomes occur during the course of taking responsibility for another individual's physical well-being, seeing that individual decline toward chronic or terminal illness, and eventually witnessing that individual's institutionalization and/or death. In order to properly address the physical, social, economic, and mental health needs of the growing informal caregiver population, researchers must continue to take a life-course perspective on care provision. This study was one of the first to examine pre-existing relationship quality as a potential factor in post-transition caregiver outcomes; the results indicate that beyond the effects of caregiver age, health, or socioeconomic status, life-long family relationships play a critical role in determining responses to late-life events. It is equally clear that a wide range of individual differences converge to produce both positive and negative responses to caregiving transitions.

Improved identification and prevention of risk factors associated with poor adjustment to these transitions will be essential to reducing both immediate and long-term problems incumbent in relinquishing the caregiver role. This research illustrates how some caregivers suffer greatly from the experience, carrying burden from the caregiver role well beyond the cessation of care. Other caregivers thrive under the stress and gain valuable personal growth from their experiences. Still others experience a mixed bag of positive and negative outcomes that may lead to ambiguous feelings that are difficult to resolve. Taken as a whole, this research suggests that not everyone can, or should, become a full-time care provider. Before accepting the primary caregiver role, families must be encouraged to reflect on their individual and collective abilities to provide adequate care to an elderly relative. Decisions that may seem unfeeling or unkind by

current social standards should nevertheless be considered in light of the potential consequences that those decisions will have on the long-term health and well-being of both receivers and providers of care.

REFERENCES

- Agency for Healthcare Research and Quality (2000). *Long-term care users range in age and most do not live in nursing homes: Research alert*. Rockville, MD: Agency for Healthcare Research and Quality, Rockville, MD.
- Aldwin, C. M., (1994). *Stress, coping, and development: An integrative perspective*. New York: Guilford Press.
- Alspaugh, M. E. L., Stephens, M. A. P., Townsend, A. L., Zarit, S. H., & Greene, R. (1999). Longitudinal patterns of risk for depression in dementia caregivers: Objective and subjective primary stress as predictors. *Psychology and Aging, 14*, 34-43.
- 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.
- Anthony-Bergstone, C. R., Zarit, S. H., & Gatz, M. (1988). Symptoms of psychological distress among caregivers of dementia patients. *Psychology and Aging, 3*, 245-248.
- Barber, C. E. (1993). Spousal care of Alzheimer's disease patients in nursing home versus in-home settings: Patient impairment and caregiving impacts. *Clinical Gerontologist, 12*, 3-30.
- Bass, D. M., & Bowman, K. (1990). The transition from caregiving to bereavement: The relationship of care-related strain and adjustment to death. *Gerontologist, 30*, 35-42.
- Bass, D. M., Bowman, K., & Noelker, L. S. (1991). The influence of caregiving and bereavement support on adjusting to an older relative's death. *Gerontologist, 31*, 32-42.

- 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.
- Beery, L. C., Prigerson, H. G., Bierhals, A. J., Santucci, L. M., Newsom, J. T., Maciejewski, P. K., et al. (1997). Traumatic grief, depression, and caregiving in elderly spouses of the terminally ill. *Omega: Journal of Death and Dying, 35*, 261-279.
- Bernard, L. L., & Guarnaccia, C. A. (2002). Husband and adult-daughter caregivers' bereavement. *Omega: Journal of Death and Dying, 45*, 153-166.
- 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. *Gerontologist, 43*, 808-816.
- Biegel, D. E., Sales, E., & Schulz, R. (1991). *Family caregiving in chronic illness: Alzheimer's disease, cancer, heart disease, mental illness, and stroke*. Thousand Oaks, CA: Sage.
- Bodnar, J. C., & Kiecolt-Glaser, J. K. (1994). Caregiver depression after bereavement: Chronic stress isn't over when it's over. *Psychology and Aging, 9*, 372-380.
- 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.
- Bradburn, N. M. (1969). *The structure of psychological well-being*. Oxford, England: Aldine.
- Breckenridge, J. N., Gallagher, D., Thompson, L. W., & Peterson, J. (1986). Characteristic depressive symptoms of bereaved elders. *Journal of Gerontology, 41*, 163-168.
- Brody, E. M., Dempsey, N. P., & Pruchno, R. A. (1990). Mental health of sons and daughters of the institutionalized aged. *Gerontologist, 30*, 212-219.

- Buck, D., Gregson, C. H., Bamford, P., McNamee, K., Wright, K., & Bond, J. (2000). Psychological morbidity among informal caregivers of older people: A 2-year follow-up study. *Psychological Medicine*, 30, 943-955.
- Burton, L. C., Zdaniuk, B., Schulz, R., Jackson, S., & Hirsch, C. (2003). Transitions in spousal caregiving. *Gerontologist*, 43, 230-241.
- The Canadian Study of Health and Aging Working Group (CSHAWG) (2002). Patterns and health effects of caring for people with dementia: The impact of changing cognitive and residential status. *Gerontologist*, 42, 643-652.
- Chentsova-Dutton, Y., Shacter, S., Hutchin, S., Strause, L., Burns, K., Dunn, L., Miller, M., & Zisook, S. (2002). Depression and grief reactions in hospice caregivers: From pre-death to 1 year afterwards. *Journal of Affective Disorders*, 69, 53-60.
- Cohen, C. A., Gold, D. P., Shulman, K. I., Wortley, J. T., McDonald, G., & Wargon, M. (1993). Factors predicting the decision to institutionalize dementing individuals: A prospective study. *Gerontologist*, 33, 714-720.
- Cohen, D., & Eisdorfer, C. (1988). Depression in family members caring for a relative with Alzheimer's disease. *Journal of the American Geriatrics Society*, 36, 885-889.
- 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.
- Collins, C., Stommel, M., Wang, S., & Given, C. W. (1994). Caregiving transitions: Changes in depression among family caregivers of relatives with dementia. *Nursing Research*, 43, 220-225.
- Deimling, G. T., Bass, D. M., Townsend, A. L., & Noelker, L. S. (1989). Care-related stress: A comparison of spouse and adult-child caregivers in shared and separate households.

- Journal of Aging and Health, 1*, 67-82.
- Derogatis, L. R. (1974). The Hopkins symptom checklist: A self-report symptom inventory. *Behavioral Sciences, 19*, 1-15.
- Derogatis, L. R. (1983). *SCL-90-R administration, scoring, and procedures manual* (Vol. 2). Baltimore: Clinical Psychometric Research.
- Draper, B. M., Poulos, R. G., Poulos, C. J., & Ehrlich, F. (1996). Risk factors for stress in elderly caregivers. *International Journal of Geriatric Psychiatry, 11*, 227-231.
- Dura, J. R., Stukenberg, K. W., & Kiecolt-Glaser, J. K. (1990). Chronic stress and depressive disorders in older adults. *Journal of Abnormal Psychology, 99*, 284-290.
- Elder, G. H. (1994). Time, human agency, and social change: Perspectives on the life course. *Social Psychology Quarterly, 57*, 4-15.
- Esterling, B. A., Kiecolt-Glaser, J. K., Bodnar, J. C., & Glaser, R. (1994). Chronic stress, social support, and persistent alterations in the natural killer cell response to cytokines in older adults. *Health Psychology, 13*, 291-298.
- Family Circle and Kaiser Family Foundation (September, 2000). *The Family Circle/Kaiser Family Foundation national survey on health care and other elder care issues: Summary of findings and chart pack*. The Henry J. Kaiser Family Foundation, Menlo Park, CA.
- Gabriel, C. S. (2000). *Characteristics of elderly nursing home current residents and discharges: Data from the 1997 national nursing home survey. Advance data from vital and health statistics, No. 312*. Hyattsville, MD: National Center for Health Statistics.
- Gaugler, J. E., Zarit, S. H., & Pearlin, L. I. (1999). Caregiving and institutionalization: Perceptions of family conflict and socioemotional support. *International Journal of Aging and Human Development, 49*, 1-25.

Gallant, M. P., & Connell, C. M. (1998). The stress process among dementia spouse caregivers:

Are caregivers at risk for negative health behavior change? *Research on Aging*, 20, 267-297.

George, L. K., & Gwyther, L. P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *Gerontologist*, 26, 253-260.

Gilbar, O., & Ben-Zur, H. (2002). Bereavement of spouse caregivers of cancer patients.

American Journal of Orthopsychiatry, 72, 422-432.

Gold, D., 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, 10-16.

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, 477-486.

Grasel, E. (2002). When home care ends -- changes in the physical health of informal caregivers caring for dementia patients: A longitudinal study. *Journal of the American Geriatrics Society*, 50, 843-849.

Grau, L., Teresi, J., & Chandler, B. (1993). Demoralization among sons, daughters, spouses, and other relatives of nursing-home residents. *Research on Aging*, 15, 324-345.

Haley, W. E., Levine, E. G., Brown, S. L., & Bartolucci, A. A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers.

Psychology and Aging, 2, 323-330.

Hertzog, D., VanAlstine, J., Usala, P. D., Hultsch, D. F., et al. (1990). Measurement properties of the Center for Epidemiological Studies Depression Scale (CES-D) in older populations.

- Psychological Assessment*, 2, 64-72.
- Jöreskog, K. G., & Sörbom, D. (1993). *LISREL 8 User's Reference Guide*. Chicago: Scientific Software.
- Kaplan, L., & Boss, P. (1999). Depressive symptoms among spousal caregivers of institutionalized mates with Alzheimer's: Boundary ambiguity and mastery as predictors. *Family Process*, 38, 85-103.
- Kasper, J. D., Steinbach, U., & Andrews, J. (1994). Caregiver role appraisal and caregiver tasks as factors in ending caregiving. *Journal of Aging and Health*, 6, 397-414.
- 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, 237-239.
- Kiecolt-Glaser, J. K., Dura, J. R., Speicher, C. E., Trask, O. J., & Glaser, R. (1991). Spousal caregivers of dementia victims: Longitudinal changes in immunity and health. *Psychosomatic Medicine*, 53, 345-362.
- King, S., Collins, C., Given, B., & Vredevoogd, J. (1991). Institutionalization of an elderly family member: Reactions of spouse and nonspouse caregivers. *Archives of Psychiatric Nursing*, 6, 323-330.
- Kramer, B. J. (2000). Husbands caring for wives with dementia: A longitudinal study of continuity and change. *Health and Social Work*, 25, 97-107.
- Kriegsman, D. M. W., Penninx, B. W. J. H., & van Eijk, J. T. M. (1994). Chronic disease in the elderly and its impact on the family: A review of the literature. *Family Systems Medicine*, 12, 249-267.
- Kubler-Ross, E. (1969). *On death and dying*. New York: Macmillan.
- Lazarus, R. S., & Folkman (1984). *Stress appraisal and coping*. New York: Springer.

- Lévesque, L., Cossette, S., & Lachance, L. (1998). Predictors of the psychological well-being of primary caregivers living with a demented relative: A 1-year follow-up study. *Journal of Applied Gerontology, 17*, 240-258.
- Lieberman, M. A., & Fisher, L. (2001). The effects of nursing home placement on family caregivers of patients with Alzheimer's disease. *Gerontologist, 41*, 819-826.
- Li, L. W., Seltzer, M. M., & Greenberg, J. S. (1999). Change in depressive symptoms among daughter caregivers: An 18-month longitudinal study. *Psychology and Aging, 14*, 206-219.
- Little, R. J. A., & Rubin, D. B. (1987). *Statistical analysis with missing data*. New York: John Wiley.
- Liu, K., Manton, K. G., & Aragon, C. (2000). Changes in home care use by disabled elderly persons: 1982-1994. *Journal of Gerontology: Social Sciences, 55B*, S245-253.
- Lund, D. A., Caserta, M. S., & Dimond, M. F. (1986). Gender differences through two years of bereavement among the elderly. *Gerontologist, 26*, 314-320.
- Martire, L. M., & Schulz, R. (2000). Informal caregiving to older adults: Health effects of providing and receiving care. In A. Baum, T. Revenson, & J. Singer (Eds.), *Handbook of health psychology* (pp. 477-493). Hillsdale, NJ: Erlbaum.
- Montgomery, R. J., & Kosloski, K. (1994). A longitudinal analysis of nursing home placement for dependent elders cared for by spouses vs. adult children. *Journals of Gerontology, 49*, S62-S74.
- Mullan, J. T. (1992). The bereaved caregiver: A prospective study of changes in well-being. *Gerontologist, 32*, 673-683.
- National Alliance for Caregiving and AARP (June, 1997). *Family caregiving in the U.S.:*

- Findings from a national survey*, National Alliance for Caregiving, Bethesda, MD.
- Nolan, M., & Dellasega, C. (1999). 'It's not the same as him being at home': Creating caring partnerships following nursing home placement. *Journal of Clinical Nursing*, 8, 723-730.
- 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. *Gerontologist*, 30, 583-594.
- Pinquart, M., & Sorensen, S. (2004). Associations of caregiver stressors and uplifts with subjective well-being and depressive mood: A meta-analytic comparison. *Aging and Mental Health*, 8, 438-449.
- Popek, P., & Scharlach, A. E. (1991). Adult daughters' relationships with their mothers and reactions to the mothers' deaths. *Journal of Women and Aging*, 3, 79-96.
- Pot, A. M., Deeg, D. J. H., & Van Dyck, R. (1997). Psychological well-being of informal caregivers of elderly people with dementia: Changes over time. *Aging & Mental Health*, 1, 261-268.
- Prigerson, H. G., Frank, E., Kasl, S. V., Reynolds, C. F. III, Anderson, B., Zubenko, G. S., Houck, P. R., George, C. J., & Kupfer, D. J. (1995). Complicated grief and bereavement-related depression as distinct disorders: Preliminary empirical validation in elderly bereaved spouses. *American Journal of Psychiatry*, 152, 22-30.
- Prigerson, H. G., Bierhals, A. J., Kasl, S. V., Reynolds, C. F. III, Shear, M. K., Newsom, J. T., & Jacobs, S. (1996). Complicated grief as a disorder distinct from bereavement-related depression and anxiety: A replication. *American Journal of Psychiatry*, 153, 1484-1486.
- Pruchno, R. A., Michaels, J. E., & Potashnik, S. L. (1990). Predictors of institutionalization among Alzheimer disease victims with caregiving spouses. *Journals of Gerontology*, 45, S259-S266.

- Prucho, 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.
- Radloff, L. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385-401.
- Rando, T. A. (1984). *Grief, dying, and death: Clinical interventions for caregivers*. Champaign, IL: Research Press.
- Redinbaugh, E. M., MacCallum, R. C., & Kiecolt-Glaser, J. K. (1995). Recurrent syndromal depression in caregivers. *Psychology and Aging, 10*, 358-368.
- The Resource Implications Study Group of the MRC Study of Cognitive Function and Ageing (RIS MRC CFAS) (2000). Psychological morbidity among informal caregivers of older people: A 2-year follow-up study. *Psychological Medicine, 30*, 943-955.
- Riddick, C. C., Cohen-Mansfield, J., Fleshner, E., & Kraft, G. (1992). Caregiver adaptations to having a relative with dementia admitted to a nursing home. *Journal of Gerontological Social Work, 19*, 51-75.
- Robinson-Whelen, S., Tada, Y., MacCallum, R. C., McGuire, L., & Kiecolt-Glaser, J. K. (2001). Long-term caregiving: What happens when it ends? *Journal of Abnormal Psychology, 110*, 573-584.
- 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.
- Rudd, M. G., Viney, L. L., & Preston, C. A. (1999). The grief experienced by spousal caregivers of dementia patients: The role of place of care of patient and gender of caregiver. *International Journal of Aging and Human Development, 48*, 217-240.
- Russo, J., Vitaliano, P. P., Brewer, D. D., Katon, W., & Becker, J. (1995). Psychiatric disorders

- in spouse caregivers of care recipients with Alzheimer's disease and matched controls: A diathesis-stress model of psychopathology. *Journal of Abnormal Psychology*, 104, 197-204.
- Sanders, C. M. (1993). Risk factors in bereavement outcome. In M. S. Stroebe and W. Stroebe (Eds.), *Handbook of bereavement: Theory, research, and intervention* (pp. 255-267). New York: Cambridge University Press.
- Sanders, C., & Mauger, P. (1979). *A manual for the Grief Experience Inventory*. Tampa: University of Florida, Loss and Bereavement Resource Center, Aging Studies Program.
- Schaffer, J. L., (1999). Multiple imputation: A primer. *Statistical Methods in Medical Research*, 8, 3-15.
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects study. *JAMA: Journal of the American Medical Association*, 282, 2215-2219.
- Schulz, R., Beach, S. R., Lind, B., Martire, L. M., Zdaniuk, B., Hirsch, C., Jackson, S., & Burton, L. (2001). Involvement in caregiving and adjustment to death of a spouse. *JAMA: Journal of the American Medical Association*, 285, 3123-3129.
- Schulz, R., Mendelsohn, A. B., Haley, W. E., Mahoney, D., Allen, R. S., Zhang, S., Thompson, L., & Belle, S. H. (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *The New England Journal of Medicine*, 349, 1936-1942.
- Schulz, R., Newsom, J., 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.

- Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of Alzheimer's disease caregiving: Prevalence, correlates, and causes. *Gerontologist, 35*, 771-791.
- Schulz, R., Visintainer, P., & Williamson, G. M. (1990). Psychiatric and physical morbidity effects of caregiving. *Journal of Gerontology, 45*, 181-191.
- Scott, W. K., Edwards, K. B., & Davis, D. R., Cornman, C. B., & Macera, C. A. (1997). Risk of institutionalization among community long-term care clients with dementia. *Gerontologist, 37*, 46-51.
- Select Committee on Aging, U.S. House of Representatives (1987). *Exploding the Myths: Caregiving in America*. Washington, DC: U.S. Government Printing Office
- Seltzer, M. M., & Li, L. W. (2000). The dynamics of caregiving: Transitions during a three-year prospective study. *Gerontologist, 40*, 165-178.
- Steinmetz, S.K. (1988). *Duty bound: Elder abuse and family care*. Newbury Park, CA: Sage.
- Stephens, M. A. P., Kinney, J. M., & Ogrocki, P. K. (1991). Stressors and well-being among caregivers to older adults with dementia: The in-home versus nursing home experience. *Gerontologist, 31*, 217-223.
- Stephens, M. A. P., Ogrocki, P. K., & Kinney, J. M. (1991). Sources of stress for family caregivers of institutionalized dementia patients. *Journal of Applied Gerontology, 10*, 328-342.
- Stull, D. E., Cosbey, J., Bowman, K., & McNutt, W. (1997). Institutionalization: A continuation of family care. *Journal of Applied Gerontology, 16*, 379-402.
- 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.
- U.S. Census Bureau. (2001). *The 65 years and over population: 2000* (Census 2000 Brief C2KBR/01-10). Washington, DC: Author.
- Vitaliano, P. P., Russo, J., Scanlan, J. M., & Greeno, C. G. (1996). Weight changes in caregivers of Alzheimer's care recipients: Psychobehavioral predictors. *Psychology and Aging*, 11, 155-163.
- Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, 129, 946-972.
- Wells, Y. D., & Kendig, H. L. (1997). Health and well-being of spouse caregivers and the widowed. *Gerontologist*, 37, 666-674.
- Wheaton, B. (1990). Life transitions, role histories, and mental health. *American Sociological Review*, 55, 209-223.
- Whitlatch, C. J., Feinberg, L. F., & Stevens, E. J. (1999). Predictors of institutionalization for persons with Alzheimer's disease and the impact on family caregivers. *Journal of Mental Health and Aging*, 5, 275-287.
- Whitlatch, C. J., Schur, D., Noelker, L. S., Ejaz, F. K., & Looman, W. J. (2001). The stress process of family caregiving in institutional settings. *Gerontologist*, 41, 462-473.
- Williamson, G. M., Martin-Cook, K., Weiner, M. F., Svetlik, D. A., Saine, K., Hynan, L. S., Dooley, W. K., & Schulz, R. (2005). Caregiver resentment: Explaining why care recipients exhibit problem behavior. *Rehabilitation Psychology*, 50, 215-223.
- Williamson, G. M., & Schulz, R. (1995). Caring for a family member with cancer: Past communal behavior and affective reactions. *Journal of Applied Social Psychology*, 25, 93-116.

- 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.
- Williamson, G. M., Shaffer, D. R., & The Family Relationships in Late Life Project (2000). Caregiver loss and quality of care provided: Preillness relationship makes a difference. In J. H. Harvey & E. D. Miller (Eds.), *Loss and trauma: General and close relationship perspectives*. Philadelphia: Brunner/Mazel.
- Williamson, G. M., Shaffer, D. R., & The Family Relationships in Late Life Project (2000). Relationship quality and potentially harmful behaviors by spousal caregivers: How we were then, how we are now. *Psychology and Aging, 16*, 217-226.
- Wolfelt, A. D., (1992). *Understanding grief: Helping yourself heal*. Levittown, PA: Accelerated Development.
- Wortman, C. B., & Silver, R. C. (1989). The myths of coping with loss. *Journal of Consulting and Clinical Psychology, 57*, 349-357.
- Wortman, C. B., & Silver, R. C. (2001). The myths of coping with loss revisited. In M. S. Stroebe & R. O. Hansson (Eds.), *Handbook of bereavement research: Consequences, coping, and care*. Washington, DC: American Psychological Association.
- Wright, L. K. (1994). AD spousal caregivers: Longitudinal changes in health, depression, and coping. *Journal of Gerontological Nursing, ??(??)*, 33-48.
- Zarit, S. H., & Whitlatch, C. J. (1992). Institutional placement: Phases of the transition. *Gerontologist, 32*, 665-672.
- Zisook, S., & Shuchter, S. R. (1993). Uncomplicated bereavement. *Journal of Clinical Psychiatry, 54*, 365-372.

APPENDIX

SCALES EMPLOYED IN THE STUDY

Mutual Communal Behavior Scale. The following statements have to do with the type of interactions you had with (care recipient) BEFORE he/she became ill. For each statement, please indicate which response you feel most accurately describes how you and (care recipient) interacted before his/her illness.

1. Never
2. Sometimes
3. Often
4. Always

1. If she/he was feeling bad, I tried to cheer her/him up.
2. She/he seemed to enjoy responding to my needs.
3. She/he did things just to please me.
4. When she/he had a need, she/he turned to me for help.
5. She/he went out of her/his way to help me.
6. She/he responded to my needs.
7. I enjoyed helping her/him.
8. I went out of my way to help her/him.
9. When making a decision, I considered her/his needs and feelings.
10. She/he would have done almost anything for me.

ADL Checklist. These next questions concern how much assistance YOU give (care recipient) in certain activities.

0. Care recipient never did this
 1. I do not help with this
 2. I help less than half the time
 3. I help about half the time
 4. I help more than half the time
 5. Complete help, I do this for him/her all the time
-
1. Bathing or showering
 2. Dressing
 3. Eating
 4. Getting in and out of bed or chairs
 5. Walking or using wheelchair
 6. Getting outside
 7. Using the toilet, including getting to the bathroom on time
 8. Transporting to places out of walking distance
 9. Personal grooming (wash face, shave, comb hair, brush teeth)
 10. Taking medications
 11. Laundry
 12. Preparing meals
 13. Shopping for items that people usually shop for themselves (clothing, toiletries, etc.)
 14. Managing money (such as keeping track of expenses or paying bills)
 15. Taking care of personal business (insurance claims, taxes, etc.)
 16. Using the telephone
 17. Doing heavy work (such as scrubbing floors, mowing lawn)
 18. Doing light work (such as doing dishes, straightening up)

Care Recipient Controlling Behavior. Next, I'm going to ask you some questions about behaviors that people sometimes use in attempts to control things or get their own way. In the last month, how often has (care recipient) behaved in each of these ways?

- 0 = Never
- 1 = Almost never
- 2 = Sometimes
- 3 = Almost always
- 4 = Always

1. Screamed or yelled
2. Pouted or withdrawn to his/her room
3. Refused to eat or spit out food
4. Refused or spit out medication
5. Refused medical treatment
6. Manipulated family members (caused trouble between family members for his/her own Purposes
7. Cried in an attempt to control things or get his/her own way
8. Hit, slapped, or thrown things
9. Used his/her illness to gain control
10. Called police or other help for imagined threats
11. Tried to make you feel guilty, acted like a martyr
12. Didn't respect your opinions
13. Was self-centered (e.g., thought only of him/herself)
14. Invaded your privacy

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.

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

- 1. Caring for yourself
- 2. Caring for others
- 3. Doing household chores
- 4. Going shopping
- 5. Visiting friends
- 6. Working on hobbies
- 7. Sports and recreation
- 8. Going to work
- 9. Maintaining friendships

Center for Epidemiological Studies Scale – Depression (CES-D). 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 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."

Caregiver Grief. Each of the following statements may or may not reflect your true beliefs and feelings. For each statement, tell me which of the following responses is most appropriate.

- 0 = strongly disagree
- 1 = disagree
- 2 = neither agree nor disagree
- 3 = agree
- 4 = strongly agree

1. (Care recipient's) death/placement 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 a situation like this.
4. I didn't expect that I would have as hard a time adjusting to (care recipient's) death/placement as I did.
5. Life has lost its meaning.
6. Life seems empty and barren.
7. I feel as if I am '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) was taken/placed.
12. I cry when I think of (care recipient).
13. Since (care recipient's) death/placement, I have trouble having enough energy to get things done.
14. Since (care recipient's) death/placement, I have trouble controlling my grief.
15. Since (care recipient's) death/placement, I have trouble getting good advice or suggestions about how to manage this situation.
16. Since (care recipient's) death/placement, I have trouble because my physical or emotional health has changed for the worse.

Caregiver Relief. The following statements represent feelings that some caregivers experience after the death/nursing home placement of a relative or close friend. For each statement, please give the response that reflects your true feelings best.

- 1 = definitely true
- 2 = somewhat true
- 3 = somewhat false
- 4 = definitely false

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.

Overall Relief. 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/placement?