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University of Kentucky, katie.terhune@insightbb.com

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DEMENTIA CAREGIVING OUTCOMES:
THE IMPACT OF CAREGIVING ONSET, ROLE OCCUPANCY, AND
CARE-RECIPIENT DECLINE

DISSERTATION

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in Gerontology
at the University of Kentucky

By
Katherina Nikzad-Terhune
Lexington, KY

Director: Dr. Pamela B. Teaster,
Professor and Director
Graduate Center for Gerontology

2011

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ABSTRACT OF DISSERTATION

DEMENTIA CAREGIVING OUTCOMES: THE IMPACT OF CAREGIVING ONSET, ROLE OCCUPANCY, AND CARE-RECIPIENT DECLINE

Dementia is characterized as a progressive loss of brain function that results in the deterioration of many cognitive and physical abilities. Alzheimer's disease (AD) is the most common form of dementia, causing steady declines in memory, functional abilities, and mental functioning. With a projected increase of degenerative illnesses, such as AD, family caregiving for individuals with the disease is also steadily increasing. Caring for an individual with AD has been characterized as a "career," and within this career are a number of key transitions, including the onset of caregiving. Preexisting caregiving research reveals a number of negative consequences for AD family caregivers, including depression, overload, and physical health complications. The purpose of this study was to examine how different patterns of caregiving onset (gradual and abrupt) and role occupancy (how many roles the caregiver is holding) impact mental health and physical health outcomes for AD caregivers. This study also explored how cognitive decline and behavioral problems found within the care-recipient have the potential to moderate these relationships.

Cross-sectional, quantitative data from one hundred participants completing self-administered surveys was used in this study. A series of one-way ANOVAS and multiple regression analyses were conducted to address the study's aims. Results indicated that care-recipient cognition and behavioral problems moderated the relationship between caregiving onset and mental health outcomes, including depression, role overload, and role captivity for caregivers who experienced a more abrupt entry into the caregiving role. Results suggest the importance of considering moderating factors within the caregiving career, as well as different caregiving onset transitions. Clinical implications of the findings are discussed, as well as directions for future research, including prospective caregiving research.

KEYWORDS: Alzheimer's disease, caregiving, onset, roles, outcomes

Student's Signature

Date

DEMENTIA CAREGIVING OUTCOMES:
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CARE-RECIPIENT DECLINE

By

Katherina Nikzad-Terhune

Pamela B. Teaster, Ph.D.
Director of Dissertation

Graham D. Rowles, Ph.D.
Director of Graduate Studies

October 14, 2011

This dissertation is dedicated to my husband and best friend, Jon Terhune,
and to my parents and dear friends, Arsalan Nikzad and Jane Leonard.

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CHAPTER ONE

An Introduction to Dementia Caregiving

Introduction and Purpose of Study

Dementia caregiving is a widely recognized societal phenomenon that impacts the lives of both caregivers and care-recipients. Providing care for an individual with a dementia diagnosis is a dynamic and intricate process, one that involves many transitions, changes, and forms of adaptation. Additional research within the realm of dementia caregiving is especially warranted due to societal increases in both caregiving and the prevalence of degenerative disorders that transpire as populations age (Hebert, Scherr, Bienias, Bennett, & Evans, 2003; Querfurth & LaFerla, 2010). As a result of biomedical advances that have led to the aging of the U.S. population across diverse racial and ethnic contexts, the numbers of those living in the United States who are ages 65 and older is projected to increase from 35-82 million in the first half of the 21st century (Angel & Hogan, 2004). Biomedical advances have also allowed many individuals to live longer with chronic illnesses, such as dementia, which will ultimately and significantly impact the nature of caregiving.

Family Caregiving and Alzheimer's Disease

Family caregivers have been the focus of much attention over the years due to the increasing number of individuals who provide care for a relative/friend and the substantial increases in degenerative illnesses, such as dementia. Dementia is characterized as a progressive loss of brain function that results in the deterioration of many cognitive, physical, emotional, and functional abilities. There are currently over 100 different types of dementia, with Alzheimer's disease (AD) being the most rapidly

increasing form. With a projected increase of degenerative illnesses such as AD, family caregiving for individuals with dementia is also steadily increasing. Nearly 11 million Americans provide unpaid care for persons with AD or another form of dementia. These unpaid caregivers are primarily family members, but many are friends. In 2009, caregivers provided an estimated 12.5 billion hours of unpaid care, totaling approximately \$144 billion (National Alliance for Caregiving/American Association of Retired Persons (AARP) Survey on Caregiving in the United States, 2009). Caregivers of individuals with AD, on average, provide more hours of care than individuals caring for other older adults (National Alliance for Caregiving/AARP Survey on Caregiving in the United States, 2009).

AD caregiver demographics.

Women comprise approximately 60 percent of family and other unpaid caregivers of individuals with AD and other dementias (MetLife Mature Market Institute, 2006). The 2009 National Alliance for Caregiving (NAC)/AARP survey on caregiving in the United States found that 94 percent of dementia caregivers provide care for a relative, including caring for a parent or parent-in-law (62%), a grandparent (17%), a spouse (6%) or another relative (9%). The remaining 6 percent of caregivers care for friends. This survey also revealed that 21 percent of dementia caregivers lived in the same household as their care-recipient(s) (The National Alliance for Caregiving/AARP Survey on Caregiving in the United States, 2009).

In regard to age, caregivers may range from very young to very old. Results of the 2009 NAC/AARP survey found that 14 percent of dementia caregivers were under age 35. Results also revealed that 26 percent were between the ages of 35–49; 46 percent

were between the ages of 50–64; and 13 percent were aged 65 and over. The average age of dementia caregivers is age 51 (The National Alliance for Caregiving/AARP Survey on Caregiving in the United States, 2009).

AD caregiving tasks.

The types and levels of help provided by family and other unpaid caregivers are dependent upon the specific needs of the person with AD and the changes that often occur as the disease progresses. Caregiving tasks can include instrumental activities of daily living (IADLs), including meal preparations, shopping, providing transportation, monitoring medication use, managing finances and legal issues, and providing supervision to ensure safety of the care-recipient. Caregiving tasks may also include activities of daily living (ADLs), such as bathing, dressing, feeding, toileting or managing incontinence, and managing behavioral symptoms. Findings from the 2009 NAC/AARP survey on caregiving showed that family caregivers of individuals with AD are more likely than caregivers of other older people to provide ADL assistance. In conjunction with ADL assistance, caregivers of individuals with AD are more likely than caregivers of other older people to arrange for services from outside agencies, and are more likely to advocate for their care-recipient (e.g., with service providers and government agencies) (The National Alliance for Caregiving/AARP Survey on Caregiving in the United States, 2009).

Duration of AD caregiving.

Due to the usually slow progression of AD, most caregivers spend many years in the caregiving role. The number of AD caregivers who have been providing care for five years or longer is estimated to be 32 percent. Of these individuals, 12 percent have been

providing care for 10 years or longer. An additional 43 percent have been providing care for one to four years, while 23 percent have provided care for less than one year.

Caregivers of older adults who do not have an AD diagnosis are more likely to provide care for less than one year (34 percent) (The National Alliance for Caregiving/AARP Survey on Caregiving in the United States, 2009).

It is well established that caregiving in the 21st century is now considered a life course role, with caregiving spanning many years when caring for an individual with a chronic neurodegenerative illness. Furthermore, as the population ages, the healthcare industry has placed greater emphasis on families providing care at home in an attempt to contain costs associated with long-term and palliative care (Family Caregiver Alliance, 2007). Home-based care may entail a great deal of economic, emotional, and psychological costs. Family caregivers must often relinquish time from work in order to spend a great deal of time per week providing care for care-recipients. Subsequently, caregivers are often subject to increased emotional health issues (e.g., depression), as well as physical health complications that they must address in the midst of their complex caregiving responsibilities (Pinquart & Sörensen, 2003a, 2003b). Additionally, services for family caregivers are likely to become more circumscribed due to the economy's focus on other concurrent and pressing issues (e.g., economic recession, war) (Family Caregiver Alliance, 2009). If society remains reliant on families for providing the majority of care for those living with chronic and neurodegenerative illnesses, then it is paramount that research on the needs and experiences of dementia caregivers through ongoing research continues.

Expanding beyond the economic and social ramifications of dementia caregiving, the caregiving phenomenon itself remains under-theorized and at times unpredictable. Gaps exist within the empirical and theoretical literature, especially in regard to the onset of dementia caregiving. Without a better understanding of the onset transition, we are at a disadvantage in regard to understanding subsequent caregiving transitions. Despite extensive research in family caregiving, inconsistencies continue to emerge concerning factors linked to the experiences of caregivers, including the outcomes they experience. For some, caregiving is a difficult experience resulting in serious negative consequences. For others, similar caregiving demands have little impact on their ability to maintain healthy coping and well-being and may even lead to positive outcomes. Because some dementia caregivers fare better than others, researchers have sought to map the factors that influence caregiver outcomes. The purpose of the present study is to contribute to the dementia caregiving literature by examining how differences in caregiving onset patterns and caregiver roles impact subsequent mental health and physical health outcomes experienced by AD caregivers. Furthermore, the present study aims to examine how care-recipient cognitive decline and behavioral problems, two prominent features of AD, moderate these relationships.

Specific Aims

In an attempt to address the gaps, both theoretical and empirical, in the dementia caregiving literature, and to obtain a better understanding of the implications of caregiving onset, an important transition within the caregiving career, the specific aims of this study are to:

Aim One. Determine how different sequences of caregiving onset affect subsequent mental health and physical health outcomes experienced by caregivers.

Sequences of caregiving onset can be determined by examining when caregivers actually begin providing care procedures (i.e., before or after symptom recognition or clinical diagnosis) and the time lag between such events. The notion of examining various sequences of caregiving onset is based upon findings from previous research indicating that caregivers who experience different types of entry into the caregiving role (e.g., gradual vs. abrupt) experience various caregiving outcomes (Gaugler et al., 2003a; 2003b). These findings will expand upon caregiving literature that examines sequences of caregiving onset.

Aim Two. Determine how multiple roles held by caregivers affect subsequent mental health and physical health outcomes experienced by caregivers.

Current literature regarding role occupancy suggests that certain roles held by caregivers during the time they are providing care procedures will produce variations in the level of benefits or harms that are brought about by that role (Waldron et al., 1998). Using the role theory framework (explained in the next chapter), this study explores which roles held by caregivers (i.e., employee, parent) during the time in which they are providing care procedures for an individual with AD are more likely to contribute to higher levels of distress experienced by the caregiver. Results from this study can help clarify contradictory findings found in much of the literature regarding caregiving and additional roles.

Aim Three. Examine variables within the caregiving context that serve as moderators in regard to mental health and physical health outcomes experienced by caregivers.

Although caregiving onset may play an important role in impacting subsequent outcomes for caregivers, its importance may be influenced by various moderating factors found within the caregiving context. For the purposes of this study, moderating variables explored will be the cognitive status of the care-recipient and the amount of behavioral problems exhibited by the care-recipient. Selection of these variables is determined based on their noted impact within the caregiving career as demonstrated through previous caregiving research (Gaugler, Davey, Pearlin, & Zarit., 2000; Zhang, Vitaliano, & Lin, 2006).

One specific caregiving transition that has received little attention is the onset of caregiving, the event(s), patterns, and timing in which an individual assumes intensive care responsibilities for a disabled loved one. Onset is a particularly important transition in the caregiving career, as the experience of caregiving onset may influence how families decide to manage and maintain caregiving roles over time. Thus, understanding how onset impacts caregiving outcomes is warranted. Because the caregiving career is multifaceted and complex, a host of other factors related to both the caregiver and care-recipient must also be considered when examining key mental and physical health outcomes for caregivers.

Significance of the Present Study

The present study expands on previous caregiving literature in three ways: (a) examining how different sequences of caregiving onset impact subsequent mental health

and physical health outcomes experienced by caregivers, (b) exploring how multiple roles held by caregivers affect subsequent mental health and physical health outcomes experienced by caregivers, and (c) examining variables within the caregiving context that serve as moderators in regard to mental health and physical health outcomes experienced by caregivers. Examining the caregiving onset transition more closely within the caregiving context can contribute to a more sophisticated understanding of the ramifications that this transition entails. Findings will emphasize the importance of considering timing when examining adaptation in informal long-term care. A need also exists to consider alternative explanations that diverge from earlier results suggesting that a longer duration of care can produce more negative outcomes for caregivers. Prior research has focused heavily on a “wear and tear” hypothesis when examining longitudinal effects of informal long-term care. Proposing that the sequencing of various onset events has the potential to impact caregiving outcomes and placing more emphasis on how caregivers enter their role responsibilities may be more beneficial than focusing solely on length of caregiving procedures by providing a more detailed picture of how the caregiving career progressed. Likewise, many caregiving interventions are administered later in the caregiving career once negative outcomes (e.g., burden, stress, lack of resources) have already occurred. Designing interventions that specifically target caregivers who may be more vulnerable to experiencing negative outcomes may either help prevent negative outcomes or mitigate later negative consequences as they occur. Focusing on caregiving onset may provide a stronger apparatus for designing interventions of this nature.

Investigating the impact of having multiple roles, while maintaining the dementia caregiving role, has generated mixed results in preexisting literature (Bainbridge, Cregan, & Kulik, 2006; Moen, Robinson, & Fields, 1994; Pavalko & Woodbury, 2000; Penning, 1998; Perkins, 2010). Since many dementia caregivers occupy various roles simultaneously (e.g., parent, employee, volunteer), understanding how these additional roles either benefit or exacerbate the caregiving experience is merited. Likewise, having a more accurate understanding of the impact of role occupancy during the dementia caregiving experience may lead to the development and implementation of more useful interventions for caregivers undergoing stress as a result of having multiple roles.

Additionally, this study examines moderating relationships found within the caregiving context. Moderating variables are those that influence the strength of a relationship between two other variables (Baron & Kenny, 1986). Examining moderating variables within the caregiving context offers new insights and explanations for various outcomes that may have once been attributed to examining only direct relationships. Because most existing research on caregiving and stress tends to examine direct relationships, it is also important to examine moderating variables when ascertaining the influence of key transitions and various components of the stress process on caregivers' emotional adaptation.

Finally, the majority of caregiving research has focused on negative implications of dementia caregiving. Unfortunately, positive outcomes of caregiving have largely been ignored and are not as well understood as negative outcomes. There are several areas of emotional satisfaction that caregivers may experience as a result of their caregiving career, including a strengthened relationship with the care-recipient, increased confidence

in abilities, and personal growth (Tarlow et al., 2004; Singer, 1996). Identifying different types of positive experiences that caregivers encounter in conjunction with stressful outcomes may offer a new perspective on existing literature that focuses heavily on the negative aspects of caregiving. This in turn may more adequately inform prevention and intervention strategies designed to meet the diverse needs of dementia caregivers.

This study utilizes cross-sectional, quantitative data from AD caregiving who completed self-administered surveys. This dissertation proceeds with literature reviews on the theoretical perspectives in dementia caregiving (Chapter Two), a review of the literature concerning the onset of dementia caregiving and caregiver roles (Chapter Three) and the impact of cognitive decline and behavioral problems on key caregiving outcomes (Chapter Four). Methods for data collection are detailed in Chapter Five. Key findings are presented in Chapters Six. Discussion and implications of the findings comprise Chapter Seven.

CHAPTER TWO

Theoretical Perspectives in Dementia Caregiving

Overview

Dementia caregiving has been a prominent focus in the literature for several decades, with various conceptual and theoretical foundations aspiring to understand the particular nature of caregiving, and to guide important caregiving research efforts. This chapter addresses background literature on extant theories and conceptual models related to the dementia caregiving career and the variation of experiences found within this career. The focus of this chapter is to first explore how dementia caregiving and the transitions found within this trajectory are conceptualized using principles of the life course and Caregiver Identity Theory. Second, this chapter provides a more in-depth analysis of two prominent frameworks germane to the realm of caregiving: Role Theory and the Stress Process Model.

The Caregiving Career

The long-term trajectory of chronic disabilities has led to the characterization of dementia family caregiving as a “career,” in which caregiving is no longer considered a discrete and static phenomenon but rather a construct involving phases and changes over time (Aneshensel et al., 1995; Pearlin & Aneshensel, 1994). Similar to how one would view the organizational structure of an occupational career, conceptualizing dementia caregiving as a career stems from its sequence of experiences, shifting responsibilities, and activities acquired by the caregiver as time progresses. In contrast with an occupational career, however, the caregiving career is far more ambiguous in regard to the timing in which specific transitions occur. For instance, when individuals embark upon a financially compensated career, they typically are aware of when and how they

will enter into that role. There tends to be clearly defined schedules and ranks within an occupational role, which are often quite imprecise within the caregiving career. The caregiving career is often unplanned, thus acquiring the expression “the unexpected career” in dementia caregiving literature (Aneshensel et al., 1995).

Transitions.

Years of observations (both empirical and qualitative) within the realm of dementia caregiving have revealed various stages within the caregiving career, each containing importance and its own distinctive forms of stress. Often found within the caregiving career are *transitions*, or movement from one status to another experienced by caregivers. A life course perspective (see Elder 1985; Hagestad & Neugarten, 1985; Price, Mckenry, & Murphy, 2000) conceptualizes transitions as distinct life changes, often associated with distinct events occurring within a trajectory. A trajectory is therefore conceptualized as a sequence of situations occurring within a defined range of behaviors or experiences (e.g., a career). A trajectory may include long-term periods of both stability and change, and numerous transitions. The timing of these transitions, also heavily emphasized within the life course framework, can impact the efficacy of the transition within a particular trajectory (e.g., becoming a dementia caregiver while still caring for young children at home). The life course posits that transitions occurring within a trajectory often lead to role changes, which may generate new societal norms and expectations. Moreover, transitions typically result in a change in status, social identity, and role involvement (Elder 1985; Moen, Elder, & Lüscher, 1995).

Expanding on changes in role involvement and social identity, the Caregiver Identity Theory (Montgomery & Kosloski, in press, Montgomery, Rowe, & Kosloski,

2007) views the caregiving career as a series of transitions that transpire due to changes occurring within the caregiving context (e.g., changes in the cognitive or functional status of the care-recipient). This theoretical notion surfaces from the belief that the caregiving role emerges from preexisting roles, including familial roles such as spouse or child. The caregiver thus carries this preexisting relationship, along with a set of beliefs and expectations regarding his/her obligation to provide care, into the caregiving situation. As the nature of caregiving changes as a result of increasing demands, the relationship between caregiver and care-recipient may also change. This can result in caregivers changing how they view their role in relation to their care-recipients. This *role identity* change takes place because the care required in order to maintain the well-being of the care-recipient is now inconsistent with the expectations related to the caregiver's initial role in relation to the care-recipient. For example, a son providing intensive care procedures for his cognitively disabled mother (i.e., bathing or toileting) does not conform to his initial role identity as her son. This incongruence has the potential to cause distress in the individual experiencing changes in his/her role identity (Montgomery & Kosloski, in press, Montgomery, Rowe, & Kosloski, 2007).

Many researchers suggest that subjective stress is a response to life events that challenges one's identity. In the context of caregiving, stressors may occur at each transition point, and as a result of an involuntary transformation of a familial relationship closely linked to one's identity. Each transition within the caregiving career has potentially important implications for family caregivers, including how they will respond and adapt to each transition and the outcomes they may experience during and after each transition (Aneshensel et al., 1995; Gaugler, Anderson, Zarit, & Pearlin, 2004; Schulz et

al., 2004; Whitlatch et al., 2001). To help elucidate how changes in one's roles and identity impact subsequent outcomes found within the caregiving career, the components of Role Theory, an important perspective in dementia caregiving, are further explored.

Role Theory

An important approach to investigating dementia caregiving is through the lens of Role Theory (Biddle, 1986; Moen, Erickson, & Dempster-McClain, 2000; Robbins, Chatterjee, & Canda, 2006; Schumacher, 1995; Waldron, Weiss, & Hughes, 1998).

Exposure to one particular stressor may lead to exposure to other secondary stressors over time. Referred to as "stress proliferation," this phenomenon is often seen within the caregiving career as new demands and new situations present themselves to caregivers and care-recipients. Components of Role Theory shed light specifically on whether or not multiple concurrent roles have the capacity to reduce or exacerbate caregiver stress.

Answers to this question rely heavily upon the type and content of the role acquired; the quality of the experience brought forth by a role; the perceived benefits of the role; and whether or not a role is anticipated, chosen freely, or obtained unexpectedly (Penning, 1998).

Role Theory posits that human behavior is guided by both expectations held by the individual and by expectations held by others. These expectations correspond to the different roles that are enacted in individuals' lives on a daily basis. People typically acquire and maintain multiple roles, which consist of a set of norms and rules that serve as a behavioral guide. Furthermore, roles indicate the goals that individuals pursue and the performances that are expected within a given situation. Role Theory upholds that much of observable human behavior is a result of what the individual is aware of in

regard to that particular role. For example, the role of a secretary, firefighter, or a father each has certain behavioral expectations and goals, thus these known expectations will guide behavior. Additionally, according to Role Theory in order to change behavior, it is necessary to change roles. Because roles correspond closely to behavior, they have a significant impact on beliefs and attitudes. Therefore, changes in beliefs and attitudes correspond with changes in roles (Biddle, 1986; Waldron, Weiss, & Hughes, 1998).

Sociological foundations and applications of role theory.

Contemporary Role Theory has evolved from two existing sociological concepts: a structural approach to social roles and symbolic interactionism. Structural theorists uphold the belief that scripts, containing norms and behaviors, are inherent in the social positions that exist within society. Consequently, an individual who occupies a particular role must follow this script by learning the appropriate behaviors and acting accordingly. In contrast, Symbolic Interactionism theorists maintain that although the notion of a “script” may provide broad guidelines for behavior, specific behaviors of human beings are contingent upon their interactions with others and the experiences they encounter. Thus, rather than acting according to a structured script, people have the potential to be creative and spontaneous in their roles and adapt to different situations (Moen, Erickson, & Dempster-McClain, 2000; Robbins, Chatterjee, & Canda, 2006; Schumacher, 1995).

Because both concepts offer valuable and insightful explanations, modern Role Theory emphasizes an integrated approach that blends the concepts maintained in both Structural Role Theory and Symbolic Interactionism. This integrated approach argues that Role Theory should encompass both the concepts of Structural Role Theory and Symbolic Interactionism because roles held by human beings reflect both a structured set

of expectations and individualistic qualities (Robbins, Chatterjee, & Canda, 2006; Schumacher, 1995).

Role Theory encompasses the following propositions:

1. People spend much of their lives participating as members of groups and organizations;
2. Within these groups, people occupy distinct positions;
3. Each of these positions entails a role, which is a set of functions performed by the person for the group;
4. Groups often formalize role expectations as norms or even codified rules, which include rewards that result when roles are successfully performed and what punishments will result when roles are not successfully performed;
5. Individuals usually carry out their roles and perform in accordance with prevailing norms. In other words, Role Theory assumes that people are primarily conformists who try to live up to the norms that accompany their roles;
6. Group members check each individual's performance to determine whether it conforms with the norms; the anticipation that others will apply sanctions ensures role performance.

(Adapted from Biddle, 1986)

Role enhancement and role strain.

More recently, Role Theory has evolved as a predominant framework for understanding how the multifaceted nature of caregivers' lives affects his/her subsequent health and well-being. Two prominent ideologies found within this framework are *role enhancement* and *role strain*, which are conceptualized as competing views explaining how role involvement affects an individual's life. Role enhancement posits that individuals who occupy more roles are likely to experience greater levels of well-being due to the augmentation of resources, prestige, support, and emotional fulfillment that

multiple roles provide. Alternatively, role strain posits that multiple demands placed on an individual as a result of too many roles will lead to negative consequences, such as role overload (not having enough time or resources to adequately manage multiple roles) and role conflict (conflicts in role expectations due to differing internal and external role expectations) (Moen, Robison, & Dempster-McClain, 1995; Mui, 1992; Rozario, Morrow-Howell, & Hinterlong, 2004). Research investigating the effects of the number of roles held by individuals has primarily supported the notion of role enhancement (e.g., Adelman, 1994, Moen, Dempster-McClain, & Williams, 1992). In conjunction with the concepts of role enhancement and role strain, role contexts also provide a framework with which to understand the beneficial and detrimental aspects of roles (Moen et al., 1992; Simon, 1995). In other words, examining the contexts in which roles are occurring is an essential principle of the theory.

In regard to dementia caregiving, the concepts of role enhancement and role strain become especially relevant in understanding the experiences of women caregivers who provide care for their own families, maintain employment, and assume the role of caregiver for an elderly or widowed parent. This notion of being “sandwiched” in the middle (Penning, 1998) holds significant implications because it posits that occupying multiple roles may intensify role related stress. Holding multiple roles may place individuals at risk for experiencing limited time, energy, and resources, thus prompting heightened psychological stress. This would be consistent with the role strain hypothesis embedded within role theory. Alternatively, others postulate that several benefits may arise from occupying multiple roles (Hong & Seltzer, 1995; Spitze & Logan, 1990; Stoller & Pugliesi, 1989). For example, multiple roles may provide caregivers with

additional supportive resources, self-esteem, and a heightened sense of self-efficacy. These outcomes would espouse the role enhancement hypothesis found within role theory.

Active participation.

Another important component of Role Theory is the notion of active participation. Active participation involves the levels of participation put forth by individuals in defining their role(s) and creating meaning for that role (Thoits, 1994). The importance of viewing individuals as “activists” within their own roles is key to understanding why some are likely to exit a particular role because of the harmful effects it produces.

Role Theory in relation to caregiving also draws attention to the nature of specific roles and to role combinations. Role theory posits that roles can be defined as the behavioral expectations assigned to a social position (Waldron et al., 1998). Moreover, the nature of this social position will produce variations in the level of benefits or harms that are produced by that role. In regard to this presumption, empirical research has revealed that roles such as marriage, volunteering, and employment often produce many benefits for individuals. Furthermore, empirical research has also shown that roles such as parenting often produce mixed effects for individuals within that role (Meneghan, 1989; Verbrugge, 1983; Waldron et al., 1998). Caregiving research has typically revealed that caring for an ill or disabled individual (in most cases, a family member) will have a negative impact on health and well-being (see reviews by Pinqart & Sørensen, 2003a, 2003b; Vitaliano, Zhang, & Scanlan, 2003). In contrast, more recent caregiving research has found that the positive aspects of caregiving have the potential to mitigate the harmful effects of caregiving (Pinqart & Sørensen, 2004; Tarlow et al., 2004).

Examining the permutations of active participation and the nature of a specific role offers insight into one of the most important questions that theorists seek: how do roles evolve and change over time? The evolving literature on caregiving has helped to conceptualize the notion of a role as a “career,” in which multiple stages are evident within that role. In regard to caregiving, the multiple stages of a role may include role acquisition, role enactment, and role disengagement (Aneshensel et al., 1995). Aneshensel and colleagues (1995) postulate that a role should not be conceptualized as a stable or static experience, but rather as a phenomenon that will alter throughout time. By examining roles in this manner, researchers can better account for changes in health and well-being that are often found within the caregiving career and how fluctuations occur during different stages.

Role Theory and the dynamics of its different components can be called upon to answer important questions dealing with the onset of the dementia caregiving role and beyond. For instance, Role Theory can be used to first address questions dealing with factors that influence who will be more likely to enter into the caregiving role (i.e., spouses, daughters, sons, daughter-in-laws, etc.) and how their outcomes will differ. Similarly, the theory helps explain how health and well-being differ among those who demonstrate different patterns of role entry (e.g., abrupt or gradual entry). Further, Role Theory provides a framework in which to determine the extent to which other roles act either as constraints or as buffers for managing the caregiving role (e.g., parenting and employment roles). Finally, the components of Role Theory can also be utilized to address questions dealing with which roles individuals are more likely to maintain or exit and whether or not it is possible for individuals to exit a role, even in the event that the

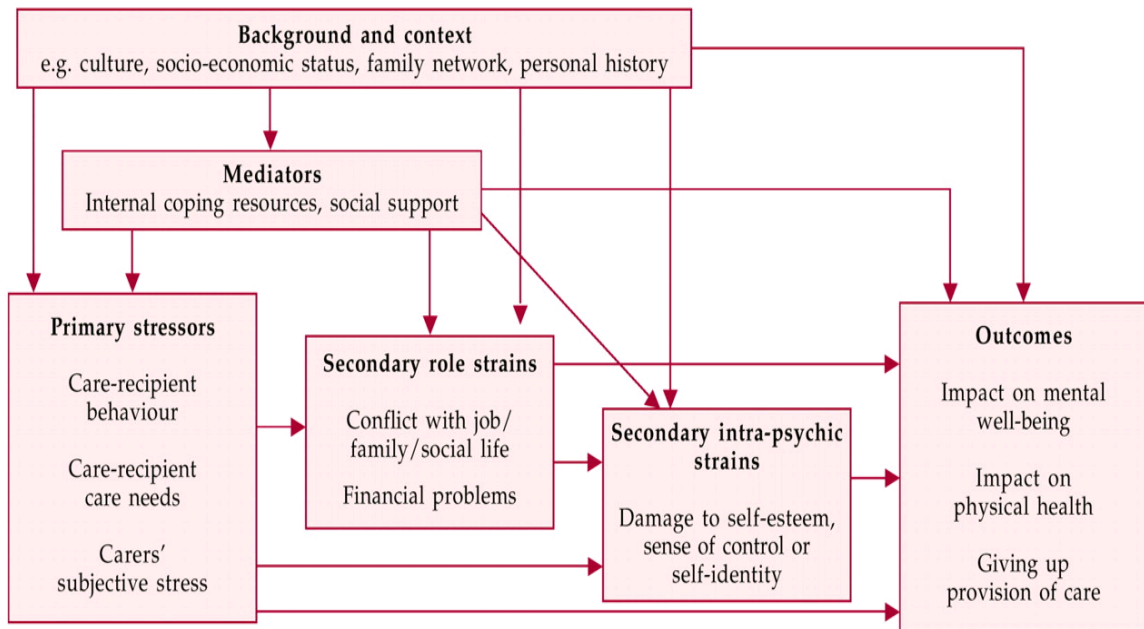
role is highly stressful (e.g., can a daughter exit the caregiving role when there is no one else to provide care?).

The above theoretical underpinnings offer valuable guidance for understanding and examining the caregiving experience, including ways in which dementia manifests itself in an individual, how one enters into the caregiving role, unique factors related to the caregiver, and resources available to both caregivers and care-recipients in the caregiving context. Examining transitions as potential stressors that have the capacity to disrupt daily living, however, is the unique function of the Stress Process Model, which conceptualizes the dementia experience in care-recipients and their caregivers. The Stress Process Model is widely utilized in the realm of caregiving to yield a better understanding of this complex trajectory and its many interacting dynamics.

The Stress Process Model

The Stress Process Model (Pearlin, Mullan, Semple, & Skaff, 1990) evolved as a way to assess the informal caregiving process and how it affects outcomes for caregivers. A product of years of research evaluating both stress processes and family caregiving experiences, the Stress Process Model not only identifies characteristics that may cause stress but also evaluates how these characteristics evolve and how they relate to other domains (see Figure 2.1).

Figure 2.1: *The Stress Process Model*



(Adapted from Pearlin et al., 1990)

Because the outcomes associated with dementia care often vary widely among families, a comprehensive approach such as this is important in order to capture the diversity of the caregiving context, care demands, and emotional outcomes. Paralleling the notion that caregiving is conceptualized as a career, the Stress Process Model reflects processes that are dynamic and *change* over time. Pearlin and colleagues (1990) utilized four domains to construct their model, with each domain being comprised of multiple components. The four domains include: the background and context of stress, the stressors, the mediators of stress, and the outcomes or manifestations of stress.

Background and context of stress.

The background and context of stress component of the Stress Process Model deals with key characteristics of the caregiver. Because nearly every aspect of caregiving may be influenced by these particular factors, it is crucial that they be considered when examining other variables within the caregiving career. Characteristics of the caregiver include factors such as caregiver age, gender, ethnicity, socioeconomic status, educational attainment, occupation, and family composition. Also within the Background and Context of Stress component of the model is a historical account of the caregiver, which includes the caregiver's relationship with the care-recipient (e.g., spouse, adult child) and the nature of past and current relationships (e.g., amiable or problematic). These characteristics become especially relevant within the caregiving process because they help explain how preexisting factors (e.g., nature of past relationship) may impact current caregiving situations. Likewise, these processes may help indicate the type of stressors to which different caregivers may be exposed, as well as the personal and social resources that are available to assist in coping with these identified stresses (Judge,

Menne, & Whitlatch, 2010; Pearlin et al., 1990).

Stressors.

Pearlin and colleagues (1990) defined stressors within their model as the problematic and difficult circumstances affecting the caregiver. Stressors are considered to be at the “heart” of the Stress Process Model in that they define what will ultimately threaten and exhaust caregivers. Within the model, stressors are designated as *primary* and *secondary stressors*. Primary stressors are further categorized into primary objective stressors and primary subjective stressors. *Primary objective stressors* concern the care-recipient and the needs she or he exhibits, and the extent of these needs. Among these stressors are the cognitive status of the care-recipient (e.g., memory loss, communication deficits, failure to recognize); behavioral problems (e.g., irritability, swearing, incontinence); and activities of daily living (e.g., bathing, feeding, dressing, toileting). These three indicators can help gauge types and amount of care the caregiver will encounter. This leads to examining *primary subjective stressors*, which refer to subjective experiences of the caregiver. Two indicators of primary subjective stress put forward by the Stress Process Model are role overload (i.e., burnout experienced by the caregiver) and relational deprivation (i.e., lack of reciprocity between caregiver and care-recipient) (Pearlin et al., 1990).

Although primary stressors reflect the demands put forth by the care-recipient and the relationship dynamics between the caregiver and care-recipient, secondary stressors are those that are expected to affect primary stressors. Included within the model are two types of secondary stressors: *role strains* and *intrapsychic strains*. *Role strains* account for what is found within the roles and activities that occur outside of the caregiving arena

(e.g., employment). Also considered to be central among secondary stressors are family, occupation, and economic strains. Intrapyschic strains, on the other hand, involve aspects of the caregiver's self concepts; specifically role captivity (i.e., being an unwilling participant of the caregiver role); loss of self (i.e., loss of identity); competence (i.e., adequacy of caregiving performances); and gain (i.e., growth and enrichment experienced as a result of caregiving) (Judge et al., 2010; Pearlin et al., 1990).

It is important not only to recognize and understand the types of stressors individuals face, but also to recognize and understand the timing and interrelationship of these stressors. Because stressors rarely occur in isolation from one another, it is possible for primary stressors to lead to secondary stressors. This process is referred to as *stress proliferation*, in which stressors in one role or domain of life may impact other domains or roles (e.g., experiencing stressors at home may impact one's employment role). The Stress Process Model helps account for the short-term and long-term ramifications of stress proliferation as relevant to the caregiving context (Aneshensel et al., 1995; Pearlin et al., 1990).

Mediators of stress.

Primary and secondary stressors reflect the dynamic interconnectedness between various factors surrounding both the caregiver and the care-recipient. Years of caregiving research have revealed that stressors, although similar in nature, affect different people in different ways (Aneshensel et al., 1995; Pinquart & Sörensen, 2003a, 2003b). In other words, why do Caregiver A and Caregiver B, who are in similar situations, demonstrate such variability in how they react and cope with their experiences? Mediators are called upon to help answer this question. According to the Stress Process Model, the mediators

of relevance are coping and social support.

Coping signifies the behaviors and practices in which an individual engages during stressful situations. In regard to dementia caregiving, coping can be conceived of in terms of managing the situation causing stress (e.g., learning about the illness, being firm in directing relative's behavior, knowing what to let go); managing the meaning of the situation such that its threat is reduced (e.g., accepting the relative for who she or he is, focusing on the present, keeping a sense of humor, finding positive experiences in present situations, spirituality); and managing stress symptoms that result from the situation (e.g., eating right, exercising, medication, sleep, spending time alone, hobbies).

In regard to social support, the model conceptualizes two types of support: instrumental support, in which there is tangible support from someone who assists in caregiving procedures, and expressive support, or the perceived availability of a person who is caring and trustworthy. The Stress Process Model suggests that social support may not actually alter the stress itself, but rather alters caregivers' appraisal of it. It is also important to note that social support can prevent or inhibit the development of secondary stressors (Judge et al., 2010; Pearlin et al., 1990).

Outcomes.

Stress outcomes are conceptualized as the psychological, emotional, or physiological conditions that result from exposure to stressors. The Stress Process Model characterizes outcomes as physical and mental health effects that result from caregiving. Many researchers have sought to better understand caregiving outcomes, both in terms of physical and mental health. Of particular interest are mental health outcomes, such as depression, anxiety, and cognitive disturbances. Physical health is also widely examined

within caregiving research, which may include common health problems, injuries, and other physical limitations impacting one's ability to engage in caregiving procedures.

By examining the caregiving experience within this multidimensional framework, the Stress Process Model provides a sound conceptual foundation on which to examine caregiver subjective stress. The model suggests that caregiver well-being is affected not only by primary stressors originating directly from the illness and care of the care-recipient, but also from secondary stressors that exist (e.g., family conflict, reduced social activities). Further, social support and appraisal of the meaning of stressors can mediate the effects of primary caregiving stressors on caregiver well-being. Social support, as a multidimensional construct, encompasses structural characteristics, such as social network size and the frequency of network contacts, as well as functional characteristics, including types of support received (e.g., tangible or emotional), negative interaction, dissatisfaction with the support system and perceived need for support (Mitrani et al., 2006; Pearlin et al., 1990).

The Stress Process Model has been a predominant organizational framework for dementia caregiving research because of its effectiveness in explicating how various intervening factors impact how an individual will respond to the caregiving role. The strength of this model is that it accounts for background variables, characteristics of the caregiving situation, characteristics of the caregiver, coping, and social factors. Furthermore, this model considers factors that may mitigate stress, as well as those that have the potential to magnify it. Though caregiving may be inherently demanding, the extent to which it produces stress is contingent upon various factors, including the status of the care-recipient, the social and economic resources available to the caregiver, and a

variety of events associated with the life course. Drawing upon this comprehensive model also allows for a more accurate and holistic understanding of the caregiving experience. Of equal importance is the ability of the Stress Process Model to provide researchers with the crucial foundation needed to systematically study the dementia caregiving experience, from the onset of caregiving, through the many transitions that subsequently may follow.

In conclusion, the theoretical foundations presented in this chapter allow for more sophisticated analyses of specific dynamics found within the dementia caregiving career. The aims of this study are rooted in the constituents of these theories and conceptual models, and are explained further in subsequent chapters. Expanding upon the conceptual foundations of transitions, Role Theory, and the Stress Process Model, the next chapter presents a review of literature concerning the onset of dementia caregiving, as well as the implications of holding various roles in conjunction with the caregiving role.

CHAPTER THREE

The Onset of Dementia Caregiving & Caregiver Role Occupancy

Overview

Theoretical notions outlined in Chapter Two help provide a conceptual foundation for understanding transitions, identity changes, and stressors as they occur in an individual's life. The following chapter extends theoretical concepts outlined in the previous chapter and provides an empirical understanding of the onset of dementia caregiving, and caregiver role occupancy.

Examining Transitions in the Caregiving Career

More recently, caregiving research literature has examined transitions that often occur within the caregiving career and the ramifications of these transitions for family caregivers. The transition from non-caregiver to caregiver and how specific patterns of entry affect subsequent caregiving outcomes (e.g., depression, role overload, burden) often mark the beginning of the caregiving career and have important longitudinal implications for the caregiver. As onset, or the self-perceived start of caregiving, is often characterized as the first major transition marked within the caregiving career, other transitions occur as the course of the caregiving career unfolds over time (Aneshensel et al., 1995; Seltzer & Li, 1996). Transitions that have been characterized in the caregiving literature are institutionalization and bereavement (Boerner, Schulz, & Horowitz, 2004; Gaugler, Kane, Kane, Clay, & Newcomer, 2003; Schulz et al., 2004). Although studies have characterized the institutionalization process as the end of caregiving, contemporary caregiving research has characterized it as yet another caregiving transition, one in which care does not cease following institutionalization but rather shifts in terms of its place, duration and intensity. Various caregiving studies have examined this particular transition

in terms of what constitutes institutional placement and the effects placement has on caregivers (see Gaugler, Kane, Kane, Clay, & Newcomer, 2003; Schulz et al., 2004; Seltzer & Li, 2000; Yaffe et al., 2002; Zarit & Whitlatch, 1992). Similar to institutionalization, the concept of bereavement has become a well characterized transition within caregiving literature. Research regarding bereavement has demonstrated variability in terms of outcomes that it produces for caregivers and subsequent adaptation. These findings pose several implications for caregivers as well, including pre-loss and post-loss experiences and how caregivers adapt to challenges and stress surrounding the bereavement process (Boerner, Schulz, & Horowitz, 2004; Schulz et al., 2003).

Although specific transitions such as institutionalization and bereavement have received some attention in the dementia caregiving literature (e.g., see Gaugler, Zarit, & Pearlin, 2003c; Schulz et al., 2004), less is known about how families actually assume care responsibilities. The process of assuming care responsibilities is classified as dementia caregiving *onset*, or the manner in which an individual enters into a caregiving role.

The Onset of AD Caregiving

The notion of onset may be conceptualized in different ways. Utilizing other chronic disease contexts, the term *onset* may be defined as the time period in which an illness or disease process begins to manifest itself within an individual. For example, the onset of AD or Parkinson's disease is typically characterized when there is substantial evidence of the disease, such that clinical manifestations are demonstrated within an individual (e.g., memory impairment, psychomotor changes). Onset within the context of

AD caregiving is generally defined as the process of an individual taking on care responsibilities for a person with AD. The onset of AD caregiving can be considered in terms of timing, the events surrounding the role acquisition, and the type of entry pattern. Thus, the onset of caregiving does not necessarily need to correspond with the onset of a disease process. This is important, as symptoms of AD may not manifest themselves in ways that are overtly obvious to family members. Thus, family members may begin providing levels of care for up to several years before symptoms may be regarded as problematic, or warranting medical attention. In the absence of reliable early detection procedures for AD, caregivers may spend several years in the caregiving role before seeking medical assistance or receiving a formal diagnosis. This distinction between the onset of the disease process and the actual onset of caregiving has led to important findings regarding how caregivers enter into the caregiving role, how they define themselves as caregivers, and how role entry affects later caregiving outcomes (see Aneshensel et al., 1995; Gaugler, Zarit & Pearlin, 2003b). The following sections highlight findings from previous caregiving onset research.

The onset of AD caregiving research.

Early research findings have provided evidence for the existence of a hierarchical model of caregiving, hypothesizing that the person closest to the individual needing care assumes primary care responsibilities. This typically meant that spouses are most likely to enter into the caregiving role, followed by adult daughters (Cantor & Little, 1985). Other areas of research regarding entry into the caregiving role were derived from various retrospective analyses, indicating that some caregivers are able to identify when they began care procedures, while others are less aware of when care provision actually

began. Similarly, not all caregivers are able to identify when they began considering themselves to be caregivers (Seltzer & Li, 1996). Heterogeneity surrounding the events of caregiving role acquisition suggests that caregiving onset is a dynamic process, requiring examination of the various ways in which the onset of dementia caregiving occurs.

Individuals may transition into the caregiving role through a variety of circumstances, including the diagnosis of an acute or chronic illness, the occurrence of a health-related crisis, or the early recognition of symptoms. Due to the potentially unpredictable nature of AD symptoms, family caregivers of AD patients are often faced with unanticipated care situations and responsibilities, particularly in the early stages of AD care (Adams, 2006; Perry, 2002). For example, an individual exhibiting early symptoms of AD may engage in unpredictable behaviors, such as wandering away from home, forgetting to manage finances for extended periods of time, or experiencing a sudden fall. These occurrences, often unpredictable for family members, place potential caregivers in situations that require unanticipated, and often immediate attention. This, in turn, requires caregivers to make accommodations in their own lives as they attempt to manage unanticipated events occurring in the care-recipient's lives.

Several studies have examined caregiving onset and how caregivers make the distinction between being a "non-caregiver" to a "caregiver." A key longitudinal study of caregiving onset was conducted by Aneshensel and colleague's (1995), which aimed to identify the point at which family members were able to indicate when they first considered themselves as caregivers and when caregiving procedures actually began. Three different measures were used to help determine when the process initiated: symptom recognition (i.e., when family members first began to notice changes in

cognition and behavior), care provision (i.e., when families began providing care), and diagnosis (i.e., when families received a formal diagnosis from a physician). Results indicated that variations in the onset of caregiving (i.e., gradual vs. abrupt entries) occurred within different families. Some families began noticing symptoms immediately, which prompted seeking a diagnosis. Others began providing care for family members without actually recognizing identifiable symptoms. The various ordering of these events found in different families suggests that entry into caregiving is a highly dynamic and complex procedure.

Expanding on the work of Aneshensel and colleagues (1995), other research has utilized these indices of onset to determine how different patterns of entry into the caregiving role impact subsequent caregiving outcomes (Gaugler et al., 2003). Dementia caregivers were classified into four different onset sequences: recognition-diagnosis (i.e., symptom recognition occurred prior to the provision of care and a diagnosis), care provision (i.e., provision of help occurred prior to symptom recognition or actual diagnosis), recognition-care (i.e., symptom recognition and care provision occurred prior to diagnosis), and diagnosis dependent (i.e., clinical diagnosis was sought prior to or at the same time that symptom recognition and/or provision of care occurred). The aims of Gaugler and colleagues were to examine how various characteristics of the caregiver and care-recipient (e.g., caregiver health, time since onset, care-recipient status) were related to caregiving onset. Results indicated that the status of the care-recipient was strongly related to the caregivers' classification in the different entry patterns in that caregivers within the recognition-diagnosis, recognition-care, and care provision groups tended to

experience more gradual entries into the caregiving role as compared to caregivers within the diagnosis-dependent group.

These findings have implications for family caregivers such that the length of caregiving procedures may not be the only factor relevant in determining subsequent caregiving outcomes (i.e., what has commonly been postulated by the wear-and-tear hypothesis). Rather, the types of entry into the caregiving role may be more indicative of subsequent caregiving experiences and future caregiving transitions (i.e., institutional placement).

Gaugler, Zarit and Pearlin (2003b) further examined patterns of entry into the caregiving role, again revealing the dynamic processes of caregiving onset. Using three-year longitudinal data, the four onset sequences identified by Gaugler et al. (2003) were examined. Findings indicated that caregivers classified in the diagnosis-dependent, recognition care, and recognition diagnosis group were more likely to institutionalize the care-recipient in comparison to caregivers classified in the care-provision group. Additionally, caregivers in the care-provision group reported significant decreases in role overload and depression over the course of longitudinal analysis. Explanations for this finding may include the notion that caregivers who are more 'entrenched' in the caregiving process prior to recognizing illness symptoms or receiving a formal diagnosis may better adapt to the caregiving process, thus leading to better outcomes and a decreased likelihood of institutionalization for the care-recipient. Furthermore, results of the study lend credence to the importance of characterizing role entry in terms of being abrupt or gradual, which may constitute the differences found among caregivers classified in different role entry groups.

Various caregiving studies have sought to identify the earliest behavioral changes exhibited by care-recipients with AD, resulting in either recognition of symptoms or required assistance provided by family members. In a qualitative study involving husbands caring for wives, caregivers reported detecting personality changes rather than cognitive impairments prior to receiving a dementia diagnosis (Samuelsson, Annerstedt, Elmstahl, Samuelsson, & Grafstroem, 2001). All participants in this study reported experiencing heavy burden in the early stages of their caregiving career. Another study found that apathy, as well as withdrawal from social and leisure activities, were the most frequently reported changes detected by family caregivers, indicating recognition of functional decline prior to recognition of cognitive decline (Derouesne et al., 2002).

Subjective experiences in the onset of caregiving.

More recent research attempts have aimed to elucidate caregiver's subjective experiences in relation to their onset into the dementia caregiving role. Adams (2006) utilized qualitative analyses to explore adjustment patterns of spouses and adult daughters entering into the caregiving role. Participants were encouraged to describe the earliest changes they detected in their daily lives and relationships based on cognitive impairment experienced by their care-recipients. These changes included caregivers acquiring new responsibilities, primarily involving decision-making (e.g., managing finances, making decision about continued driving) and supervision tactics.

The interactive nature of many of these decisions led caregivers to characterize them as new sources of stress within their lives. Subjective outcomes reported by caregivers included feelings of frustration, impatience, grief, relational deprivation, and resentment. Additional outcomes included heightened protectiveness over the care-

recipient as well as increases in tenderness toward the care-recipient. Interestingly, several of the caregivers were also found to be ambivalent in regard to seeking or accepting help in the beginning of their caregiving careers, desiring to maintain “normalcy” for as long as possible. Overall, results determined that many of the caregivers reported experiencing changes within their own lives prior to any obvious functional impairment displayed by their care-recipients. Information provided by these caregivers revealed gradual and subtle shifts into the caregiving role by first providing support and guidance, followed by actual assistance with activities of daily living (ADLs) (Adams, 2006).

A recent study examining entry into the caregiving role utilized a life course perspective to better understand pathways of entry into the illness trajectory. Seeking to move beyond the utilization of caregiver characteristics, Carpentier and colleagues (2010) proposed to track social interactions of caregivers and those in their support system to better comprehend various typologies of entry into the caregiving role. The first life course principle used to guide this research was that of family history (i.e., family support systems, family experiences). This principle asserts that families providing care for an individual diagnosed with dementia must be understood in lieu of prior familial experiences and transitions. Hence, entry into the caregiving trajectory is heavily influenced by a family history that has been shaped over time. The second life course principle used in the research was linked lives (i.e., the belief that individual’s lives are interrelated). The notion of linked lives supposes that the distribution of caregiving responsibilities among family members originates from negotiations and compromises within the family system. Thus, events within the caregiving career can either generate

closeness within the family system or create distance between them. Human agency, the third life course principle employed by the authors, reflects upon the autonomy that individuals possess in order to respond to events, make choices, manage conflict, and seek solutions. The final life course principle was that of organizational factors, which focuses on an individual's living environment, organizational practices, and public policy. Incorporating a qualitative process informed by these four life course principles, the authors identified typologies of five types of entry into the caregiving trajectory for 60 dementia caregivers (Carpentier et al., 2010).

The first typology suggests the notion that all trajectories of care reflect family history, and that dementia is not always the only health problem with which individuals must cope. Because of these past experiences (either dealing with physical or mental health complications), caregivers falling into this typology tended to be more experienced, possessed more ease in navigating the health care system, and often received diagnoses sooner. In other words, members had already begun to act as caregivers prior to a formal diagnosis being made. The second entry typology involved individuals with smaller social networks and isolation between support systems. The care trajectory therefore commences following a significant event (e.g., admission to the hospital) that prompts family members to react, resulting in at least one member of the family providing care for the care-recipient (Carpentier et al., 2010). Typology three exemplifies the influence of organizational structures (e.g., healthcare environment) on the caregiving trajectory. Within this typology, families often begin care before they are ready, namely due to an early diagnosis, prompting families to quickly adopt the caregiving role. Typology four encompasses individuals who experience a slower

progression of the disease process, which prompts the support network to begin seeking help. These caregivers classified were often able to facilitate services and problem solving techniques in a more calm and effective manner. Although still stressful and difficult, this process helped mitigate negative outcomes often experienced by caregivers. The final typology was marked by trajectories that reflected unpredictability, adverse consequences, and a longer duration before diagnosis. A history of conflict existed among the family networks, which led to ambiguity, lack of support, and difficulty in decision making. Implications from this study offer new information regarding how entry into the caregiving role impacts the overall care trajectory, and how obtaining a more sophisticated understanding of entry patterns can lead appropriate interventions for various caregiving circumstances (Carpentier et al., 2010).

Prospective studies of caregiving onset.

Although most studies involving caregiving onset tend to be retrospective in nature, few studies have employed prospective, longitudinal procedures by following non-caregivers over time until they enter into the caregiving role. Kramer and Lambert (1999) examined husbands transitioning into the caregiving role, finding that new role acquisitions (e.g., new household chores) and difficulties within the marital relationship were more prevalent among new caregiver husbands compared to husbands who never acquired the caregiving role. Seltzer and Li (2000) examined the onset of caregiving in daughters and wives, finding that wives experienced more deleterious effects from entering into the caregiving role as compared to daughters entering into the caregiving role. These prospective research attempts contribute to existing literature regarding caregiving onset by providing additional insight into the experiences, stressors, and

heterogeneity surrounding entry into the caregiving role.

It is evident from the research that exists on the onset of dementia caregiving that the onset transition has many important implications for dementia caregivers as they progress through the caregiving career. Although existing research has placed much emphasis on caregiving once individuals have already assumed the caregiver role, relatively little work has examined caregiving onset and potential outcomes associated with it. In particular, how various onset events affect key measures of caregivers' mental and physical health has remained unexplored.

In addition to examining the caregiving onset transition and its implications, the present dissertation also aims to investigate how various roles held by AD caregivers, in conjunction with their caregiving role, impacts subsequent mental and physical health outcomes. The following section synthesizes existing literature on caregiver roles, and highlights discrepancies found within the literature.

Roles Held By AD Caregivers

Whether an AD caregiver is a spouse, adult child, or another relative or friend, it is likely that she or he maintains other roles in addition to the caregiving role. Over the years, increased attention has been focused on AD caregivers and the multiple roles they hold. In particular, research has focused on the relationship between multiple roles and caregiver psychological well-being. Aneshensel and colleagues (1995) discuss the relationship between holding multiple roles, and stress proliferation (the tendency for stressors to create additional stressors). Caregivers often hold multiple roles. They may be parents, siblings, employees, friends, parishioners, and community activists, just to name a few. Ordinarily, these roles and the structure and relationships found within them

are temporally and spatially separated. This separation helps avoid disorder and competition among different roles, enabling individuals to maintain and sustain them in a more systematic and orderly fashion. Despite this notion of maintaining segregation and order within roles, there is only one individual fulfilling each. When an individual experiences difficulty or stressors within one particular role (e.g., the caregiving role), there is the potential for other roles in that person's life to be impacted as well. The caregiving role, especially, demands much time, effort, commitment, and energy. This effort often results in the restructuring of other roles and priorities (e.g., reducing work hours, giving up leisure activities). Although the restructuring process may not necessarily induce great amounts of stress, the potential exists for some caregivers to experience problematic outcomes related to the demands of caregiving and the effects these demands may have on additional roles. For this reason, exploring the dynamic nature of multiple roles, held in conjunction with that of the caregiving role, is critical for better understanding outcomes within the caregiving career (Aneshensel et al., 1995).

The implication of holding multiple roles is of particular interest within the realm of AD caregiving as the number of caregivers continues to increase, and the phenomenon of "sandwich caregiving" continues to surface. Many AD caregivers also have children living at home, suggesting multiple layers of caregiving. The 2009 NAC/AARP survey on caregiving in the United States found that 30 percent of family and other unpaid caregivers of people with AD had children or grandchildren under age 18 living at home (The National Alliance for Caregiving/AARP Survey on Caregiving in the United States, 2009). The phrase "sandwiched" or "in the middle" encapsulates the concept of an individual in the middle years of his/her life, one who is in the middle from a

generational standpoint and one who is caught in the middle of fulfilling the requirements of various roles. Women in particular have fallen into this category, as they often assume the multiple roles of spouse, employee, caregiver for children, and caregiver for aging parents (Pavalko & Woodbury, 2000). The theme of middle aged adults, primarily women, being “caught in the middle” has prompted further study into the experiences of individuals holding various demanding roles and providing multiple levels of care. As role theory postulates, holding multiple roles has the potential to elicit both positive and negative experiences on behalf of the individual occupying multiple roles. Existing research on this dichotomous view sheds light onto the actual experiences of caregivers simultaneously managing multiple roles (Adelmann, 1994; Moen, Robison, & Dempster-McClain, 1995; Mui, 1992; Rozario, Morrow-Howell, & Hinterlong, 2004).

AD caregiving and the outside work role.

Many dementia caregivers attempt to balance their caregiving responsibilities simultaneously with an outside work role (Bainbridge, Cregan, & Kulik, 2006). One of the most frequently asked questions in regard to this experience is whether the caregiver can effectively manage both roles, or whether efforts to sustain the roles leads to negative effects on the caregiver. Prior research has generated mixed results (Enright & Friss, 1987, Skaff & Pearlin, 1992). Utilizing the concepts of role strain and role enhancement, Bainbridge and colleagues (2006) examined whether hours of paid work were associated with caregiver stress outcomes. The researchers also explored whether or not a moderating effect existed in regard to the caregiving role, hypothesizing that the severity of the disability found within the care-recipient would moderate the effects found from holding multiple roles. Their analysis revealed that participating in a work role produced

neither harmful nor beneficial impacts on stress outcomes for caregivers. In regard to the moderating effect of care-recipient disability, caregivers caring for an individual with a mental disability actually benefited from spending more time in their work role. This moderating effect appears to provide support for the role-enhancement perspective of role theory, but data are limited to care-recipients with mental disabilities. This finding also provides support for the notion that holding multiple roles can lead to stress reduction through the availability of expanded resources found across roles (Bainbridge, et al., 2006).

In an attempt to capture the fluidity and dynamic nature of multiple roles, Pavalko and Woodbury (2000) utilized principles from role theory (symbolic interactionist perspective) (Stryker & Statham, 1985), life course perspectives (Elder, 1996; Moen et al., 1992; 1995), and the stress process model (Aneshensel et al., 1995; Pearlin et al., 1990) to emphasize that roles are changing and adapting over the course of role careers. Embedded in these theoretical concepts, the researchers explored how multiple roles (employment and caregiving) impacted women's health. Examining changes in physical and psychological health over a two-year period, increases in psychological distress were found as women moved into the caregiving role and continued providing care for an individual in their household who was ill or disabled. This implies that the process of caring over time may lead to an accumulation of emotional health complications over the course of the caregiving career. Caregiving was found to have less of an impact on physical health. Interestingly, changes in physical health were more stable over time, suggesting possible adaptation to the situation. Findings also implied that employment had a moderating effect on physical health, as employed women demonstrated little

variation in health changes compared to non-employed women, suggesting that employed women may have a stronger buffering effect against health decline in the first few years of their caregiving careers. The relationship between employment and caregiving also revealed that being employed did not prevent women from assuming the caregiving role. However, women who were already caregiving at the time baseline data were collected were less likely to still be employed (Pavalko & Woodbury, 2000).

Expanding on the concepts of role strain and role enhancement, Edwards and colleagues (2002) explored role overload and role conflict in those providing care for cognitively impaired adults and maintaining simultaneous employment. No differences were found between employed and non-employed caregivers on measures of role overload, depression, strain, and worry. For employed caregivers, however, greater conflict at work was associated with higher role overload, worry, and strain. Beneficial work experiences, on the other hand, were only weakly associated with lower role overload, worry, and strain. Positive work experiences, however, appeared to moderate the effects of role overload on depression. These results again suggest the considerable variability found in caregivers' experiences while holding multiple roles, as well as how they adapt and respond to multiple roles.

It is clear from the existing literature that caregiver roles, along with caregiving onset, have several implications for AD caregivers that need to be better understood. Moreover, how the impact of caregiving onset and caregiver roles changes in the presence of other dynamics occurring simultaneously in the caregiving career remains an important area of inquiry in the caregiving literature. The following chapter introduces the moderating variables that this present research examines: care-recipient cognition and

care-recipient behavioral problems. This next chapter also details how cognition and behavioral problems have the potential to impact subsequent caregiving outcomes for caregivers, including mental and physical health outcomes.

Chapter Four

The Impact of Cognitive Decline and Behavioral Problems on Caregiving Outcomes

Overview

The following chapter introduces two hallmark features of AD: cognitive decline and behavioral problems. As these two features are closely examined in the present study, their noted impact on key caregiving outcomes is explored. The caregiving outcomes examined in this study and addressed in this chapter are depression, role overload, role captivity, relational deprivation, positive caregiving outcomes, and caregiver physical health.

Cognitive Decline in Alzheimer's Disease

Common patterns of symptom progression have been well documented throughout the years through research and clinical observations of AD (Cohen-Mansfield, Reisberg, Bonnema, & Berg, 1996; Reisberg, 1982). Identifying symptom progression has led to the development of staging based on patterns that typically manifest themselves in individuals with AD. Myriad changes occur within an individual over the course of AD that appear to progress in recognizable patterns. Each stage of AD is characterized by different levels of impairment, behavioral changes, and mood alterations. Although it is sometimes difficult to place an individual within a specific stage of AD, the stages that have most recently been identified provide a framework for better understanding the clinical outcomes of AD (Alzheimer's Association, 2010; Reisberg et al., 1982). The first stage, Stage One, is often classified as the normal function stage in which no impairment or memory problems are evident.

In Stage Two, referred to as Very Mild Cognitive Decline, an individual may begin to recognize small memory lapses (e.g., forgetting familiar words, misplacing common objects). It is difficult to determine whether this is an early sign of AD, or it reflects common age-related changes. At this stage, family members, friends, and medical professionals often do not detect any changes or complications in memory or activities of daily living (Alzheimer's Association, 2010; Reisberg et al., 1982).

Stage Three is classified as Mild Cognitive Decline. In this instance early stage AD can be diagnosed. Oftentimes family, friends, and employers will detect subtle difficulties in the individual exhibiting symptoms. Difficulties most common in this stage concern memory and concentration, including trouble producing accurate words and names, misplacing or losing essential objects, and difficulty retaining information recently learned (e.g., forgetting material recently read). Complications with planning, organizing, and performing tasks within social and occupational settings may also present (Alzheimer's Association, 2010; Reisberg et al., 1982).

Stage Four, referred to as Moderate Cognitive Decline, is considered mild or early-stage AD. Thorough medical evaluations most likely will detect noticeable complications in areas involving complex tasks and executive functioning tasks, such as planning for future events. Individuals in this stage of AD may also begin forgetting details regarding their own personal history, as well as details involving recent events. It is also during this stage that individuals may begin to exhibit mood alterations and withdrawal from social situations (Alzheimer's Association, 2010; Reisberg et al., 1982).

Moderately severe cognitive decline characterizes Stage Five, often referred to as Moderate or Mid-Stage AD. During this juncture of the disease process memory and

thinking limitations become obvious to others, and the individual begins requiring care with common instrumental activities of daily activities (IADLs) (e.g., managing finances, cooking meals, maintaining the home). Although individuals may still recall significant details involving themselves and their families, they are often unable to remember information such as their home address or the year that they graduated from high school (Alzheimer's Association, 2010; Reisberg et al., 1982).

Stage Six, or Moderately Severe/Mid-Stage AD, marks severe cognitive decline. Declines in memory continue to occur, with significant information about self and others beginning to deteriorate. Personality changes become more evident, and assistance with activities of daily living (ADLs) (e.g., bathing, dressing, feeding, toileting) is needed. Additional hallmark symptoms of later stage AD begin to emerge, including behavioral problems (e.g., wandering, delusions) and incontinence (Alzheimer's Association, 2010; Reisberg et al., 1982).

Stage Seven, Severe or Late-Stage AD, is the final stage in the disease process during which severe cognitive decline is palpable. Individuals with severe AD often lose their ability to interact with and respond to environmental surroundings. Physical movements may be inhibited, and the ability to communicate in full sentences is often lost. Extensive assistance with ADLs is required, as the individual has experienced much physical deterioration (e.g., muscle rigidity, difficulty swallowing, inability to hold head up) in the end stage process (Alzheimer's Association, 2010; Reisberg et al., 1982).

How and when the symptoms of AD, including cognitive decline, manifest themselves varies depending on whether an individual is diagnosed with early-onset AD or late-onset AD. Early-onset AD, a rarer form of the disease, is diagnosed before the age

of 65. Late-onset AD, which occurs after age 65, is the most common form of AD (Licht, McMurtray, Saul, & Mendez, 2007). The early indicators of early-onset AD are similar to those of late-onset AD. These symptoms include losing items on a regular basis, difficulty completing basic tasks, forgetfulness, personality changes, confusion, poor judgment, challenges with basic communication and language, social withdrawal and problems following simple directions. Clinically, cognitive distinctions have been noted between early and late-onset AD, including a seemingly more rapid decline in those diagnosed with early onset (Licht et al., 2007). While cognitive decline is viewed as the trademark attribute of AD, other symptoms, including behavioral problems, often manifest themselves in individuals diagnosed.

Behavioral Problems in Alzheimer's Disease

The changes outlined in each of the progressive stages of AD demonstrate obvious levels of impairment that occur over time in those with the disease. The cognitive, emotional, and personality changes that accompany AD have the potential to affect AD caregivers as they witness and continually adapt to the changing nature of AD. One factor consistently linked to distress experienced among AD caregivers is behavioral problems exhibited by the care-recipient over the course of the disease (Cohen-Mansfield, 2009; Gaugler, Kane, Kane, & Newcomer, 2005). Behavior problems pose many challenges for caregivers because of the difficulty in managing physical and verbal behavioral symptoms. Research has shown that increased behavior problems can be detrimental to the emotional well-being of caregivers and are often more upsetting for AD caregivers than losses in cognitive and functional abilities experienced by the care-recipient (Gaugler et al., 2000; Ladislav, & Hurley, 2003). Probable explanations for the

emotional impact of behavior problems include the disruptive nature of behavioral disturbances (e.g., keeping the caregiver up at night, emotional outbursts, inappropriate social interaction) and the unpredictable nature of behavioral disturbances. These can be problematic for family caregivers and may exacerbate the challenges that caregivers face in managing behavior problems.

Existing literature on behavioral problems in AD has revealed different types of behaviors along two dimensions: aggressive vs. non-aggressive, and physical vs. vocal/verbal. Physically non-aggressive behaviors may include inappropriate dressing, undressing in public, inappropriate eating/drinking behaviors, hiding or hoarding objects, exit seeking behaviors, pacing, exhibiting repetitious behaviors, and restlessness. Alternatively, physically aggressive behaviors encompass actions such as biting, kicking, hitting, pushing, scratching, spitting, throwing items, tearing items, inappropriate sexual gestures, or inducing harm to oneself or others. Verbally non-aggressive behaviors include repetitive questions, speaking with negative connotations, complaining, and engaging in attention seeking behaviors. Finally, verbally aggressive behaviors involve screaming, cursing, making bizarre sounds, and making verbal sexual advances (Cohen-Mansfield, 2009; Cohen-Mansfield & Libin, 2005).

Different etiologies have been found in regard to each of these four classifications of behaviors. An observational study involving 175 individuals diagnosed with dementia established that verbally agitated behaviors were affiliated with females who exhibited the following characteristics; poor ADL functioning, cognitive decline, depressed affect, and impairments related to social functioning. Physically non-aggressive behaviors were positively correlated with cognitive impairment. Females were also found to have higher

rates of verbal agitation and disruptiveness as compared to their male counterparts (Cohen-Mansfield & Libin, 2005).

Expanding on the different types of behaviors, Cohen-Mansfield (2009) aimed to examine the relationship between the type, frequency, and disruptiveness of behavioral problems exhibited by individuals with a dementia diagnosis. Utilizing the four categories described above (physically aggressive behaviors, physically non-aggressive behaviors, verbally aggressive behaviors, and verbally non-aggressive behaviors), obtained data from 191 participants revealed information on the frequency and level of disruptiveness of the different types of agitated behavior (Cohen-Mansfield, 2009). Overall, the highest frequencies found were for verbal non-aggressive behaviors, with verbal aggression being the most disruptive. An overall finding in this study was that the frequency of a particular behavior and whether or not it was aggressive served as determining factors for disruptiveness. For example, verbal non-aggressive behaviors were least disruptive at low levels of frequency, whereas physical non-aggressive behaviors at high levels of frequency were least disruptive. This finding suggests that an aggressive behavior displayed at low frequencies has the potential to become more disruptive than a non-aggressive behavior displayed at a high frequency. Consequently, verbal aggression (i.e., screaming and cursing) occurring more frequently can actually be more disruptive than an aggressive behavior (e.g., hitting, kicking) occurring less frequently. These findings demonstrate the importance of recognizing both the type of behavior and its frequency in order to ascertain the full impact of behavioral problems in dementia (Cohen-Mansfield, 2009).

In conjunction with behavioral problems serving as stressors for AD caregivers, they may also serve be an important factor in helping family members recognize that something is wrong with their relative. Eustace and colleagues (2006) found that 29 percent of their caregiver participants failed to recognize memory disturbances in their relatives. Despite obvious complications with memory, caregivers tended to associate cognitive decline with “normal aging,” or remained in denial that something was indeed wrong with their relative. Interestingly, recognition of memory disturbances by caregivers was associated with the occurrence of behavioral disturbances exhibited by the care-recipient. Overall, behavioral problems had a stronger influence on recognition of a problem than both cognitive and functional decline. These findings substantiated earlier findings that supported the notion of behavioral problems serving as key indicators of recognizing that there is a problem (Ross, Abbot, & Petrovitch, 1997; Macdonald & Carpenter, 2003). These findings are important and have implications with regard to timing of referral and seeking treatment for an individual with dementia. If family members are more reliant on the exhibition of behavioral problems in order to recognize problems in their care-recipients, then diagnosis and other medical referrals may be delayed, thus leading to a delay in subsequent treatments and interventions.

Cognitive decline and behavioral problems are powerful illustrations of the progression found within the AD process, and have important implications for AD caregivers. The ways in which these two forms of care-recipient decline lead to subjective stress outcomes, as emphasized in the Stress Process Model, have been demonstrated through empirical research. The remainder of this chapter synthesizes the literature regarding the key caregiving outcomes examined in this study: depression, role

overload, role captivity, relational deprivation, positive aspects of caregiving, and physical health. The subsequent sections also exemplify how cognitive decline and behavioral problems may exacerbate these outcomes.

Subjective Stress Outcomes: Depression

It is well documented in the literature that dementia caregiving is often associated with declines in caregiver emotional and physical health (Clark & Diamond, 2010; Pinquart & Sörensen, 2003a, 2003b, 2004). A great deal of research has also continually found that dementia caregivers have higher levels of mental and physical health complications when compared to non-caregivers (Pinquart & Sörensen, 2003a, 2003b, 2004). Various forms of emotional distress are evident among dementia caregivers, most notably caregiver depression.

As confirmed through a plethora of research studies investigating emotional distress found in caregivers, one of the most common and detrimental outcomes experienced by dementia caregivers is depression (Cuijpers, 2005; Pinquart & Sörensen, 2003a, 2003b; Chang, Chiou, & Chen, 2010). Nearly 50 percent of caregivers experience depressive symptomology, a rate substantially higher than the estimated 10 percent found within the general population (Cuijpers, 2005; Lu et al., 2007; Pitceathly, Maguire, Haddad, & Fletcher, 2004). This disproportionate rate highlights the deleterious nature of dementia caregiving and has prompted further research exploring various facets of depression found within the caregiving realm.

To better understand the development of depression in AD caregivers, researchers have explored potential risk factors for developing depression along the caregiving continuum. Some areas of research have linked caregiver and care-recipient

characteristics (e.g., the number of hours spent caregiving) with caregiver depression (Pinquart & Sörensen, 2003; Sherwood, Given, Given, & Von Eye, 2005). Covinsky and colleagues (2003) examined depression among primary caregivers of individuals diagnosed with moderate to severe dementia across the United States, concluding that 32 percent of the caregivers investigated (n=5,627) in the study were classified as depressed. Independent care-recipient predictors included younger age (e.g., less than 65 years old), Caucasian and Hispanic ethnicity (compared to African-American ethnicity), ADL dependency (dependence in two or more ADLs compared to those with no ADL dependency), and behavioral disturbances, primarily angry or aggressive outbursts. Independent caregiver predictors included low income, relationship to the care-recipient (wives were more likely to experience depression than adult children), hours spent caregiving (those caring more than 40 hours per week were more likely to experience depression as compared to those providing fewer than 40 hours of care per week), and functional dependence (ADL dependent compared to IADL dependent). Results of the study highlight the importance of exploring caregiver and care-recipient characteristics in order to more thoroughly comprehend the complex dynamics of depression (Covinsky et al., 2003).

In addition to caregiver and care-recipient characteristics, a growing number of studies have demonstrated that personality and personal disposition impact caregivers' mood. Personality factors (e.g., introversion versus extroversion) and coping mechanisms (e.g., problem-focused coping versus emotion-focused coping) impact caregiver depression in different ways. Although findings remain inconclusive, these traits may in fact influence how caregivers choose to cope with depression and burden experienced

during their caregiving careers (e.g., problem-focused coping may serve as a buffer against depressive symptoms) (Hayslip, Han, & Anderson, 2008; Roberts et al., 2007).

The impact of cognitive decline and behavioral problems on depression.

Because a number of studies examining the effects of dementia caregiving on caregiver health and psychological well-being, comprehensive meta-analyses have been conducted in order to better understand which caregiving variables are more consistently linked with caregiver burden and depression (Pinquart & Sörensen, 2003a, 2003b). In their meta-analysis regarding stressors and uplifts of caregiving, Pinquart and Sörensen (2003a) integrated results on the association between stressors and uplifts (e.g., beneficial caregiving outcomes) in regard to caregiver's psychological health. Two classes of stressors were central to this analysis: *care-recipient impairment* and the *level of caregiver involvement*. Three domains of care-recipient impairment were related to caregiver outcomes: the level of care-recipient physical impairment (e.g., ADL and IADL deficits), the level of cognitive impairment (e.g., memory problems), and behavior problems (e.g., aggression, disruptive behaviors). In regard to care-recipient impairment, inconsistent conclusions have been found pertaining to whether or not greater care-recipient impairment is positively correlated with caregiver depression and burden. It is suggested that perhaps the relationship between these two factors may be moderated by additional variables (e.g., physical deterioration in the care-recipient may be more difficult for spousal caregivers who are likely to experience their own health complications that may interfere with the caregiving process). In terms of cognitive impairment, results regarding the relationship between level of cognitive impairment and caregiver burden and depression also remain inconsistent. This is mainly due to sample

sizes and non-representative samples of caregivers. More consistent are the results with respect to behavioral problems, which steadily reveal a stronger relationship between behavioral problems of the care-recipient and caregiver burden and depression (Pinquart & Sörensen, 2003a). This meta-analysis also revealed a consistent association between behavioral problems and caregiver depression and burden, suggesting that behavioral problems play a greater role than do cognitive deficits and physical limitations.

When examining caregiver involvement (e.g., the number of caregiving hours and the number of caregiving tasks), Pinquart and Sörensen (2003a) also found inconsistent results in the existing literature. This is not surprising due to the competing hypotheses that attempt to explicate the relationship between caregiving stressors and the outcomes of these stressors. Different theoretical models are commonly utilized in various research attempts in order to understand the association between duration of caregiving and the psychological impacts of caregiving. The *wear-and-tear hypothesis* posits that the longer caregiving endures, the greater the deterioration of caregiver well-being. Alternatively, the *adaptation hypothesis* insinuates that caregivers are more likely to adapt to the stressors of caregiving over time, thus resulting in negative caregiving effects declining as the duration of caregiving persists. The *trait hypothesis* indicates that preexisting resources (e.g., coping, resilience) will aid caregivers in maintaining steady levels of adaptation, despite continued care-recipient deterioration.

Although all three theoretical stances offer valuable explanations, contradictory results continue to exist in regard to duration of caregiving and its link to caregiving stressors (Pinquart & Sörensen, 2003a). The authors of this meta-analysis found small linear relationships between the duration of caregiving and caregiving outcomes. This

finding may provide support for the trait hypothesis, or it may suggest that the relationship between duration of caregiving and caregiving outcomes is a nonlinear one (Pinquart & Sörensen, 2003a).

A subsequent systematic review was conducted by Pinquart and Sörensen (2004) specifically regarding research on depression and the subjective well-being of caregivers (e.g., life satisfaction, positive affect, quality of life). Examining results from 60 studies exploring caregiver well-being, the authors contrasted these results with those of studies exploring caregiver depression. This particular meta-analysis differs from their first in that it proposes subjective well-being as a new variable and compares the strength of associations between stressors, uplifts, and subjective well-being to the strength of associations between stressors, uplifts, and depression. The premise of this analysis stems from earlier results suggesting that caregivers who report burden and depression may still maintain ample levels of subjective well-being (e.g., positive affect, life satisfaction). The authors of this meta-analysis first hypothesized that caregiving stressors would be moderately positively associated with depression but weakly negatively correlated with caregiver subjective well-being. Second, they analyzed whether care-recipient impairments (e.g., physical impairment, cognitive impairment, behavioral problems) would reveal stronger negative relationships with subjective caregiver well-being as compared to caregiving intensity (e.g., number of caregiving hours provided per week, number of caregiving tasks). Last they examined whether correlations with subjective well-being varied by sample characteristics. Results indicated that caregiving stressors were significantly related to caregiver depression. Perceived uplifts of caregiving were associated with greater subjective well-being and lower levels of depression. Results also

revealed that physical impairment and behavioral problems exhibited by the care-recipient showed a stronger association with low subjective well-being as compared to caregiving intensity. In regard to their third hypothesis, a significant difference surfaced in that behavioral problems in the care-recipient were more strongly associated with low subjective well-being among dementia caregivers compared to non-dementia caregivers. Findings from this study provide valuable information by revealing that although caregivers may experience depression as a result of caregiving stressors, they may also experience adequate amounts of subjective well-being simultaneously, thereby suggesting caregivers' ability to protect positive aspects of their lives, despite experiencing difficult caregiving dynamics (Pinquart & Sörensen, 2004).

Spousal caregiving and depression.

The nature of the caregiver/care-recipient relationship may also affect caregiving outcomes, including depression. It has been suggested that spousal caregivers may exhibit more distressing outcomes than adult children caregivers because of health and functional complications related to spousal caregivers' age. It is not as well understood how cognitive deficits, behavioral problems, and duration of caregiving differ in regard to impacting spousal and adult children caregivers. Earlier research attempts have found that adult children, although often physically healthier, may be more vulnerable to experiencing distressing outcomes due to conflicting roles and demands (e.g., employment, raising families) (Baring, MacEwen, Kelloway, & Higginbottom, 1994; Reid & Hardy, 1999; Stephens, Franks & Townsend, 1994).

Although it is less clear whether spouses or adult children are at greater risk for experiencing depression as a result of caregiving, it is more apparent that spousal

dementia caregivers are more likely to experience depression compared to non-caregivers. Adams (2008) explored differences found on the CES-D depression screening scale (Radloff, 1977) between caregiving (n=391) and non-caregiving spouses (n=226). After controlling for group differences, dementia caregiving spouses had significantly more depressive symptoms than caregiving spouses. Significant differences were found in 11 out of the 20 CES-D items. Spouses who were caring for an individual diagnosed with dementia experienced less hope for the future, less happiness, and less enjoyment in life compared to non-caregiving spouses. Caregiving spouses also reported a higher degree of sadness, loneliness, and feeling bothered compared to their non-caregiving counterparts. Lack of positive affect was also more prevalent among dementia caregivers. These findings provide added support for the notion that dementia caregivers have a higher risk of developing depressive symptomology compared to those who are not currently occupying a caregiving role (Adams, 2008).

Subjective Stress Outcomes: Role Overload, Role Captivity, Relational Deprivation

Depression is just one distressing outcome commonly found among AD caregivers. Other forms of subjective distress often surface throughout the duration of dementia caregiving, causing negative outcomes for dementia caregivers. Of particular interest in this study are role overload, role captivity, and relational deprivation experienced by dementia caregivers. Emerging from preliminary analyses (Aneshensel et al., 1995; Pearlin et al., 1990) and being substantiated through subsequent research analyses (Gaugler, Zarit, & Pearlin, 2003a), these commonly found outcomes are important in understanding experiences that dementia caregivers often endure.

Role overload.

Role overload refers to an individual's experience of feeling overwhelmed by tasks related to providing care. Role overload does not refer to the extent of care performed by the caregiver; rather, it encapsulates emotions that result when a caregiver perceives caregiving tasks as too demanding and too exhausting (Aneshensel et al., 1995).

Role captivity.

Role captivity refers to feeling as if one is an involuntary participant in the caregiving role. Role captivity also consists of feelings of entrapment in a particular role. Role captivity does not refer to the actual responsibilities found within the caregiving role. Rather, it captures the obligatory emotions of the caregiver regarding remaining in the role, despite desiring to relinquish or diminish the demands of the role. Regardless of the level of difficulty, individuals experiencing role captivity view this role as unwanted (Aneshensel et al., 1995).

Relational deprivation.

Because of the deteriorating nature of AD, persons affected often lose many of the traits, abilities, and characteristics unique to their personality. These permanent and inevitable losses impact the relationship between the caregiver and care-recipient, as the caregiver must proceed in a relationship with someone who continues to demonstrate altered abilities, memories, and personality characteristics. Relational deprivation encompasses the attitudes and emotions of caregivers as they become increasingly separated from the original shared experiences and characteristics with their care-recipients (Aneshensel et al., 1995).

The impact of cognitive decline and behavioral problems.

Earlier cross-sectional caregiving studies have provided support for the assertion that behavioral problems found along the AD trajectory are strongly linked to negative outcomes experienced by caregivers, including role overload, role captivity, relational deprivation, burden, and other mental health complications (e.g., depression) (Aneshensel et al., 1995; Deimling & Bass, 1986; Pruchno & Resch, 1989). These studies also suggest that behavioral problems have the capacity to instigate more subjective stress in dementia caregivers than cognitive decline and ADL dependency, two additional prominent characteristics found within the caregiving career. Expanding on these earlier studies, Gaugler, Davey, Pearlin, and Zarit (2000) utilized growth curve modeling to explore how changes in care demands (including changes in behavioral problems) influence changes found in caregiver adaptation processes. In particular, the researchers examined the longitudinal impact of care demands on caregivers' emotional adaptation. Results indicated that behavioral problems were strong predictors of role overload in caregivers over the course of several years. This finding supports earlier findings from the comprehensive longitudinal analyses by Aneshensel et al. (1995), in which role overload and role captivity were positively associated with behavioral problems over a three-year period.

Expanding on these longitudinal implications, Gaugler, Kane, Kane, and Newcomer (2005) examined how behavioral problems exhibited early in the caregiving career impact subsequent emotional adaptation, as well as nursing home placement, an important and difficult transition often found within the caregiving career. Utilizing three-year data from dementia caregivers (classified as early career caregivers), results

indicated that caregivers who experienced more severe and early behavioral problems reported increases in depression and burden over the course of the study period. Furthermore, caregivers who experienced a higher frequency of behavioral problems early in their dementia caregiving careers were also more likely to place their care-recipients in long-term care earlier than those who did not. These findings imply that behavioral problems present early in the caregiving career may pose more challenges and difficulties for caregivers, thus prompting institutionalization of the care-recipient. Findings also support existing literature (Aneshensel et al., 1995; Gaugler et al., 2000) that has consistently demonstrated the harmful effects of behavioral problems throughout the duration of the dementia caregiving career.

Additional studies have examined different types of agitated behaviors exhibited by individuals with AD. Agitation is a hallmark behavioral symptom of AD and is distinguished by verbal or motor activity deemed inappropriate by those observing the behavior (Cohen-Mansfield, 2009; Cohen-Mansfield & Billig, 1986). Agitation can manifest itself in several ways, including screaming, cursing, or other vocalizations viewed as irrelevant to a current situation, as well as wandering, restlessness, handling objects inappropriately, and display of strange movements (Cohen-Mansfield, 2009). The occurrence and impact of agitation, as well as other behavioral symptoms in dementia, have been examined over the years. Tan and colleagues (2005) revealed that behavioral and other neuropsychiatric symptoms found in individuals diagnosed with AD and other forms of dementia, including delusions, anxiety, and agitation, were positively correlated with caregiver distress. Kaufer and colleagues (1998) reported findings indicating that

behavioral problems were found to be more distressing for caregivers than the cognitive decline that occurred in their care-recipients.

Bauer and colleagues (2001) examined caregiving outcomes in female spousal dementia caregivers. Using care-recipient cognitive status, a cross-sectional comparison of two groups of caregivers was conducted. Results indicated that female caregivers caring for those having more severe cognitive decline experienced more relational deprivation and lower levels of mastery compared to those caring for individuals with less cognitive decline. Ducharme and colleagues (2007) assessed mental and physical health outcomes in older husband caregivers, finding that a higher frequency of disruptive behaviors was linked to more psychological distress in participants. Role overload was associated with psychological distress, as well as lower self-perceived health. Role captivity was associated with not only psychological distress, but the intent to cease in-home caregiving. Likewise, high reports of relational deprivation were also related to an increased likelihood in ending in-home caregiving (Ducharme et al., 2007).

It is evident from existing research that dementia caregivers experience negative outcomes as a result of their caregiving trajectories. It is also apparent that cognitive decline and behavioral problems exhibited by care-recipients have the capacity to intensify these outcomes. Although negative caregiving outcomes have been a central focus in the caregiving literature, emerging research has begun to focus on the positive consequences associated with dementia caregiving.

Positive Outcomes for AD Caregivers

Extensive research conducted in the realm of dementia caregiving has revealed a plethora of results linking dementia caregiving to a number of negative outcomes

experienced by family caregivers (Adams, 2008; Pinquart & Sörensen, 2003a, 2003b, 2004; Vitaliano, Zhang, & Scanlan, 2003). Caregiving research is often viewed within theoretical frameworks that outline stress and coping mechanisms to help mitigate stress (George, 1990; Pearlin et al., 1990). Use of these models, although valuable, has led to a predominant focus on negative outcomes often associated with dementia caregiving. Recognizing the heavy focus on negative outcomes and the inattentiveness to potential positive outcomes associated with dementia caregiving has gradually prompted researchers to begin focusing on outcomes that caregivers consider to be positive. Understanding both positive and negative outcomes associated with dementia caregiving provides a more holistic and realistic understanding of the experiences of dementia caregivers.

Although dated, the few studies that have aspired to identify and understand positive aspects of dementia caregiving have provided some insight into the role of positive outcomes within the caregiving career. Kinney and Stephens (1989) investigated the role of hassles (caregiving stressors) and uplifts (caregiving satisfactions) in 60 primary dementia caregivers in four areas: (a) assisting care-recipients in ADLs, (b) care recipients' cognitive functioning, (c) care recipients' behavior, and (d) practical/logistical aspects of caregiving. The researchers aimed to identify care-recipient and caregiver characteristics associated with hassles and uplifts, as well as the direct effects of hassles, the interactive effects of hassles and uplifts, and the net effects of hassles and uplifts on caregivers' social and psychological well-being. Findings demonstrated that levels of distress could be predicted by the events occurring within caregiving routines. Caregivers who reported more care uplifts (e.g., feeling useful) actually cared for more physically

disabled care-recipients, thus suggesting a positive correlation between amount of assistance and reported caregiver satisfaction. In regard to cognitive and behavioral uplifts, women caring for care-recipients with fewer cognitive limitations reported more uplifts. The most satisfaction reported in terms of care-recipient behavior came from younger caregivers who spent more time per day providing care and who cared for care-recipients who were less socially withdrawn. Overall, characteristics of the care-recipient were stronger predictors of hassles, while characteristics related to caregivers were stronger predictors of uplifts.

Exploring the dynamics of positive aspects in caregiving, Lawton and colleagues (1989; 1991) measured caregiving appraisal and well-being in adult and spousal dementia caregivers. The researchers utilized a model that encompassed stressors, caregiving resources, and subjective appraisals of caregiving. Findings revealed that for spouses, caregiving satisfaction was a significant determinant of positive affect. For adult children, high levels of caregiving involvement resulted in both high levels of caregiving satisfaction and burden. Positive aspects of caregiving were related to the caregiver's satisfaction with the relationship prior to the disease onset (Lawton et al., 1989; 1991).

Examining both positive and negative impacts of dementia caregiving, Talkington-Boyer and Snyder (1994) explored additional factors associated with both caregivers and care-recipients, including locus of control, self-esteem, depression, perceived support, and problem solving mechanisms. A caregiver's ability to employ problem-solving coping mechanisms positively correlated with life satisfaction and self-rated health. It also negatively correlated with caregiver depression. Additionally, prior

relationship satisfaction with the care-recipient and satisfaction with social support were positively correlated with positive aspects of caregiving.

Pinquart and Sörensen (2003a) also examined uplifts in caregiving. In this meta-analysis, perceived uplifts in caregiving were associated with lower levels of caregiver depression, indicating that caregiving uplifts may help reduce the negative impacts of caregiving (Pinquart and Sörensen, 2003a).

Several limitations exist with studies measuring positive outcomes in dementia caregiving. First, samples were small and cross-sectional in nature, and participants were often selected using convenience sampling strategies. A second and greater limitation, however, is the variation of measures used within each of the studies. Varying measurement strategies have led to inconsistent results, making it difficult to generalize findings. Aiming to rectify the gaps and limitations in existing research, Tarlow and colleagues (2004) proposed a measure of positive aspects of caregiving that provided a more accurate understanding of positive caregiving outcomes. Framed within an integrated stress-health model (i.e., a theoretical model that included elements of stress-coping models and adaptive capabilities of the caregiver), the Positive Aspects of Caregiving scale was developed and tested on 1,229 participants of the REACH study (see Coon, Schulz, & Ory, 1999; Tarlow et al., 2004; Wisniewski et al., 2003).

Developed through modifications of prior instruments (see Lawton et al., 1989 and Beach et al., 2000), this measurement consists of nine items phrased as statements concerning the affective state of the caregiver in regard to his/her caregiving experience. The measure is also a combination of two components; self-affirmation and outlook on life. Through its use on large and diverse caregiving samples, this measure has demonstrated

validity and reliability and has the potential to help promote a more thorough understanding of the experiences of dementia caregivers (Tarlow et al., 2004).

Overall, the modest number of studies that have identified positive caregiving outcomes revealed that the majority of caregivers did in fact identify positive aspects of caregiving in conjunction with negative outcomes. This finding highlights the complex and dynamic nature of dementia caregiving and the importance of understanding the influential impacts of positive experiences within the caregiving career.

Physical Health Outcomes for AD Caregivers

Emotional and psychological outcomes are prevalent in the dementia caregiving career. Not only have these types of outcomes been largely scrutinized within the caregiving literature, outcomes related to caregiver physical health have also been observed due to the long-term nature of AD caregiving and the chronic stress often endured throughout the process. Research in the general population has revealed a link between chronic stress and physical health outcomes, including difficulty sleeping, poor diet, and the development of various illnesses (Taylor, 1995). Existing research has also revealed connections between mental stress and physical responses. As an example, distress has the potential to elevate stress hormones, which can further activate additional physiological activities that may lead to negative health outcomes (e.g., elevated levels of insulin, hyperglycemia, high blood pressure). If these health responses are prolonged, they may lead to further and more serious health complications, including diabetes, obesity, poor immune functioning, slow wound-healing responses, and cardiac complications (Grant, 1999; Kanel et al., 2010; Lovallo, 1997, Vitaliano, Young, & Zhang, 2004).

One of the first reviews of caregiver physical and mental health (Schulz, Visintainer, & Williamson, 1990) shed light on physical health risks that caregivers experience. Although the majority of the literature reviewed included self-reported health rather than objective health measures, some studies revealed poorer health outcomes among caregivers compared to non-caregivers. Expanding on their early review, Schulz and colleagues (1995) reviewed 40 additional studies examining caregivers as compared to non-caregivers in regard to physical health. Results were inconsistent regarding self-reported chronic health problems and use of medications.

Later reviews rectified the conflicting results found among earlier reviews of physical health outcomes among caregivers. Vitaliano, Zhang, and Scanlan (2003) performed a meta-analysis of 23 studies, spanning 38 years, comparing a large number of caregivers to non-caregivers who were similar in regard to age and sex. Eleven health categories were examined, including five categories of self-reported health and six physiological categories of health. Analyses revealed that caregivers reported poorer global health and took more medications for physical health complications as compared to non-caregivers. Also, caregivers had 23 percent higher levels of stress hormones and 15 percent lower levels of antibody responses. These findings are important, as prolonged physiological reactions to heightened stress hormones can lead to increased risks of health problems such as diabetes, hypertension, and reduced resistance to viruses (Vitaliano, Zhang, & Scanlan, 2003). The relationship between caregiving and self-reported health was also greater for older participants, suggesting that increases in physical illnesses are evident in older age and may be exacerbated by ongoing distress related to caregiving. This analysis also revealed that for women caregivers, caregiving

was related more strongly to self-reported global health than to physiological measures of health. In contrast, male caregiving was related to both self-reported health and physiological measures of health (Vitaliano, Zhang, & Scanlan, 2003).

Subsequent studies have contributed to our understanding of the link between caregiving and physical health complications. Sawatzky and Fowler-Kerry (2003) indicated that caregivers experience several physical complications, including back injuries, arthritis, hypertension, gastric ulcers, and headaches. Although it is unclear whether or not caregiving actually causes these physical impairments, it is likely that performing caregiving procedures may exacerbate these health conditions. Additional research attempts reveal that caregivers experience a decline in physical health following the hospital discharge of care-recipients requiring long-term care procedures (Douglas & Daly, 2003).

Similar to their previous meta-analyses conducted on caregiver psychological health outcomes (2003a), Pinquart and Sörensen (2003b) conducted a meta-analysis examining differences between caregivers and non-caregivers in regard to both psychological and physical health. The researchers hypothesized that caregivers would have significantly lower levels of psychological and physical health when compared to matched controls. As anticipated, greater differences for spousal caregivers were found compared to other relatives (e.g., adult children). It was theorized that this was due to spousal caregivers exhibiting more age-related health complications and disabilities than other relatives. Spousal caregivers also provide, in general, greater amounts of care as compared to other relatives. Finally, spousal caregivers are more likely to lack additional roles and social activities to buffer negative outcomes associated with caregiving. For

similar reasons, the authors also anticipated greater differences in older caregivers than in younger caregivers. As anticipated, results demonstrated that caregivers had lower levels of physical health as compared to non-caregivers. Few physical health differences, however, were found with regard to age, gender, and familial relationship to the care-recipient. Nonetheless, this meta-analysis supports earlier claims suggesting that caregivers, overall, experience more physical health complications than those who are not in the caregiving role (Pinquart & Sörensen, 2003b).

More recent research continues to produce findings related to caregiving and physical health complications. Two studies using structural equation modeling have examined relationships among caregiver burden, mental health, and physical health. Both found significant associations between caregiver physical health and mental health (e.g., depression and anxiety) (Groß, Fossa, Sorebo, & Dahl, 2006; Chang, Chiou, & Chen, 2010). Although not as well studied as psychological outcomes, physical health outcomes among caregivers remains an important area of inquiry to better comprehend the physical health risks of dementia caregivers.

Prior caregiving research has identified both important transitions and outcomes in the dementia caregiving career, both which are complex in nature and require further examination in order to better understand the dynamic caregiving process. To help contribute to preexisting caregiving research, the following hypotheses were developed to address the specific aims of this study.

Study Hypotheses

Caregiving onset hypotheses.

Hypothesis one. Caregivers who began providing care when they received a formal AD diagnosis or at the same time that symptom recognition occurred (abrupt entry) will report more mental health and physical health complications as compared to caregivers who began providing care prior to symptom recognition and diagnosis (gradual entry) (Aim 1). This hypothesis is based on literature suggesting that sequencing of various events surrounding AD caregiving leads to different forms of caregiving onset (Aneshensel et al., 1995; Gaugler et al., 2003; Gaugler, Zarit, & Pearlin, 2003b).

Hypothesis two. The effects of caregiving onset will be moderated by the care-recipient's level of cognition and behavior problems. Thus, for those caregivers experiencing an abrupt onset into the caregiving role, higher incidences of cognitive decline and behavioral problems found within the care-recipient will be associated with more mental health and physical health outcomes experienced by caregivers. In contrast, for those caregivers experiencing a gradual onset into the caregiving role, care-recipient cognition and behavioral problems will not be related to mental health and physical health outcomes experienced by caregivers (Aim 3). Selection of these moderating variables was determined based on their noted impact within the caregiving career as demonstrated through previous caregiving research (Cohen-Mansfield, 2009; Gaugler et al., 2000; Tan et al., 2005; Zhang, Vitaliano, & Lin, 2006).

Caregiver role hypotheses.

Hypothesis one. Caregivers who are currently occupying additional roles (e.g., parent or grandparent who is still providing care to an underage child(ren) living within

the home, employee) during the time in which they are serving as primary caregivers will report more mental health and physical health complications compared to caregivers who are not currently occupying roles in addition to their caregiving role (Aim 2). Selection of these roles was based on research identifying major stressors for caregivers holding multiple roles in addition to the caregiver role (i.e., employee, parent) (Edwards et al., 2002; Pavalko & Woodbury, 2000).

Hypothesis two. The effects of caregiver role occupancy will be moderated by the care-recipient's level of cognition and behavior problems. For those caregivers occupying the role of parent and/or employee, higher incidences of cognitive decline and behavioral problems found within the care-recipient will be associated with more mental health and physical health outcomes experienced by the caregiver. In contrast, for caregivers who are not currently occupying these additional roles, care-recipient cognition and behavioral problems will not be related to mental health and physical health outcomes experienced by caregivers (Aim 3). Selection of these moderating variables was determined based on their noted impact as demonstrated through previous caregiving research (Cohen-Mansfield, 2009; Gaugler et al., 2000; Tan et al., 2005; Zhang, Vitaliano, & Lin, 2006).

Due to the deleterious and progressive nature of AD, years of caregiving research has helped characterize the long-term nature of the dementia caregiving career and outcomes and implications found within it. Although significant strides have been made in understanding the risks and outcomes associated with AD caregiving, several knowledge gaps still exist. The next chapter, the study's methods, details the study design and measures used to investigate how caregiving onset, role occupancy, and various moderating factors affect key AD caregiving outcomes, including depression, role

overload, role captivity, relational deprivation, positive caregiving outcomes, and physical health.

CHAPTER FIVE

Methods

The present study employed a retrospective cross-sectional, quantitative study to investigate how caregiving onset, role occupancy, and various moderating factors impact key caregiving outcomes. Quantitative data were gathered from participants using measures designed to capture the various elements outlined in the study's aims: determine how different sequences of caregiving onset affect subsequent mental health and physical health outcomes experienced by caregivers; determine how multiple roles held by caregivers affect subsequent mental health and physical health outcomes experienced by caregivers; and examine variables within the caregiving context that serve as moderators in regard to mental health and physical health outcomes experienced by caregivers. A series of one-way ANOVAs and multiple linear regressions were utilized in order to address the specific aims of the study.

Participants

The sample for this study consisted of 100 caregivers providing primary care procedures for individuals with a diagnosis of AD. As the caregiving literature notes, the majority of caregivers are women (approximately 75%), consequently, extra efforts were made to ensure that men (who represent approximately 25% of caregivers) were adequately represented in the sample in accordance with this ratio. Efforts included targeting women care-recipients receiving community services from the recruitment sites, as there was a probable chance that these women's spouses were serving as their primary caregiver. Other efforts included targeting individuals who may have two caregivers, one of whom may be a man serving as the primary caregiver. Participants were recruited

primarily through the local Kentucky and Greater Indiana Chapter of the Alzheimer's Association and local caregiver support groups held at various locations throughout Lexington, Kentucky. Once approval from the Institutional Review Board (IRB) at the University of Kentucky was obtained (see Appendix B), IRB approved flyers were also dispersed throughout the University of Kentucky's campus and local areas in the Lexington community, including The Lexington Senior Center, Family Counseling Service, Eldercare, and Helping Hands Adult Daycare. Inclusion criteria were explained to potential participants. Once interest to participate in the study was expressed, individuals were provided with the study materials.

Participants had to identify themselves as the primary caregiver for an individual diagnosed with AD. For the purposes of this research, a primary caregiver was defined as a relative of an older individual, who assisted the care-recipient with the majority of activities of daily living (e.g., bathing, feeding, dressing, toileting), instrumental activities of daily living (e.g., managing finances, transportation), and service provisions required by that individual. Individuals participating in this study were required to be in the role of primary caregiver in order to ensure that all participants were providing comparable levels of care. In addition to the primary caregiver being a relative of the care-recipient, they were also required to be living in the same residence as the care-recipient, and could only be caring for one older adult at the time of the study. Maintaining the specific caregiver criteria was critical in order to address the study hypotheses, to help reduce caregiver variability, and to help ensure that all participants within the study were indeed providing the majority of care for the care-recipients.

Care-recipients had to be over the age of 50 and were required to have a probable

diagnosis of AD determined by a physician in order for their caregiver to participate in this study. Prior to participating in this study, caregivers verified, either in person or via telephone, that their care-recipients had received a probable diagnosis of AD from their physician. Including the age and diagnosis criteria for care-recipients was done in order to help reduce care-recipient variability. Many different types of dementia exist, with each type clinically manifesting itself differently in individuals. For example, vascular dementia (typically caused by a stroke) may occur in a stepwise manner rather than in the form of a gradual progression found in AD, and may also cause more physical complications in an individual. Dementia with Lewy bodies and dementia related to Parkinson's disease are more likely to cause hallucinations in individuals, while frontotemporal dementia often leads to more severe personality changes (Alzheimer's Association, 2010). Therefore, ensuring that care-recipients had a probable diagnosis of AD as opposed to another type of dementia allowed for more accuracy in regard to caregiving experiences. It was undetermined in this study whether care-recipients developed early onset AD or late onset AD. There were no specific caregiver age criteria to participate in this study. The participant response rate in this study was 85.5 percent.

Data Collection Procedures

The process of data collection consisted of each participant completing the survey instruments (described below). Each participant was provided with a packet containing an explanation of the study; consent forms; survey instruments; and a self-addressed, stamped envelope for returning the consent form and survey instruments. Participants completed the survey instruments in the privacy of their own homes at their own pace and convenience. All completed survey instruments in this study were based upon the

caregiver's self-report about his/her caregiving experience, as well as the current status of his/her care-recipient. As individuals with AD experience diminished capacities and abilities with progression of the disease, family caregivers often become the primary source for information and assessment regarding the extent and severity of the care-recipient's status.

Completed materials were returned to the researcher directly via mail. Participants were compensated for their time in an attempt to increase participation (\$25.00 per participant). Survey instruments took approximately 30 minutes to complete (this was determined by the primary investigator completing the survey materials prior to dissemination). Participants had two weeks to complete and return the survey instruments. The primary investigator of this study was available for questions through telephone, email, or in-person contact in the event that a participant required assistance with completing the study materials.

Measures

Questions developed specifically for this study were included in the survey instruments in order to obtain information regarding onset patterns into the caregiving role, and the number of roles held by the caregivers participating in this study. An array of psychosocial measures was used to determine care-recipient cognition, care-recipient behavioral problems, and caregiving outcomes.

Caregiver Demographics. Caregiver demographics were obtained for descriptive purposes and to provide a more thorough perspective of the sample. Demographics included caregiver age, sex, race, marital status, education level, income, work status, and relationship to the care-recipient (see Appendix A, p. 136).

Independent variables.

Caregiving onset sequences. Participants were originally categorized into one of four different onset sequence groups based on their pattern of entry into the caregiving role: care provision group (i.e., provision of care occurred prior to symptom recognition or actual diagnosis), recognition-care group (i.e., symptom recognition and care provision occurred prior to diagnosis), recognition-diagnosis group (i.e., symptom recognition occurred prior to the provision of care and a diagnosis), and diagnosis dependent group (i.e., clinical diagnosis was sought prior to or at the same time that symptom recognition and/or provision of care occurred).

Caregivers were classified by their responses to a series of questions regarding entry into their caregiving role. *Symptom recognition* was determined by asking caregivers when they first began to recognize something was wrong with their relative. *Duration of care* was established by asking caregivers when they first began providing care procedures for their relative, and how long they continued providing care. *Diagnosis* was gauged by asking a series of questions regarding when the care-recipient obtained a formal diagnosis of AD from a physician (Gaugler et al., 2003; Gaugler, Zarit, & Pearlin, 2003b). Based on how caregivers responded to the provided questions, they were classified into one of the four onset groups. For analyses purposes, caregivers were further categorized into two groups. Those who were originally classified into the care

provision and recognition-care group were considered to have experienced a gradual entry into the caregiving role. Caregivers classified in the recognition-diagnosis and diagnosis dependent group were considered to have experienced an abrupt entry into the caregiving role (see Appendix A, p. 138). This categorization process was utilized due to a small sample size in the current study, thus preventing the categorization of caregivers into four caregiving onset groups.

Caregiver roles. A list of roles was provided for participants, who were asked to identify which of the roles they were currently occupying in addition to their caregiving role. Participants were also asked to estimate the length of time spent in the identified role, importance of the role to them, and satisfaction with the role upon being a caregiver (see Appendix A, p. 140). Caregivers were categorized into two groups according to their responses: (a) currently has no roles in addition to the caregiving role and (b) currently holds role(s) in addition to the caregiving role. Specifically, the additional roles examined in the current study included the role of employee and the role of parent. For the purposes of this study, the researcher chose to categorize participants in this way based on supporting literature that has identified major stressors for caregivers holding multiple roles in addition to the caregiver role (e.g., employee, parent) (Edwards et al., 2002).

Moderating variables.

Care-recipient cognition. The care-recipient's cognitive status was measured using Pearlin's *Cognitive Status Scale* (see Appendix A, p. 143). This measure has demonstrated reliability and validity throughout several research efforts (Pearlin et al., 1990). The *Cognitive Status Scale* is an eight-item, subjective assessment of the care recipient's cognitive ability obtained by having caregivers assess their care-recipients at

the time of their participation in the study. Each item is scored from 0 (*not at all difficult*), to 4 (*cannot do at all*). The *Cognitive Status Scale* measures general cognitive ability, time orientation, place orientation, short-term memory, visual recognition, and language skills. In the current data set, Cronbach's alpha revealed an internal reliability of .894. For analyses purposes, summary scores were computed. The variable was also centered in regression analyses in order to reduce multicollinearity.

Care-recipient behavior problems. Care-recipient behavior problems were measured using Pearlin's *Measure of Problematic Behaviors* (see Appendix A, p. 144), a 14-item scale assessing the frequency of socially inappropriate behaviors within the past week. Response categories ranged from 1 (*no days*) to 4 (*5/more days*). This measure has demonstrated reliability and validity throughout several research efforts (Pearlin et al., 1990). In the current data set, Cronbach's alpha revealed an internal reliability of .894. For analyses purposes, summary scores were computed. The variable was also centered in regression analyses in order to reduce multicollinearity.

Outcomes variables.

Depression. The *Center for Epidemiologic Studies Depression Scale (CES-D)*, a 20-item self-report measure that assesses symptoms of depression in the general population, was used to assess depression in caregivers (Radloff, 1977). Each item on the scale states an experience related to depression that the respondent may have experienced within the past week. Sixteen of the items express negative experiences and four items express positive experiences. In the original study, Radloff (1977) reported high internal consistency among items (ranging from .84 to .90); Miller-Johnson and Maumary-Gremaud (1995) also found high internal consistency. These studies have also supported

the validity of the CES-D in regard to its utilization with diverse populations, including older adults and minorities (see Hertzog, Van Alstine, Usala, & Hultsch, 1990; Knight, Williams, McGee, & Olaman, 1997; Nguyen, Kitner-Triolo, Evans, & Zonderman, 2004; Radloff, 1977; Wong, 2000). Respondent answers were summed and the total score was used as an indicator of depressive symptoms (see Appendix A, p. 146). Because the caregiving sample in this study involved individuals across a variety of ages, the CES-D was chosen as an alternative to the Geriatric Depression Scale (Yesavage, 1982), which is also a commonly used measure of depression.

Role overload. Role overload occurs when too many tasks must be performed in too short a time period, leading to caregivers feeling overwhelmed and exhausted with caregiving responsibilities. To measure role overload, participants completed Pearlin et al.'s (1990) *Measure of Overload* scale, which has demonstrated adequate reliability (see Appendix A, p. 147). This is a three-item scale with response categories ranging from 1 (*not at all*) to 4 (*completely*). In the current data set, Cronbach's alpha revealed an internal reliability of .894. For analytic purposes, summary scores were computed.

Role captivity. Role captivity refers to the caregiver being an unwilling and involuntary incumbent of the caregiving role (e.g., caregivers are obligated to care for a debilitated relative when they would rather be doing something else), and experiencing a sense of being trapped in the caregiving role. To measure role captivity, participants were asked a series of questions from Pearlin's et al.'s (1990) *Measure of Role Captivity* (see Appendix A, p. 148). The *Measure of Role Captivity* is three-item scale assessing the unwanted aspects of the caregiving role. Response categories ranged from 1 (*not at all*) to 4 (*very much*). In the current data set, Cronbach's alpha revealed an internal reliability of

.894. For analyses purposes, summary scores were computed.

Relational deprivation. The *Measure of Relational Deprivation* scale by Pearlin et al. (1990) was used in this study. The measure includes two subscales: the first involves the exchange of intimacy between the caregiver and care-recipient (deprivation of intimate exchange) (alpha = .77), and the second involves the goals and social activities that were once shared with the care-recipient but are no longer attainable (deprivation of goals and activities) (alpha = .67) (see Appendix A, p. 149). Three items measured deprivation of intimate exchange, ranging from 1 (*not at all*) to 4 (*completely*), and three items measured deprivation of goals and activities, ranging from 1 (*not at all*) to 4 (*completely*). The scales were combined for analyses in the present study. In the current data set, Cronbach's alpha revealed an internal reliability of .894. For analyses purposes, summary scores were computed.

Positive aspects of caregiving. This study utilized the *Positive Aspects of Caregiving Questionnaire* (Tarlow et al., 2004) to measure participants' positive caregiving experiences. Reflecting earlier work by Lawton et al. (1989), this questionnaire consists of 9 items, in the form of statements, concerning the caregiver's mental and affective state in regard to their caregiving experience (see Appendix A, p. 150). Participants were asked to rate each item on a 5-point scale ranging from 1 (disagree a lot) to 5 (agree a lot). The response options provided variability in caregiver responses (as opposed to typical yes/no questionnaires), and helped increase reliability. This measure has been shown to be valid and reliable through several research efforts (see Tarlow et al., 2004). In the current data set, Cronbach's alpha revealed an internal reliability of .914. For analyses purposes, summary scores were computed.

Caregiver physical health. Caregivers were assessed using an illness checklist and several subjective items modified from the Rand-36 (also known as the SF-36) (Hays, Sherbourne, & Mazel, 1993). A list containing various illnesses was included (e.g., arthritis, high blood pressure, diabetes, cancer, Parkinson's disease), and caregivers were asked place a check mark by any of the illnesses that she/he currently had. Caregivers also had the opportunity to list any illnesses they currently had that were not included in the provided checklist (see Appendix A, p. 151). The selected items from the Rand-36 also asked participants to rate their health as excellent, very good, good, fair, or poor (overall health rating). Participants were also asked to rate their health compared to one year ago. For analytic purposes, the overall health rating scale and the health compared to one year ago scale were used. Selected items from the Rand-36 were included based on their common use to determine health status among individuals (Hays, Sherbourne, & Mazel, 1993; Ware & Sherbourne, 1992) (see Appendix A, p. 152).

Care-recipient physical health. For this study, an illness checklist and several subjective items modified from the Rand-36 (Hays, Sherbourne, & Mazel, 1993) were used to determine care-recipients' physical health. Caregiver participants completed this section of the questionnaire (see Appendix A, p. 151). The selected items from the Rand-36 asked participants to rate their care-recipient's health as excellent, very good, good, fair, or poor. Participants were also asked to rate their care-recipient's health compared to one year ago. The selected items from the Rand-36 were included based on their common use to determine health status among individuals (Hays, Sherbourne, & Mazel, 1993; Ware & Sherbourne, 1992). Data on the physical health of the care-recipient were used for descriptive purposes in this study (see Appendix A, p. 152).

Data Entry

All data were manually double entered into SPSS (version 18). Data were screened for missing fields and for any pattern that may emerge within the missing data. Distributions were also checked. Scales were checked to ensure internal consistency, and scale scores were computed.

Analysis

Data analyses were designed to answer the primary hypotheses of the proposed study:

Caregiving onset hypotheses.

Hypothesis one. The first hypothesis was analyzed using a series of one-way ANOVAs with caregiving onset treated as the independent variable. The two onset sequence groups into which the caregivers were classified included gradual entry and abrupt entry. The following variables were used as dependent variables: depression, role overload, role captivity, relational deprivation, positive caregiving outcomes, and caregiver physical health.

Hypothesis two. A series of linear regression models were conducted to address this moderation hypothesis. Variables included the predictors (caregiving onset), the moderators (care-recipient cognition and care-recipient behavioral problems), the interaction between moderators and predictors, and the outcome variables (depression, role overload, role captivity, relational deprivation, positive caregiving outcomes, and caregiver physical health).

Caregiver roles hypotheses.

Hypothesis one. A series of one-way ANOVAs were conducted using caregiver role occupancy as the independent variable. Caregivers were categorized into two groups according to their responses: (a) currently has no roles in addition to the caregiving role and (b) currently holds role(s) in addition to the caregiving role. The following variables were used as dependent variables: depression, role overload, role captivity, relational deprivation, positive caregiving outcomes, and physical health of caregivers.

Hypothesis two. A series of linear regression models were conducted to address this moderation hypothesis. Variables included the predictors (caregiver roles), the moderators (care-recipient cognition and care-recipient behavioral problems), the interaction between moderators and predictors, and the outcome variables (depression, role overload, role captivity, relational deprivation, positive caregiving outcomes, and caregiver physical health).

Mediation hypotheses were originally proposed in the current study. For mediation to occur, there must first be a relationship between the independent and dependent variables (Baron & Kenny, 1986). Upon further examination of correlations in the present study, however, it was found that mediation did not hold. Therefore, moderation hypotheses were developed and utilized in this study. A moderator is a variable (quantitative or qualitative) that affects the direction and/or strength of the relationship between an independent or dependent variable. Moderation implies that the causal relation between two variables changes as a function of the moderator variable (Baron & Kenny, 1986).

Power Analysis

To determine the sample size needed for the proposed analyses, two power analyses were conducted: one for the ANOVA analyses and one for the regression analyses to ensure that the sample size was sufficient for both types of analyses. The power analyses for the one-way ANOVAS with two groups (caregiving onset; caregiver roles) using $p < .05$, power = .85, effect size = medium revealed that a total of 125 participants were needed. The power analyses for the regression analyses with three predictors using $p < .05$, power = .85, effect size = medium revealed that a total of 87 participants were needed. To ensure that the sample size was adequate for all analyses, it was determined that 125 participants would be included in the present study. Following recruitment procedures for this study, a total of 100 caregivers participated in the study.

CHAPTER SIX

Results

Chapter Six provides the results of the current study, including a description of participants. The chapter's dominant focus is on analyses that address the primary hypotheses of this study. Data were analyzed using SPSS for Windows, version 18.0.

Caregiver Descriptive Information

Basic demographic information for the caregivers in the current study is shown in Table 6.1. Caregivers were on average 57 (SD = 15.24) years old and spent an average of 60 months caring for their care-recipients. The caregiver sample was 77% female.

Table 6.1

Descriptive Characteristics of Caregivers

	Caregivers (N = 100)
Caregiver average age (years)	57.01 (Range 29-88)
Caregiver gender (%)	
Male	23.0
Female	77.0
Caregiver race (%)	
White	82.0
Black	14.0
Asian	2.0
Hispanic	2.0
Other	0.0
Marital status (%)	
Married and/or living with partner	80.0
Divorced	10.0
Separated	5.0
Never married	5.0
Caregiver's level of education (%)	
High school or less	15.0
Some college	41.0
Bachelor's degree and beyond	44.0
Caregiver income (%)	
\$5,000-\$19,999	7.0
\$20,000-\$39,999	30.0
\$40,000-\$79,999	41.0
\$80,000 or over	22.0
Caregiver employment (%)	
Working a full-time job	39.0
Working a part-time job	10.0
Keeping house full-time	20.0
Retired	29.0
Unemployed	2.0

Table 6.1

Descriptive Characteristics of Caregivers

Caregiver relationship to care- recipient (%)	
Spouse	31.0
Daughter	47.0
Son	11.0
Grandchild	3.0
Daughter-in-law	5.0
Son-in-law	1.0
Other	2.0
Care-recipient average age (years)	80.25 (Range 51-100)
Caregiving length (%)	
Less than 6 months	0.0
6-12 months	17.0
13-24 months	16.0
25 months to less than 5 years	30.0
5 years or more	37.0
Hours of care per week (%)	
Less than 20 hours	14.0
20-40 hours	41.0
41-60 hours	14.0
61-80 hours	8.0
81-100 hours	4.0
Over 100 hours	19.0

The moderation hypotheses in this study were tested using multiple linear regression, which included the predictors (gradual and abrupt caregiving onset; caregiver roles), the moderators (care-recipient cognition and care-recipient behavioral problems), and the moderator interaction between the moderator and predictor terms (caregiving onset/caregiver roles x cognition/behavioral problems) on the outcome. The moderator hypotheses state that the relationship between the predictor variables (caregiving onset and caregiver roles) and the outcome variables (depression, role overload, role captivity, relational deprivation, positive caregiving outcomes, and physical health) may change in strength or direction in the presence of the moderator variables (care-recipient cognition and behavioral problems) (Baron & Kenny, 1986) (see Figure 6.1).

Figure 6.1

Diagram of the Moderation Model (Caregiving Onset)

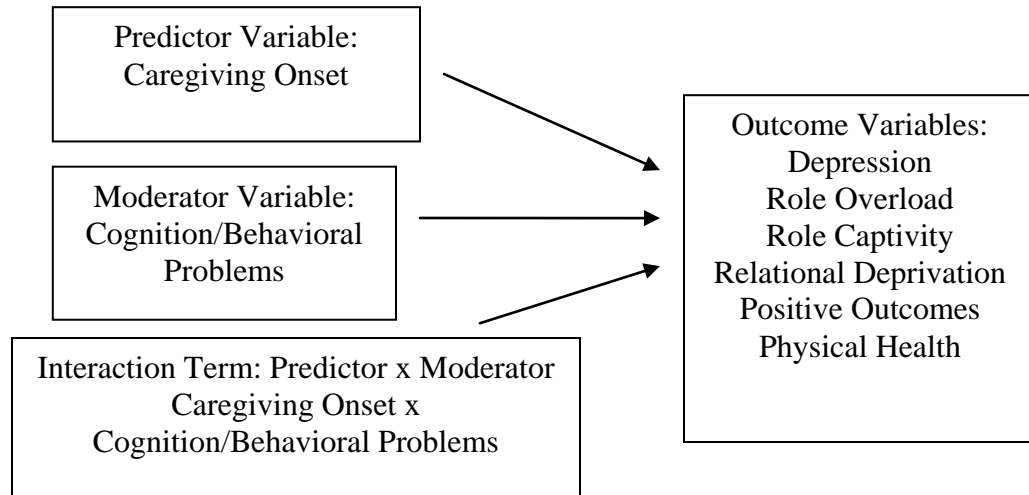
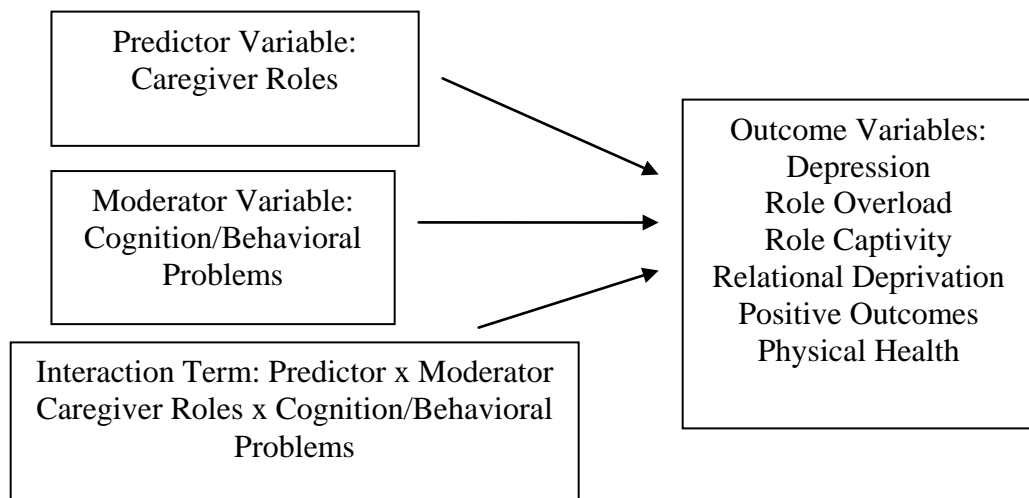


Diagram of the Moderation Model (Caregiver Roles)



To address the aims of this study, analyses for caregiving onset are presented first, followed by analyses for caregiver roles.

Analyses for Caregiving Onset

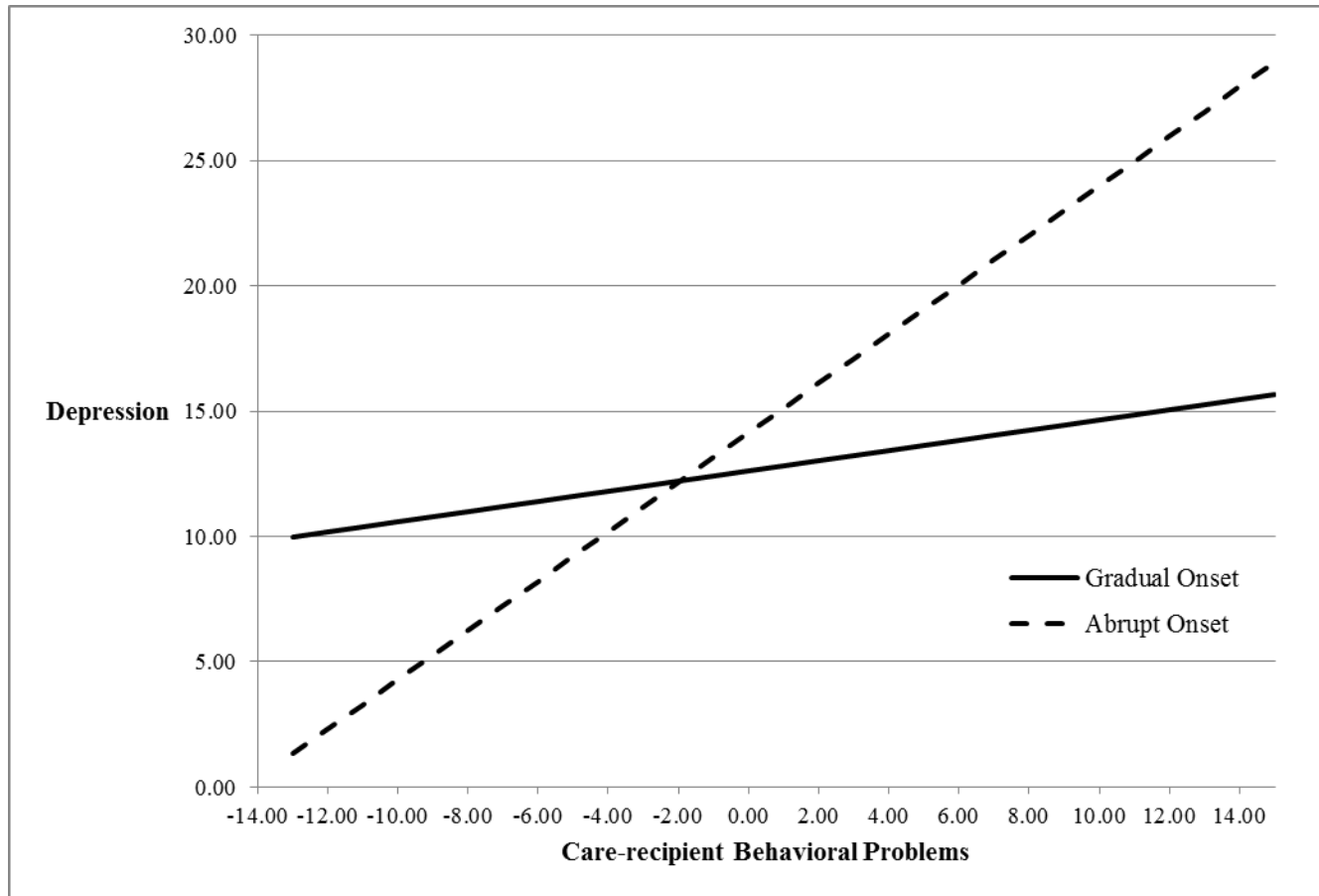
Depression.

The first specific aim of this study addressed the effects of caregiver onset on caregiver mental and physical health. The first hypothesis addressed how caregiving onset was related to subsequent mental health and physical health outcomes experienced by caregivers. To address this first aim, a one-way ANOVA was conducted. The independent variable was caregiving onset (gradual and abrupt onsets). The dependent variable was depression. The ANOVA failed to reveal a significant difference between a gradual entry ($M = 12.81$, $SD = 9.88$) and abrupt entry ($M = 15.58$, $SD = 11.48$), [$F(1, 98) = 1.56$, $p = .22$, $\eta^2_{\text{partial}} = .215$].

To determine if care-recipient cognition or behavior moderated the caregiving onset and depression relationship (Aim 3), multiple regression analyses were conducted. The overall regression model for caregiving onset, care-recipient cognition, and depression was not significant [$F(3, 96) = 1.35$, $p = .26$, $R^2 = .04$] (see Table 6.2). However, the overall model that addressed behavioral problems as a moderator of caregiving onset and depression was significant [$F(3, 96) = 5.94$, $p = .00$, $R^2 = .16$]. Neither the effect of onset nor behavior was significant (see Table 6.3). The interaction between onset and behavioral problems was, however, significant (see Table 6.3). Further inspection of the interaction revealed that care-recipient behavioral problems were not related to depression for caregivers having a gradual caregiving onset experience [$t(65) = 1.14$, $p = .26$, $\beta = .14$]. For those caregivers having abrupt caregiving onset experiences,

increases in depression were found when care-recipients experienced higher levels of behavioral problems [$t(31) = 3.92, p = .00, \beta = .58$]. (see Figure 6.2).

Figure 6.2
Significant Interaction Between Depression and Behavioral Problems

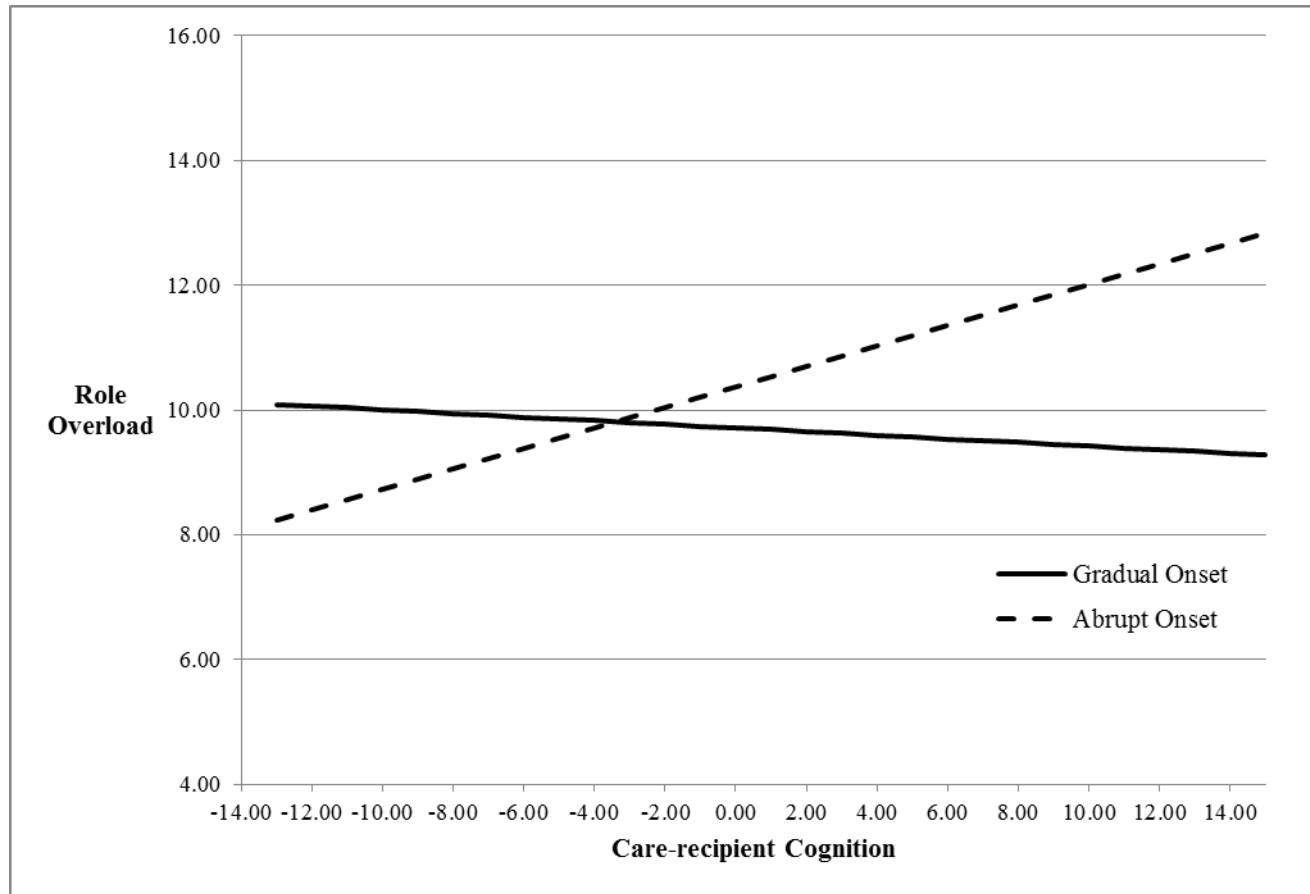


Role overload.

Analyses of the effects of caregiving onset on role overload were similar to those performed for depression. First, a one-way ANOVA was conducted (Aim 1) followed by a regression model to test for moderation (Aim 3). The ANOVA failed to reveal a significant difference between a gradual entry ($M = 9.70$, $SD = 2.48$) and abrupt entry ($M = 10.33$, $SD = 3.35$), [$F(1, 98) = 1.13$, $p = .29$, $\eta^2_{\text{partial}} = .011$].

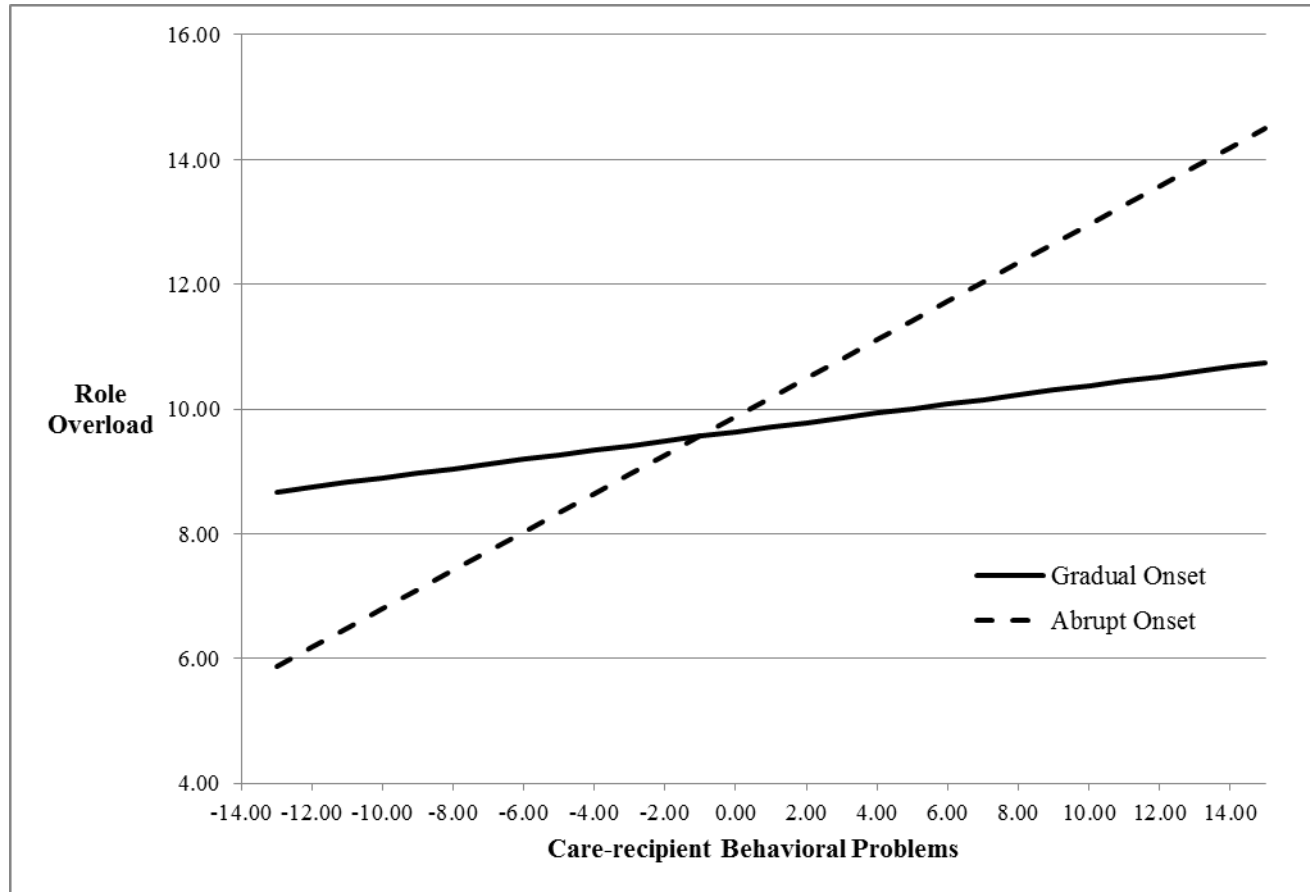
The overall regression model, with care-recipient cognition as a moderator (Aim 3), showed that there was a marginal effect for caregiving onset, care-recipient cognition, and role overload [$F(3, 96) = 2.54$, $p = .06$, $R^2 = .07$]. Neither the effect of caregiver onset or care-recipient cognition was significant for role overload. However, the interaction between onset and cognition was significant for role overload (see Table 6.2). Decomposition revealed that for caregivers who had a gradual caregiving onset experience, care-recipient cognition was not related to role overload [$t(65) = -.59$, $p = .56$, $\beta = -.07$]. For caregivers who had an abrupt caregiving onset experience, however, increases in caregiver role overload were found when care-recipients experienced higher levels of cognitive decline [$t(31) = 2.13$, $p = .04$, $\beta = .36$]. (see Figure 6.3).

Figure 6.3
Significant Interaction Between Role Overload and Cognition



The overall regression model was also significant for caregiving onset, behavioral problems, and role overload (Aim 3) [$F(3, 96) = 8.49, p = .00, R^2 = .21$]. The effect of onset and the effect of behavior was not significant (see Table 6.3). The interaction between onset and behavioral problems was significant (see Table 6.3). Decomposition revealed that care-recipient behavioral problems were not related to role overload for caregivers classified as having a gradual caregiving onset experience [$t(65) = 1.69, p = .10, \beta = .21$]. For caregivers classified as having abrupt caregiving onset experiences, analyses determined that increases in role overload were found when care-recipients experienced higher levels of care-recipient behavioral problems [$t(31) = 4.36, p = .00, \beta = .62$]. (see Figure 6.4).

Figure 6.4
Significant Interaction Between Role Overload and Behavioral Problems

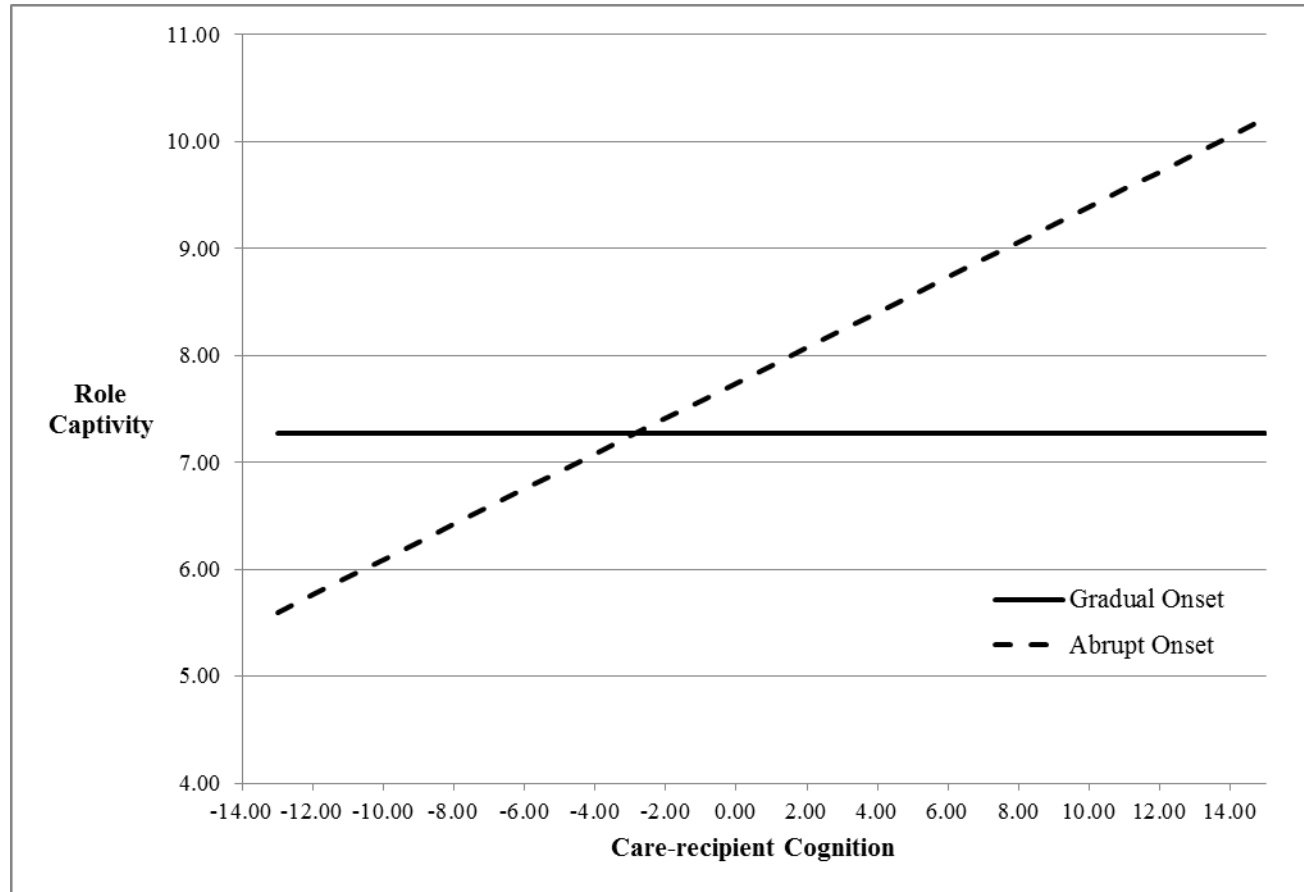


Role captivity.

To examine the effect of caregiving onset on role captivity, a one-way ANOVA was conducted (Aim 1). The ANOVA failed to reveal a significant difference between a gradual entry ($M = 7.23$, $SD = 2.74$) and an abrupt entry ($M = 7.70$, $SD = 2.82$), [$F(1, 98) = .53$, $p = .47$, $\eta^2_{\text{partial}} = .005$].

The overall regression model for caregiving onset, care-recipient cognition, and role captivity (Aim 3) revealed a marginal effect [$F(3, 96) = 2.33$, $p = .08$, $R^2 = .07$] (see Table 6.2). Neither the effect of onset nor cognition was significant for role captivity. The interaction between onset and cognition, however, was significant for role captivity (see Table 6.2). Analyses revealed that for those caregivers having a gradual caregiving onset experience, care-recipient cognition was not related to role captivity [$t(65) = .01$, $p = .99$, $\beta = .001$]. For caregivers having abrupt caregiving onset experiences, increases in role captivity were found in caregivers when care-recipients experienced higher levels of cognitive decline [$t(31) = 2.65$, $p = .01$, $\beta = .43$] (see Figure 6.5). The test of the model for caregiving onset, behavioral problems, and role captivity (Aim 3) was not significant [$F(3, 96) = 1.23$, $p = .30$, $R^2 = .04$] (see Table 6.3).

Figure 6.5
Significant Interaction Between Role Captivity and Cognition

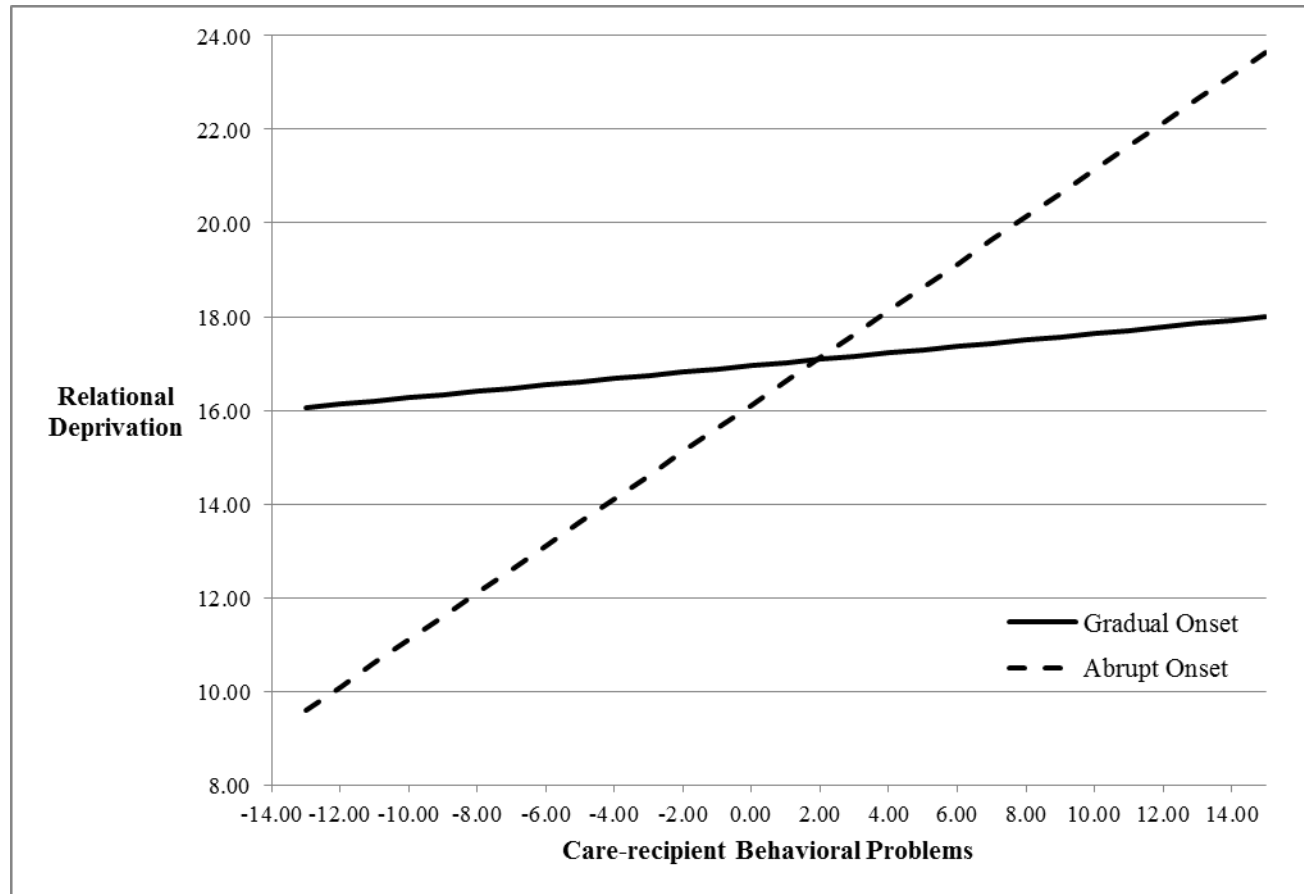


Relational deprivation.

To examine the effect of caregiving onset on relational deprivation (Aim 1), a one-way ANOVA with relational deprivation as the dependent variable was conducted. The ANOVA failed to reveal a significant difference between a gradual entry ($M = 17.01$, $SD = 4.50$) and an abrupt entry ($M = 16.85$, $SD = 5.12$), [$F(1, 98) = .028$, $p = .87$, $\eta^2_{\text{partial}} = .00$].

The overall regression model involving cognition as a moderator (Aim 3) was significant for caregiving onset, care-recipient cognition, and relational deprivation [$F(3, 96) = 6.87$, $p = .00$, $R^2 = .17$]. The effect of onset and the effect of care-recipient cognition were not significant. Likewise, the interaction between onset and cognition was not significant (see Table 6.2). The overall regression model was significant for caregiving onset, behavioral problems, and relational deprivation (Aim 3) ($F(3, 96) = 6.75$, $p = .00$, $R^2 = .17$). The effect of onset and the effect of behavior was not significant (see Table 6.3). The interaction between onset and behavioral problems was significant (see Table 6.3). Further inspection of the interaction revealed that care-recipient behavioral problems were not related to relational deprivation for caregivers who had a gradual onset experience [$t(65) = .851$, $p = .398$, $\beta = .105$]. For caregivers having abrupt onset experiences, however, increases in relational deprivation were found when care-recipients experienced higher levels of behavioral problems [$t(31) = 4.86$, $p = .00$, $\beta = .66$] (see Figure 6.6).

Figure 6.6
Significant Interaction Between Relational Deprivation and Behavioral Problems



Positive caregiving outcomes.

To examine the effect of caregiving onset on positive caregiving outcomes (Aim 1), a one-way ANOVA was conducted. The independent variable in the analysis was caregiving onset (gradual and abrupt onsets). The dependent variable was positive outcomes. The ANOVA failed to reveal a significant difference between a gradual entry ($M = 32.51$, $SD = 8.63$) and an abrupt entry ($M = 30.12$, $SD = 8.45$), [$F(1, 98) = 1.71$, $p = .19$, $\eta^2_{\text{partial}} = .017$].

The overall regression model for caregiving onset, care-recipient cognition, and positive caregiving outcomes (Aim 3) [$F(3, 96) = .56$, $p = .64$, $R^2 = .02$] was not significant (see Table 6.2). Furthermore, there was no significance found in the regression model for caregiving onset, behavioral problems, and positive caregiving outcomes (Aim 3) [$F(3, 96) = 1.07$, $p = .37$, $R^2 = .03$] (see Table 6.3).

Caregiver physical health.

To examine the effect of caregiving onset on caregiver physical health outcomes (Aim 1), two one-way ANOVAs were conducted. The independent variable in the analysis was caregiving onset (gradual and abrupt onsets). Dependent variables were caregiver physical health (the overall health rating scale and the health compared to one year ago scale). In regard to the overall health rating, the ANOVA failed to reveal a significant difference between a gradual entry ($M = 3.21$, $SD = .95$) and an abrupt entry ($M = 3.24$, $SD = .87$), [$F(1, 98) = .029$, $p = .87$, $\eta^2_{\text{partial}} = .00$]. In regard to the caregivers' health compared to one year ago, the ANOVA failed to reveal a significant difference between a gradual entry ($M = 2.62$, $SD = .67$) and an abrupt entry ($M = 2.63$, $SD = .70$) [$F(1, 98) = .004$, $p = .95$, $\eta^2_{\text{partial}} = .00$].

The overall regression models for caregiving onset, care-recipient cognition, and caregiver physical health (Aim 3) ($F(3, 96) = .13, p = .94, R^2 = .01$; $F(3, 96) = .82, p = .49, R^2 = .03$) were not significant (see Table 6.2). Also, there was no significance found in regression models involving caregiving onset, behavioral problems, and physical health outcomes (Aim 3) [$F(3, 96) = .56, p = .64, R^2 = .02$; $F(3, 96) = 1.91, p = .13, R^2 = .06$] (see Table 6.3).

Table 6.2
Cognition as a Moderator of the Effects of Onset on Outcomes

Outcome	Caregiving Onset			Cognition			Cognition x Onset			Model Summary
	<i>B</i>	<i>t</i>	<i>p</i>	<i>B</i>	<i>t</i>	<i>p</i>	<i>B</i>	<i>t</i>	<i>p</i>	
Depression	.13	1.33	.19	-.161	-.53	.60	.30	.99	.32	$F(3, 96) = 1.35$ $p = .26, R^2 = .04$
Role Overload	.12	1.20	.23	-.53	-1.77	.08	.68	2.27	.03*	$F(3, 96) = 2.54$ $p = .06, R^2 = .07$
Role Captivity	.09	.90	.40	-.40	-1.33	.19	.59	1.97	.05*	$F(3, 96) = 2.33$ $p = .08, R^2 = .07$
Relational Deprivation	.01	.05	.96	.08	.28	.78	.35	1.24	.22	$F(3, 96) = 6.87$ $p = .00, R^2 = .17$
Positive Caregiving	-.13	-1.29	.20	.01	.04	.97	-.01	-.02	.98	$F(3, 96) = .56$, $p = .64, R^2 = .02$
Physical Health	.02	.14	.89	.02	.05	.96	-.08	-.25	.80	$F(3, 96) = .13$ $p = .94, R^2 = .01$
Health Comparison	.00	.02	.98	.44	1.44	1.53	-.48	-1.57	.12	$F(3, 96) = .82$ $p = .49, R^2 = .03$

* $p \leq .05$

Table 6.3
Behavioral Problems as a Moderator of the Effects of Onset on Outcomes

	Caregiving Onset			Behavioral Problems			Behavior x Onset			Model Summary
Outcome	<i>B</i>	<i>t</i>	<i>p</i>	<i>B</i>	<i>t</i>	<i>p</i>	<i>B</i>	<i>t</i>	<i>p</i>	
Depression	.11	1.14	.26	-.38	-1.34	.18	.71	2.52	.01*	$F(3, 96) = 5.94$ $p = .00, R^2 = .16$
Role Overload	.09	.94	.35	-.39	-1.43	.16	.79	2.91	.00*	$F(3, 96) = 8.49$ $p = .00, R^2 = .21$
Role Captivity	.07	.65	.52	-.13	-.42	.68	.29	.97	.34	$F(3, 96) = 1.23$ $p = .30, R^2 = .04$
Relational Deprivation	-.04	-.40	.69	-.53	-1.90	.06	.88	3.15	.00*	$F(3, 96) = 6.75$ $p = .00, R^2 = .17$
Positive Caregiving	-.14	-1.34	.18	.19	.65	.52	-.08	-.26	.80	$F(3, 96) = 1.07$ $p = .37, R^2 = .03$
Physical Health	.02	.23	.82	.19	.61	.55	-.29	-.95	.34	$F(3, 96) = .56$ $p = .64, R^2 = .02$
Health Comparison	.02	.19	.86	.44	1.47	.15	-.60	-2.02	.05*	$F(3, 96) = 1.91$ $p = .13, R^2 = .06$

* $p \leq .05$

Analyses for Caregiver Roles

Depression.

The second set of hypotheses addressed how multiple roles held by caregivers affect subsequent mental health and physical health outcomes experienced by caregivers (Aim 2). To address this second aim, a one-way ANOVA was conducted. The independent variable in this analysis was caregiver roles (caregivers were categorized into two groups according to their responses: (a) currently has no roles in addition to the caregiving role; (b) currently has a role(s) in addition to the caregiving role). The dependent variable was depression. The ANOVA did not reveal a significant difference between caregivers having no additional roles ($M = 12.00$, $SD = 10.45$) and caregivers having additional roles ($M = 15.12$, $SD = 10.34$), [$F(1, 97) = 0$, $p = .997$, $\eta^2_{\text{partial}} = .00$]. Age was included as a covariate in the depression and caregiver role analysis, indicating that caregiver age is related to depression [$F(1, 97) = 5.7$, $p = .02$, $\eta^2_{\text{partial}} = .06$].

Caregiver roles were also examined in the context of regression, with care-recipient cognition as a moderator (Aim 3). The overall regression model for caregiver roles, care-recipient cognition, and depression [$F(3, 96) = 1.56$, $p = .21$, $R^2 = .05$] was not significant (see Table 6.4). In the analyses involving behavioral problems as a moderator (Aim 3), the overall regression model was significant for caregiver roles, behavioral problems, and caregiver depression [$F(3, 96) = 3.68$, $p = .02$, $R^2 = .10$]. The effect of caregiver roles was not significant (see Table 6.5). The effect of behavioral problems was significant, while the interaction between caregiver roles and care-recipient behavioral problems was not significant (see Table 6.5).

Role overload.

To examine the effect of caregiver roles on role overload (Aim 2), a one-way ANOVA was conducted. The ANOVA failed to reveal a significant difference between caregivers having no additional roles ($M = 9.18$, $SD = 2.72$) and caregivers having additional roles ($M = 10.51$, $SD = 2.73$), [$F(1, 97) = .55$, $p = .46$, $\eta^2_{\text{partial}} = .006$]. Age was included as a covariate in the role overload and caregiver role analysis, indicating that caregiver age is related to role overload [$F(1, 97) = 0$, $p = .18$, $\eta^2_{\text{partial}} = .02$].

The overall regression model, with care-recipient cognition as a moderator (Aim 3), revealed a marginal effect for caregiver roles, care-recipient cognition, and role overload [$F(3, 96) = 2.45$, $p = .07$, $R^2 = .07$] (see Table 6.4). The effect of caregiver roles was significant, while the effect of cognition was not significant. The interaction between caregiver roles and cognition was not significant (see Table 6.4). The overall regression model was significant for caregiver roles, behavioral problems, and role overload (Aim 3) [$F(3, 96) = 6.14$, $p = .00$, $R^2 = .16$]. The effect of caregiver roles was not significant (see Table 6.5). The effect of behavioral problems was significant, while the interaction between caregiver roles and behavioral problems was not (see Table 6.5).

Role captivity.

To examine the effect of caregiver roles on role captivity (Aim 2), a one-way ANOVA was conducted. The ANOVA failed to reveal a significant difference between caregivers having no additional roles ($M = 6.87$, $SD = 3.03$) and caregivers having additional roles ($M = 7.85$, $SD = 2.46$), [$F(1, 97) = .61$, $p = .44$, $\eta^2_{\text{partial}} = .006$]. Age was included as a covariate in the role captivity and caregiver role analysis, indicating that caregiver age is not related to role captivity [$F(1, 97) = 1.85$, $p = .18$, $\eta^2_{\text{partial}} = .02$].

Regression analyses were also completed for role captivity (Aim 3). In the regression model involving caregiver roles, care-recipient cognition, and role captivity, no significance was found [$F(3, 96) = 2.0, p = .12, R^2 = .06$] (see table 6.4). No significance was found in the regression model involving caregiver roles, behavioral problems, and role captivity [$F(3, 96) = 1.64, p = .19, R^2 = .05$] (see Table 6.5).

Relational deprivation.

To examine the effect of caregiver roles on relational deprivation (Aim 2), a one-way ANOVA was conducted. The ANOVA failed to reveal a significant difference between caregivers having no additional roles ($M = 17.11, SD = 4.64$) and caregivers having additional roles ($M = 16.84, SD = 4.76$), [$F(1, 98) = .08, p = .77, \eta^2_{\text{partial}} = .001$].

The overall regression model was significant for caregiver roles, cognition and relational deprivation (Aim 3) [$F(3, 96) = 6.28, p = .00, R^2 = .16$]. The effect of caregiver roles and the effect of care-recipient cognition was not significant (see Table 6.4). The interaction between caregiver roles and care-recipient cognition was not significant (see Table 6.4). The overall regression model was significant for caregiver roles, behavioral problems, and relational deprivation (Aim 3) [$F(3, 96) = 3.64, p = .02, R^2 = .10$]. The effect of caregiver roles was not significant. The effect of behavioral problems was significant, while the interaction between caregiver roles and behavioral problems was not significant (see Table 6.5).

Positive caregiving outcomes.

To examine the effect of caregiver roles on positive caregiving outcomes (Aim 2), a one-way ANOVA was conducted. The ANOVA did not reveal a significant difference

between caregivers having no additional roles ($M = 31.44$, $SD = 8.28$) and caregivers having additional roles ($M = 31.95$, $SD = 8.93$), [$F(1, 98) = .08$, $p = .77$, $\eta^2_{\text{partial}} = .001$].

The overall regression model showed no significance for caregiver roles, cognition and positive caregiving outcomes (Aim 3) [$F(3, 96) = .40$, $p = .76$, $R^2 = .01$] (see Table 6.4). The regression model for caregiver roles, behavioral problems, and positive caregiving outcomes (Aim 3) was not significant [$F(3, 96) = .44$, $p = .73$, $R^2 = .01$] (see Table 6.5).

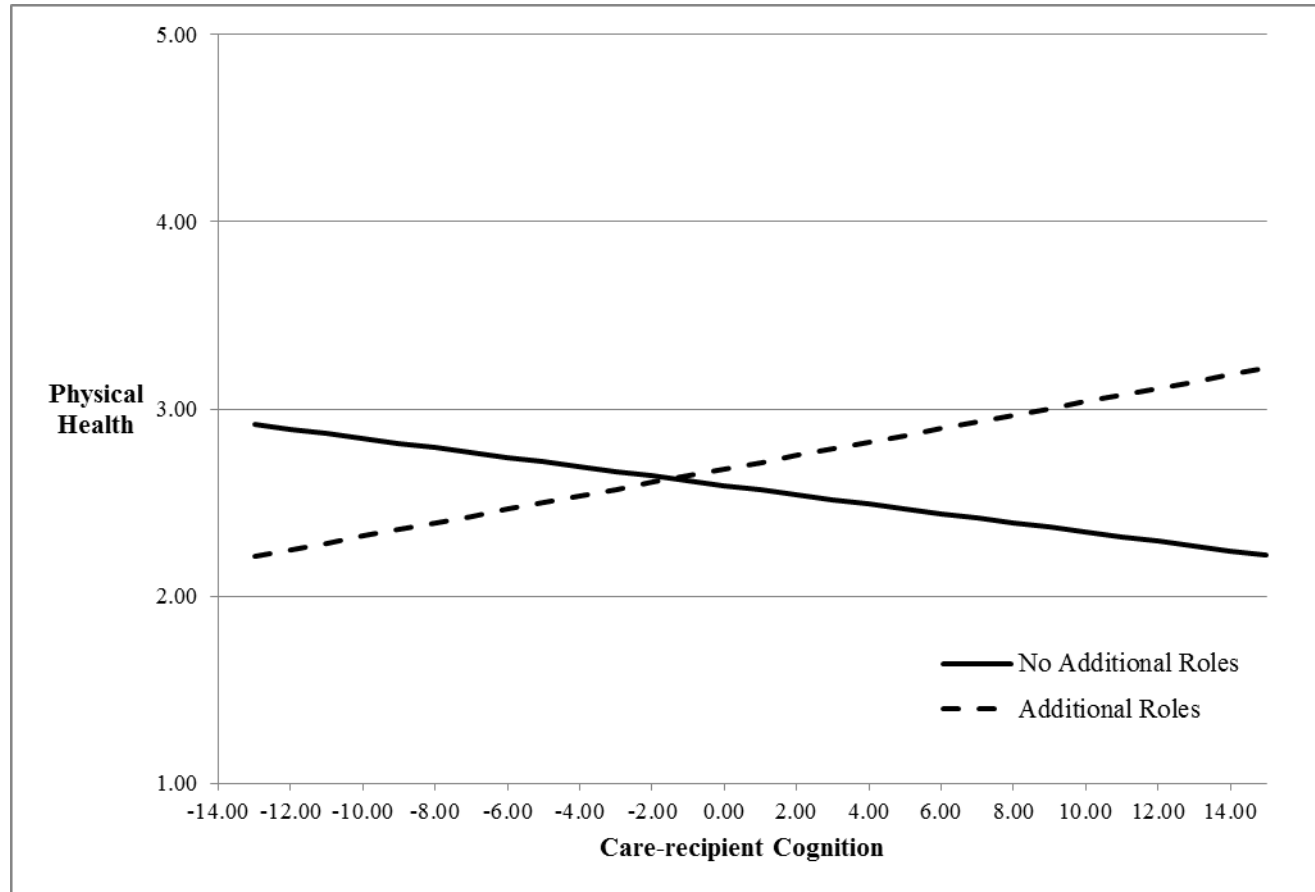
Caregiver physical health.

To examine the effect of caregiver roles on caregiver physical health outcomes (Aim 2), two one-way ANOVAs were conducted. The independent variable was caregiver roles. Dependent variables were physical health (the overall health rating scale and the health compared to one year ago scale). In regard to the overall health rating, the ANOVA failed to reveal a significant difference between caregivers having no additional roles ($M = 3.18$, $SD = 1.03$) and caregivers having additional roles ($M = 3.25$, $SD = .82$), [$F(1, 98) = .17$, $p = .68$, $\eta^2_{\text{partial}} = .002$]. With respect to the caregiver's health as compared to one year ago, the ANOVA did not reveal a significant difference between caregivers having no additional roles ($M = 2.58$, $SD = .75$) and caregivers having additional roles ($M = 2.67$, $SD = .61$) [$F(1, 98) = .49$, $p = .49$, $\eta^2_{\text{partial}} = .005$].

The overall regression model showed no significance for caregiver roles, cognition, and caregiver overall physical health rating (Aim 3) [$F(3, 96) = .58$, $p = .63$, $R^2 = .02$]. The overall regression model was significant, however, for caregiver roles, cognition, and caregiver physical health (compared to one year ago) [$F(3, 96) = 3.31$, $p = .02$, $R^2 = .09$]. The effect of caregiver roles was not significant (see Table 6.4). The effect

of care-recipient cognition and the interaction between caregiver roles and care-recipient cognition was significant (see Table 6.4). Decomposition revealed that care-recipient cognition was not related to caregiver physical health for caregivers who reported holding no other roles in addition to their caregiving role [$t(43) = -1.77, p = .08, \beta = -.26$]. For caregivers holding additional roles in conjunction with their caregiving role, improvements in caregiver physical health were related to increases in care-recipient cognitive decline [$t(53) = 2.63, p = .01, \beta = .34$] (see Figure 6.7).

Figure 6.7
Significant Interaction Between Physical Health and Cognition



The regression model for caregiver roles, behavioral problems, and caregiver physical health (Aim 3) [$F(3, 96) = .37, p = .78, R^2 = .01$; $F(3, 96) = .85, p = .47, R^2 = .03$] was not significant (see Table 6.5).

Table 6.4
Cognition as a Moderator of the Effects of Caregiver Roles on Outcomes

Outcome	Caregiver Roles			Cognition			Cognition x Roles			Model Summary
	<i>B</i>	<i>t</i>	<i>p</i>	<i>B</i>	<i>t</i>	<i>p</i>	<i>B</i>	<i>t</i>	<i>p</i>	
Depression	.16	1.56	.12	.39	1.28	.20	-.28	-.92	.36	$F(3, 96) = 1.56,$ $p = .21, R^2 = .05$
Role Overload	.25	2.49	.02*	.10	.34	.74	.02	.07	.94	$F(3, 96) = 2.45,$ $p = .07, R^2 = .07$
Role Captivity	.19	1.89	.06	.15	.49	.63	.02	.07	.95	$F(3, 96) = 2.0$ $p = .12, R^2 = .06$
Relational Deprivation	-.01	-.07	.95	.34	1.19	.23	.07	.24	.81	$F(3, 96) = 6.28$ $p = .00, R^2 = .16$
Positive Caregiving	.03	.30	.77	-.29	-.95	.35	.32	1.04	.30	$F(3, 96) = .40$ $p = .76, R^2 = .01$
Physical Health	.04	.39	.70	-.38	-1.24	.22	.35	1.13	.26	$F(3, 96) = .58,$ $p = .63, R^2 = .02$
Health Comparison	.07	.74	.46	-.86	-2.92	.00*	.90	3.07	.00*	$F(3, 96) = 3.31$ $p = .02, R^2 = .09$

* $p \leq .05$

Table 6.5
Behavioral Problems as a Moderator of the Effects of Caregiver Roles on Outcomes

	Caregiver Roles			Behavioral Problems			Behavior x Roles			Model Summary
Outcome	<i>B</i>	<i>t</i>	<i>p</i>	<i>B</i>	<i>t</i>	<i>p</i>	<i>B</i>	<i>t</i>	<i>p</i>	
Depression	.10	.97	.34	.29	2.88	.01*	-.09	-.87	.39	$F(3, 96) = 3.68$ $p = .02, R^2 = .10$
Role Overload	.17	1.81	.07	.33	3.46	.00*	-.04	-.42	.68	$F(3, 96) = 6.14$ $p = .00, R^2 = .16$
Role Captivity	.15	1.50	.14	.12	1.13	.26	.05	.53	.06	$F(3, 96) = 1.64$ $p = .19, R^2 = .05$
Relational Deprivation	-.09	-.93	.36	.32	3.26	.00*	-.08	-.77	.44	$F(3, 96) = 3.64$ $p = .02, R^2 = .10$
Positive Caregiving	.01	.05	.96	.11	1.09	.28	.01	.10	.92	$F(3, 96) = .44$ $p = .73, R^2 = .01$
Physical Health	.06	.60	.55	-.10	-.96	.34	.00	-.00	.99	$F(3, 96) = .37$ $p = .78, R^2 = .01$
Health Comparison	.10	.98	.33	-.15	-1.44	.16	.00	.02	.98	$F(3, 96) = .85$ $p = .47, R^2 = .03$

* $p \leq .05$

In summary, two of the study hypotheses were partially supported by the analyses of the data. Care-recipient cognition and care-recipient behavioral problems moderated the relationship between caregiving onset and caregiver roles on various outcome variables examined. The final chapter, Chapter Seven, discusses the significance of these findings, presents study limitations, and expands upon future research directions.

CHAPTER SEVEN

Discussion and Conclusions

This chapter summarizes study findings, and provides implications regarding each finding. This study on AD caregiving was cross-sectional, and included quantitative data to capture various dynamics experienced by AD caregivers. The specific aims of this study were to do the following:

1. Determine how different sequences of caregiving onset affect subsequent mental health and physical health outcomes experienced by caregivers.
2. Determine how multiple roles held by caregivers affect subsequent mental health and physical health outcomes experienced by caregivers.
3. Examine variables within the caregiving context that serve as moderators in regard to mental health and physical health outcomes experienced by caregivers.

Below, the findings regarding these aims are discussed in the following order: (a) caregiving onset, and (b) caregiver roles. Following these, clinical implications, study limitations, and future directions for research are discussed.

Caregiving Onset

The first aim of the study was to determine whether or not caregiving onset patterns had the potential to directly impact subsequent caregiving outcomes for AD caregivers. When examining this direct relationship, however, results yielded no significance. Several explanations exist for these findings. First, caregivers were categorized into two onset groups, based on their responses on the caregiving questionnaire--gradual onset and abrupt onset. Prior literature concerning caregiving onset has typically utilized four onset groups to more adequately capture and understand

the diverse experiences of AD caregivers (Gaugler et al., 2003; Gaugler, Zarit, & Pearlin, 2003b). Although this was the original intent of the present study, the small sample size of the present study prevented this type of categorization. Both the small sample size and the categorization strategy may account for a lack of significant findings.

Further, it may be that this direct relationship simply did not exist within the context explored in this study. Previous caregiving research has consistently demonstrated complex dynamics within the dementia caregiving career (Aneshensel et al., 1995; Gaugler et al., 2003; Gaugler, Zarit, & Pearlin, 2003a; 2003b; Pearlin et al., 1990), suggesting that many factors within the caregiving career have the potential to impact caregiving outcomes. This appears to be the case in the present study. When further examining caregiving onset in the context of other variables within the caregiving career, significant findings emerged.

Results of the current study partially support the first moderation hypothesis, which proposed that care-recipient cognitive decline and increased behavioral problems would moderate the relationship between caregiving onset and the outcome variables examined. Cognitive decline and behavioral problems, two primary stressors highlighted within the stress process model (Pearlin et al., 1990), were examined as moderators due to their well-established powerful impact on AD caregivers (Cohen- Mansfield, 2009; Gaugler et al., 2000; Pearlin et al., 1990). In the context of moderation, care-recipient cognition moderated the relationship between caregiving onset and two mental health outcomes: role overload and role captivity. Moreover, this moderating relationship transpired only in instances where an abrupt onset transition occurred, such that for caregivers who had an abrupt caregiving onset experience, increases in role overload and

role captivity were found when care-recipients experienced higher levels of cognitive decline.

Increases in role overload have been linked to progressive cognitive decline in prior research efforts (Aneshensel et al., 1995). Several explanations exist to help elucidate why caregivers experience more role overload when caring for individuals with higher levels of cognitive decline than those with lower levels. Progressive cognitive decline found in AD typically leads to care-recipients becoming more dependent on their caregivers, consequently leading to more care demands (Bergvall, 2011). Role overload occurs when caregivers perceive their caregiving tasks as too demanding and/or too exhausting (Aneshensel et al., 1995). For care-recipients who are more cognitively impaired, more in-depth assistance with their functional, emotional, and physical needs may be required of their caregivers on a more frequent basis, thus creating a higher risk of role overload taking place.

Role captivity, the feeling as if one is an involuntary participant in the caregiving role, was also associated with more cognitive decline in care-recipients. Similar to role overload, role captivity may occur when care demands become more intensive as cognitive decline progresses. Care-recipients who are more cognitively incapacitated are often more dependent on their caregivers (Bergvall, 2011), which in turn may lead to more rigidity within the caregiving career. This lack of flexibility, coupled with increasingly difficult care demands, may contribute to an escalation in role captivity.

Similar findings arose when examining behavioral problems as a moderator of caregiving onset and outcomes. Behavioral problems moderated the relationship between caregiving onset and three mental health outcomes: depression, role overload, and

relational deprivation. Again, this relationship was found only in instances in which an abrupt onset transition occurred. Thus, for caregivers who had an abrupt caregiving onset experience, increases in depression, role overload, and relational deprivation were found when their care-recipients experienced higher levels of behavioral problems.

These findings infer that behavior problems played a key role in moderating the relationship between onset and primary subjective stress. Behavior problems pose many challenges for caregivers because of difficulties in managing physical and verbal behavioral symptoms. Research has shown that increased behavior problems can be detrimental to the emotional well-being of caregivers and are often more upsetting for AD caregivers than the losses in cognitive and functional abilities experienced by care-recipients (Gaugler, Davey, Pearlin, & Zarit, 2000; Ladislav, & Hurley, 2003). Probable explanations for the emotional impact of behavior problems include the disruptive nature of behavioral disturbances (i.e., keeping the caregiver up at night, emotional outbursts, inappropriate social interaction). The unpredictable nature of behavioral disturbances can also be problematic for family caregivers and may exacerbate challenges caregivers face in managing behavior problems.

In the current study, increased depression was related to more behavioral problems displayed by care-recipients. Behavioral problems may have been viewed by caregivers as yet another indicator of change and loss found within the disease process. Witnessing these changes, as well as anticipating ongoing losses as the disease progresses, may have led to increases in depressive symptoms found in caregivers. Moreover, because behavioral problems are noted as one of the most challenging demands in AD caregiving (Cohen- Mansfield, 2009; Gaugler et al., 2000), many

caregivers feel both unprepared and incapable of managing behavioral problems due to their unpredictable and detrimental nature. This too may lead to increases in depressive symptoms, such as feelings of helplessness (Pinquart and Sörensen, 2004; Adams, 2008).

Several behavioral problems require constant vigilance from caregivers (e.g., wandering, physical aggression, undressing). Exerting constant watchfulness and control may contribute to increases in role overload, which were found within the present study. Care-recipients who are resistive to caregiver's continual efforts to manage behavioral problems may exacerbate feelings of role overload as well.

Behavioral problems also moderated the relationship between onset and relational deprivation. Relational deprivation signifies the experiences and emotions of caregivers as they become increasingly separated from the original shared experiences and characteristics of their care-recipients (Aneshensel et al., 1995). If care-recipients are exhibiting behavioral problems that are troubling and uncharacteristic of who they were prior to the disease process (e.g., using foul language, physical combativeness, inappropriate sexual advances), then caregivers may be at greater risk for experiencing relational deprivation during their caregiving career as a result of having to witness and cope with detrimental changes in their care-recipient. Furthermore, because of their disruptive and unpredictable nature, behavioral problems often prevent care-recipients from being able to participate in outside functions and social events. If participating in various social events was once a common shared experience between caregivers and their care-recipients, then increases in relational deprivation may be observed in instances where behavioral problems are more prevalent.

An overall theme of moderation occurred only in cases in which caregivers experienced an abrupt onset transition. One interpretation in particular exists for this finding. Providing care prior to symptom recognition or diagnosis (gradual onset transition) may have allowed caregivers the opportunity to better manage the frequency of care demands, such as behavior problems. Caregivers who began providing informal assistance may have already acquired skills necessary for better managing elevated cognitive decline and difficult behaviors associated with AD once symptoms were recognized. Acclimating to care demands may have provided caregivers in the gradual onset group with the opportunity to utilize personal strategies effective for managing challenging situations.

In contrast, those who provided care soon after recognizing symptoms or after receiving a diagnosis experienced a more abrupt transition into the caregiving role and experienced greater challenges in dealing with care demands. For example, an unexpected health care crisis may have occurred (e.g., a fall), leading to a more rapid decline in the functional abilities for the care-recipient. For those family members who assumed immediate care responsibilities, this transition may have been overwhelming and unexpected, causing these caregivers to experience more negative emotional outcomes (e.g., depression, relational deprivation). Caregivers who had already established daily routines for managing care demands may already have first-hand experience identifying and managing behavior problems. For caregivers classified as having an abrupt caregiving onset transition, the sudden exposure to behavioral disturbances may have put them at greater risk for experiencing subjective stress throughout the caregiving career (Gaugler, Kane, Kane, & Newcomer, 2005).

Some of the caregivers who experienced an abrupt onset transition also indicated that they sought a diagnosis of their care-recipient prior to or at the same time as recognizing symptoms and/or providing care. The diagnosis of AD holds several implications for caregivers. The diagnosis process, in and of itself, is an event that may lead to upheaval and may significantly influence the caregiver-care-recipient relationship (Gaugler et al., 2003a). More specifically, those who were engaged in care activities prior to a formal diagnosis may have been better prepared to deal with further chronic illnesses and the distressing symptoms that followed. Receiving a formal AD diagnosis can also lead to several psychosocial impacts for family members, including uncertainty about where to seek additional help, disagreements among other family members, and feelings of inadequacy to face future events (Carpentier et al., 2010; Connell, Boise, Stuckey, Holmes, & Hudson, 2004). Moreover, family caregivers may not be given sufficient assistance or referrals when preparing for the caregiving trajectory associated with AD (e.g., managing care demands). Family members who had little or no experience in providing care prior to a formal diagnosis may have been less able to maintain the psychosocial quality of the caregiver-care-recipient relationship due to overwhelming and unexpected responsibilities associated with receiving the diagnosis. In contrast, for family members who began providing care prior to the formal diagnosis, preserving relationships with care-recipients in the context of care provision may have been more feasible, thus producing a buffering effect in regard to experiencing negative caregiving outcomes.

Caregiver Roles

When examining the effects of caregiver roles on subsequent caregiving outcomes, findings mirrored results found when examining caregiving onset, in that no significant findings emerged when examining the direct relationship between caregiver roles and caregiving outcomes. The way in which caregivers were categorized in regard to the roles they held may account for the lack of significance found. Based on their responses and due to a small sample size, caregivers were categorized into two groups: currently having no roles in addition to their caregiving role, or currently holding role(s) in addition to their caregiving role. Specifically, the additional roles examined included the role of employee and the role of parent/grandparent with underage children still living at home. It may have been more beneficial to focus on both the types of roles and the number of roles caregivers held in order to avoid potential confounds (i.e., an individual holding six additional roles may not spend as much time in those roles as an individual with only two additional roles) (Bainbridge et al., 2006; Pavalko & Woodbury, 2000).

Alternative perspectives regarding multiple roles may also help explain the lack of significance found in the first role hypothesis. For some caregivers, holding multiple roles may shield them from negative mental health and physical health outcomes often experienced within the caregiving trajectory (Adelmann, 1994, Moen, Dempster-McClain, & Williams, 1992; Moen, Robison, & Dempster-McClain, 1995; Rozario, Morrow-Howell, & Hinterlong, 2004). This assertion is outlined in the role enhancement perspective, which posits that individuals who occupy more roles are likely to experience greater levels of well-being due to the augmentation of resources, prestige, support, and emotional fulfillment that multiple roles provide (Adelmann, 1994, Moen, Dempster-

McClain, & Williams, 1992; Moen, Robison, & Dempster-McClain, 1995; Rozario, Morrow-Howell, & Hinterlong, 2004). This explanation is in contrast to the role strain perspective, which suggests that multiple demands placed on an individual as a result of too many roles will lead to negative consequences (e.g., role overload and role conflict) (Moen, Robison, & Dempster-McClain, 1995; Rozario, Morrow-Howell, & Hinterlong, 2004). Perhaps participants in this study experienced greater role enhancement as a result of occupying multiple roles, in addition to their caregiving role. If this was the case, then holding multiple roles would not contribute significantly to negative caregiving outcomes.

When examining caregiver roles in the context of moderation, no significant findings emerged with respect to mental health outcomes. Thus, care-recipient cognitive decline and behavioral problems did not have the potential to moderate the relationship between caregiver roles and mental health outcomes. Interestingly, the only significant finding that transpired when examining caregiver roles involved caregiver physical health. Caregivers who were holding additional roles in conjunction with their caregiving role and whose care-recipients had higher levels of cognitive decline actually experienced improvements in their physical health within the past year. One explanation for this finding is that advanced cognitive decline in the care-recipient may actually lead to some caregivers perceiving their caregiving role to be less challenging. Although this may seem contradictory to prior explanations, greater cognitive decline may also imply fewer behavioral problems (e.g., limitations with speech may prevent verbal outbursts). If elevated cognitive decline somehow contributed to the caregiving role becoming less

complicated for caregivers, then she or he would report improvements in physical health within a one year period.

Another explanation for this finding may be that caregivers who reported having better health compared to one year earlier, despite caring for an individual with heightened cognitive decline, may have experienced a more serious physical health condition in the year prior to participating in the current study (e.g., an acute health crisis, chronic disease relapse). From this perspective, their health may have improved a great deal in the past year, thus prompting them to report improved physical health.

Finally, holding additional roles in conjunction with the caregiving role may have provided a buffering effect for caregivers who reported having better physical health within the past year. Holding additional roles, as postulated in the role enhancement perspective of role theory, may have provided caregivers with the resources and emotional support necessary to help them sustain their physical health.

In summary, a larger sample with statistical power to test the specific role hypotheses outlined in this study is needed in order to obtain more in-depth information regarding role occupancy and its potential to impact caregiving outcomes.

Clinical Implications

Understanding the impact of caregiving onset, caregiver roles, and key care demands, including cognitive decline and behavioral problems, found within the caregiving career all contribute to clinical endeavors. Findings from the current study offer potentially important contributions to the realm of caregiving. In contrast to prior research that implies that the longer caregiving endures, the more negative outcomes will occur (i.e., the “wear and tear” hypothesis), current findings suggest that the length of

time as caregiver may not be as important as how caregivers actually acquire their roles and which factors within the caregiving career moderate existing relationships. Placing more emphasis on how caregivers enter their role responsibilities may be more beneficial than focusing solely on length of caregiving procedures.

Understanding the ramifications of caregiving onset also offers several implications for the development and administration of interventions. For clinicians (i.e., physicians, nurses, social workers) who provide important clinical support to family caregivers, each transition point within the caregiving career presents opportunities for interventions (Meleis et al., 2000). Focusing more attention on the timing of service delivery and the onset experience, combined with considering the behavioral problems and cognitive status of the care-recipient, may help practitioners identify individuals who experience immediate difficulty. Depending on the level of behavioral problems and cognitive decline of the care-recipient, recognizing various caregiving onset patterns may be particularly valuable in regard to identifying which patterns (e.g., abrupt entries) are associated with more problematic outcomes and which patterns (e.g., gradual entries) may provide buffering effects for AD caregivers. Recognizing onset patterns may also provide insight in regard to which caregivers may experience more difficulty in regard to mobilizing and sustaining resources and outside assistance, which may potentially exacerbate the caregiving experience. The type and timing of caregiving interventions depend largely on where caregivers are in their caregiving careers and the ways in which they experience transitions within their careers. Understanding the implications of the onset transition more thoroughly may provide a more accurate portrait of the effects of ensuing outcomes.

Furthermore, providing early intervention tactics may result in preventing subsequent problems within the caregiving career. As reflected in these findings there may be warning signs that certain caregivers are at a higher risk of experiencing negative outcomes, such as role overload and depression. It is crucial for health care professionals to identify these “at-risk” caregivers and to tailor interventions to address their specific challenges and needs. Educating and informing caregivers of the probable stressors that they may experience as a result of onset transitions may help them better prepare for future caregiving endeavors. Preventative strategies are also key when providing interventions to family caregivers. In particular, early interventions during the role acquisition phase may prevent subsequent negative outcomes from emerging later on. For instance, implementing strategies for caregivers who experience an abrupt onset transition into the caregiving role may help assuage later outcomes, including depression, role overload, and role captivity. Opportunities for early intervention exist in regard to different sequences of caregiving onset and should be employed when possible. Preventative interventions, incorporated immediately following the caregiving onset transition, may help prevent the accumulation of stress as the caregiving career progresses, thereby reducing its deleterious effects.

Because care-recipient cognitive decline and behavioral problems present as two strong indicators of primary stress within the caregiving career, interventions targeted to help alleviate the detrimental effects associated with both are warranted. Cognitive decline and behavioral problems were found to significantly moderate the relationship between caregiving onset and outcomes. Focusing on behavioral problems specifically when providing assistance to AD family caregivers, especially early in the caregiving

career (as supported by Gaugler et al., 2005), may help reduce the impact of negative caregiving outcomes. Furthermore, behavioral problems, especially those that are more aggressive and disruptive, often have the capacity to prompt caregivers to seek alternate caregiving options for their care-recipient (e.g., institutionalization). This is often the case for caregivers who experience immediate difficulty following an abrupt or unpredictable entry into the caregiving role. Providing interventions to help these caregivers manage and cope effectively with behavioral problems may prevent caregivers from prematurely relinquishing their caregiving roles.

Strategies for alleviating or mitigating subjective stress found within the caregiving career are paramount, as caregiving research emphasizes a number of negative outcomes for AD caregivers (Pinquart and Sörensen, 2003a; 2004). Outcomes, including depression, role overload, role captivity, and relational deprivation are complex processes influenced by factors related to both caregivers and their care-recipients. Understanding specifically those factors within the caregiving career that pose heightened risks for the development of these outcomes can influence efforts to identify and treat forms of subjective stress from a multidisciplinary approach, an approach far more effective than providing interventions that may only target isolated factors. Similarly, focusing treatments on risk factors simultaneously (e.g., depression, onset pattern, behavioral problems) may also be more beneficial than concentrating on only one aspect.

Examining the impact of maintaining additional roles in conjunction with the caregiving role also has implications for AD caregivers. Understanding whether or not the types of roles (e.g., parent, employee) or the number of roles an individual is occupying at the time of providing care to an individual with AD truly impacts

subsequent caregiving outcomes is crucial knowledge to be obtained. Perhaps certain roles have the capacity to mitigate subjective caregiving stress, while others may pose more challenges for caregivers during their caregiving trajectories. Explicating these potential differences would be useful in regard to better understanding how role occupancy can either benefit or hinder the caregiving process.

Study Limitations

Although findings highlight valuable information regarding caregiving onset and other important dynamics within the caregiving career, there were several limitations in the present study. The sample is predominantly Caucasian, and the participants are better educated than the general public. In order for these results to be more generalized, more diversity in sample characteristics is needed. Many participants were recruited from agencies such as the Alzheimer's Association and Eldercare. Participants affiliated with these particular organizations may not be fully representative of all informal caregivers within the community, thus resulting in self-selection bias. Additionally, caregivers who were experiencing heightened subjective stress (e.g., role overload) at the time of recruitment may have declined participation due to lack of time and feeling overwhelmed with caregiving responsibilities. This, too, may have contributed to self-selection bias. Because data obtained in this study were based on self-report, not all responses on the caregiving questionnaire may have been accurate. Also, this study was cross-sectional in nature, and consequently, did not capture dynamics found within the longitudinal nature of the caregiving career, one that often spans many years. With cross-sectional data, determining whether the moderating relationships reported above hold over time is unknown.

Without longitudinal data, results from this study do not provide information regarding how the duration of caregiving impacts caregiving outcomes. In other words, it was not plausible to detect differences between an individual caring for a care-recipient for nine months versus a caregiver with nine years of care experience. In addition, the present study did not account for prior caregiving experiences. How and if previous caregiving experience influenced caregiving outcomes remains unknown in the current study.

The sample size for the current study (n=100) was small, as the present study was a student dissertation, with time and expenses borne by the student. This small sample size led to the categorization of participants into only two onset groups (gradual and abrupt) as opposed to the four onset groups originally proposed. In hindsight, it may have been more beneficial to classify caregivers into the four onset groups in order to fully capture their experiences. Additionally, it may be more accurate to categorize caregivers based on their types of roles rather than the number of roles that they held due to potential confounds (i.e., an individual holding six additional roles may not spend as much time in those roles as an individual with only two additional roles) (Bainbridge et al., 2006; Pavalko & Woodbury, 2000), but again, the small sample size prohibited this examination. A larger sample size would have allowed for a more effective categorization process.

Finally, although data attained in the present study provide valuable insight regarding mental health and physical health outcomes experienced by caregivers, several outcomes having noted importance within existing caregiving literature were not examined in this study (e.g., burden, anxiety, resentment). Moreover, information

regarding the care-recipients, including current medication usage or the possibility of other dementias occurring simultaneously (e.g., dementia related to Parkinson's disease or AIDS), was unknown. Finally, it was unknown whether or not caregivers in this study were receiving outside support for their caregiving procedures (e.g., in-home health care, respite care, assistance from a secondary caregiver) at the time of their participation in this study. Knowledge of these issues would have enhanced the results and provided a better understanding of co-occurring dynamics within participants' caregiving careers. Although these factors are of recognized importance in studying dementia caregiving, it is not always feasible to capture all important dynamics in a single research study.

Directions for Future Research

This study provides future direction for AD caregiving research that builds on results from this project. Although the present study included background characteristics regarding the caregiver participants, it would be valuable to include more detailed information regarding caregiver and care-recipient antecedent factors in future analyses. For example, having a better understanding of the dynamics of the preexisting caregiver/care-recipient relationship would provide insight into the salience of their kinship relationship and how relational factors may affect subsequent outcomes in the caregiving career (i.e., role overload, role captivity, relational deprivation). In particular, understanding how antecedent factors are related to caregiving onset and other moderating factors found within the caregiving career may provide a more accurate understanding of the complex nature of caregiving.

Likewise, obtaining additional information regarding caregivers' past mental health history (e.g., history of depression prior to entering into the caregiving role) would

be worthwhile in order to better understand how the caregiving role may or may not exacerbate preexisting mental health conditions. As demonstrated in the caregiving literature regarding depression and caregivers (Adams, 2008; Cuijpers, 2005; Pinquart & Sörensen, 2003a, 2003b), varying factors affect the development of depression in the caregiving career. Many are related to antecedent factors involving both caregivers and their care-recipient (e.g., personality traits, relationship dynamics). If these factors are somehow relevant to the development of depression and other mental health outcomes, devoting more research efforts to understanding their impact within the dementia caregiving career is warranted. Overall, obtaining more in-depth antecedent information regarding AD caregivers, as well as their care-recipients, allows a more accurate account of the complex dynamics that affect caregiver outcomes.

It is critical that subsequent AD caregiving research efforts gather information from the perspective of the care-recipient. Though limitations may exist due to cognitive and functional deterioration as a result of the disease process, many care-recipients have the capacity to provide important information regarding the caregiving process, including details involving the onset of caregiving. Information from the care-recipient's standpoint would augment details provided by caregivers and give them a needed voice in the caregiving literature.

A need for valid and well-established measures for capturing the onset of dementia caregiving also exists. Currently, there are no valid instruments for investigating this important caregiving transition. Without valid and reliable instrumentation, researchers continue to rely on their own methods for capturing the onset dynamic. The development of such measures will allow successive studies to scientifically obtain data regarding the

caregiving onset experience and the ways in which this dynamic process influences caregiving outcomes. Further, there is a strong need for ongoing prospective studies examining the onset of AD caregiving. Results of the current study are retrospective in nature, and although valuable, cannot provide the beneficial results that a prospective analysis would capture. Prospective examination of AD caregiving onset would also provide more precise data, as recall errors would then be eliminated.

Subsequent research should also consider implications of care-recipients having a diagnosis of early-onset AD versus those with a diagnosis of late-onset AD. This distinction is extremely important to include, as it may alter transition experiences within the caregiving career. In instances where care-recipients develop early-onset AD, which typically progresses at a more rapid pace than late-onset AD, the speed of the caregiving onset transition may be more rapid for caregivers. Because early-onset AD also occurs at a younger age, caregivers of these individuals may also be younger, suggesting the possibility of little or no prior caregiving experience. In contrast, those caring for an individual with a late-onset diagnosis may experience a more gradual entry into the caregiving role, as symptoms present themselves less rapidly. For these caregivers, who may be older than early-onset AD caregivers, having prior care experience may be more plausible. Furthermore, the emotional implications of caring for an individual with early-onset AD may differ drastically. From a life course perspective, the timing of the caregiving onset transition in cases of early-onset AD may significantly affect caregiving outcomes. For instance, an early-onset AD caregiver in his/her 50s, who still occupies the roles of employee and parent to a child living at home, may experience different

caregiving outcomes compared to an older caregiver experiencing other events along the life course trajectory.

Taking into consideration the above propositions, the most effective way to capture the caregiving experience is through the utilization of a mixed methods approach. Use of quantitative and qualitative approaches in combination provides a better understanding of the caregiving career than would either approach alone. What cannot be inferred from one approach could potentially be extrapolated from the other. Using a retrospective model, quantitative data would provide objective information concerning the onset experience, care-recipient decline, and caregiver outcomes. To enhance these findings, qualitative data, including open ended questions and opportunities for elaboration, would allow participants to provide valuable narratives that would augment quantitative information. Qualitative data would capture the subjective experiences surrounding the caregiving onset transition, as well as the impact of holding multiple roles. Qualitative data regarding caregiving outcomes (e.g., depression, relational deprivation) would help compliment the data obtained from validated instruments measuring caregiving outcomes (e.g., the CES-D). Finally, utilizing a mixed methods approach would help address gaps in the current study, including information regarding length of caregiving, prior caregiving experience, quality of the relationship with the care-recipient, and the qualitative implications of holding various roles. Employing this comprehensive methodology is suitable for capturing the complex dynamics of dementia caregiving and the transitions inherent in this career.

Conclusion

Dementia caregiving is considered an event in the life course that will continue to receive much scrutiny in the 21st century, as informal caregivers serve as the primary instrument of long-term care for persons with AD and other chronic conditions. Theoretical foundations provide a sound basis for researchers and clinicians to understand the dynamic process of caregiving through examination of the impact of key transitions, to investigating stressors and resiliencies embedded within the caregiving career. It is the obligation of ongoing research to expand both empirical and theoretical knowledge in the realm of dementia caregiving to inform practice and policy that will ultimately impact the daily lives of caregivers. The aims of the present study sought to contribute to preexisting literature by addressing gaps concerning the onset transition, caregiver roles, and factors related to care-recipient decline. The current study found that cognitive decline and behavioral problems, two important primary objective stressors, have the potential to moderate the relationship between caregiving onset and various negative outcomes. These results contribute to existing caregiving literature that seeks to better understand the influence of caregiving transitions, care demands, and subjective stress. The findings demonstrate the complexity that characterizes AD caregiving and support the importance of ongoing examinations of both direct and indirect pathways found within the caregiving career.

Appendix A:
Caregiver Questionnaire

Caregiver Background Characteristics

We would like to start by asking a few questions about your background.

Please write down today's date: _____

1. What is your age? _____ years
2. What is your gender? Male Female
3. What race or ethnic group do you consider yourself?
 White Black Asian Hispanic Other _____
4. What is your marital status?
 Married and/or living with partner
 Divorced
 Separated
 Never married
 Widowed
 Other _____
5. How much education have you received?
 Did not complete junior high/middle school Bachelor's degree
 Did not complete high school Some graduate courses
 High school degree Graduate degree
 Some college courses Other _____
 Associate's degree (2-year college)
6. What was your total household income from all sources last year?
 Less than \$5,000 \$25,000 - \$29,999
 \$5,000 - \$9,999 \$30,000 - \$39,999
 \$10,000 - \$14,999 \$40,000 - \$59,999
 \$15,000 - \$19,999 \$60,000 - \$79,999
 \$20,000 - \$24,999 \$80,000 or over

7. Can you tell me about your current work status? Are you:
- | | |
|---|--------------------------------------|
| <input type="checkbox"/> Working at a full-time job | <input type="checkbox"/> Retired |
| <input type="checkbox"/> Working at a part-time job | <input type="checkbox"/> Unemployed |
| <input type="checkbox"/> Keeping house full-time | <input type="checkbox"/> Other _____ |
8. Please indicate your relationship with the person that you are providing care for:
- | | |
|-------------------------------------|--|
| <input type="checkbox"/> Spouse | <input type="checkbox"/> Daughter-in-law |
| <input type="checkbox"/> Daughter | <input type="checkbox"/> Son-in-law |
| <input type="checkbox"/> Son | <input type="checkbox"/> Sibling |
| <input type="checkbox"/> Grandchild | <input type="checkbox"/> Other _____ |
9. How old is the relative that you are caring for? _____
10. How long have you been providing care for this person? _____
11. Approximately how many hours per week do you spend caring for your relative? ____

Onset of Dementia Caregiving

❖ Caregivers enter into their caregiving role in different ways. We are interested in learning about how you became a caregiver. Please answer the following questions regarding *how* and *when* you became a caregiver. Please add as many comments as you would like.

1. **Can you tell me the approximate date (e.g., month and year) that you first began to notice that something was wrong with your relative?**

2. **Before you began to recognize symptoms of dementia, were you providing any type of care procedures for your relative?**

Yes No

If yes, explain what types of care you were providing and how long you had been providing that care:

3. **If you were not providing care for your relative before you began to recognize symptoms, then approximately how long did you wait to provide care *after* you began to notice symptoms?**

4. Did your relative receive a formal diagnosis of dementia from a physician *before* or *after* you began providing care? _____

a. If you answered **before**, how long was it after the diagnosis that you began providing care for your relative? _____

b. If you answered **after**, how long had you been providing care for your relative before receiving the diagnosis? _____

5. Did your relative receive a formal diagnosis of dementia from a physician *before* or *after* you began to recognize symptoms of dementia?

- a. If you answered **after**, how long had you been recognizing that something was wrong?

- b. How long did you wait to take your relative to the physician after recognizing symptoms?

Grandparent Yes No

Are you currently raising grandchildren in your home? Yes No

If yes, how many? _____

How long have you been in this role? _____

How important is this role for you? (Please circle your answer)

1 2 3 4 5
Not at all important Very Important

How satisfied are you with this role now that you are a caregiver? (Please circle your answer)

1 2 3 4 5
Not at all Satisfied Very Satisfied

Employee Yes No

Full time Part time

How long have you been in this role? _____

How important is this role for you? (Please circle your answer)

1 2 3 4 5
Not at all important Very Important

How satisfied are you with this role now that you are a caregiver? (Please circle your answer)

1 2 3 4 5
Not at all Satisfied Very Satisfied

Volunteer Yes No

How long have you been in this role? _____

How important is this role for you? (Please circle your answer)

1 2 3 4 5
Not at all important Very Important

Volunteer (Continued from previous page)

How satisfied are you with this role now that you are a caregiver? (Please circle your answer)

1 2 3 4 5
Not at all Satisfied Very Satisfied

Community Involvement Yes No
Please specify _____

How long have you been in this role? _____

How important is this role for you? (Please circle your answer)

1 2 3 4 5
Not at all important Very Important

How satisfied are you with this role now that you are a caregiver? (Please circle your answer)

1 2 3 4 5
Not at all Satisfied Very Satisfied

Other (Please list) _____

How long have you been in this role? _____

How important is this role for you? (Please circle your answer)

1 2 3 4 5
Not at all important Very Important

How satisfied are you with this role now that you are a caregiver? (Please circle your answer)

1 2 3 4 5
Not at all Satisfied Very Satisfied

Care-Recipient Cognitive Status

- ❖ The following questions are related to the cognitive status of your relative that you are caring for. Please check the appropriate boxes. Currently, how difficult is it for **your relative** to:

A. Remember recent events

Can't do it at all Very difficult Fairly difficult Just a little difficult Not at all difficult

B. Know what day of the week it is

Can't do it at all Very difficult Fairly difficult Just a little difficult Not at all difficult

C. Remember (his/her) home address

Can't do it at all Very difficult Fairly difficult Just a little difficult Not at all difficult

D. Remember words

Can't do it at all Very difficult Fairly difficult Just a little difficult Not at all difficult

E. Understand simple instructions

Can't do it at all Very difficult Fairly difficult Just a little difficult Not at all difficult

F. Find (his/her) way around the house

Can't do it at all Very difficult Fairly difficult Just a little difficult Not at all difficult

G. Speak sentences

Can't do it at all Very difficult Fairly difficult Just a little difficult Not at all difficult

H. Recognize people that (he/she) knows

Can't do it at all Very difficult Fairly difficult Just a little difficult Not at all difficult

Care-Recipient Problematic Behaviors

- ❖ The following questions are related to the amount of behavioral problems your relative has. In the *past week*, on how many days did you *personally* have to deal with the following behavior(s) of your relative? Please check the appropriate boxes.

A. Keep you up at night

5/more days 3-4 days 1-2 days no days

B. Repeat questions/stories

5/more days 3-4 days 1-2 days no days

C. Try to dress the wrong way

5/more days 3-4 days 1-2 days no days

D. Have a bowel or bladder “accident”

5/more days 3-4 days 1-2 days no days

E. Hide belongings and forget about them

5/more days 3-4 days 1-2 days no days

F. Cry easily

5/more days 3-4 days 1-2 days no days

G. Act depressed or downhearted

5/more days 3-4 days 1-2 days no days

H. Cling to you or follow you around

5/more days 3-4 days 1-2 days no days

I. Become restless or agitated

5/more days 3-4 days 1-2 days no days

J. Become irritable or angry

5/more days 3-4 days 1-2 days no days

K. Swear or use foul language

5/more days 3-4 days 1-2 days no days

L. Become suspicious, or believe someone is going to harm (him/her)

5/more days 3-4 days 1-2 days no days

M. Threaten people

5/more days 3-4 days 1-2 days no days

N. Show sexual behavior or interests at wrong time/place

5/more days 3-4 days 1-2 days no days

❖ For the following 20 items, please select the choice that best describes how you have felt over the past week.

	Rarely or none of the time (<1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of the time (3-4 days)	Most or all of 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 the help from my family and friends.				
4. I felt that I was not 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 hopeless about the future.				
9. I thought my life had been a failure.				
10. I felt fearful.				
11. My sleep was restless.				
12. I was unhappy.				
13. I talked less than usual.				
14. I felt lonely.				
15. People were unfriendly.				
16. I did not enjoy life.				
17. I had crying spells.				
18. I felt sad.				
19. I felt that people disliked me.				
20. I could not get "going."				

Caregiver Role Overload

- ❖ Here are some statements about your energy level and the time it takes to do the things you have to do. For each question, please check the appropriate box.

How much does each statement describe you?

A. I am exhausted when I go to bed at night:

Completely Quite a bit Somewhat Not at all

B. I have more things to do than I can handle:

Completely Quite a bit Somewhat Not at all

C. I don't have time just for myself:

Completely Quite a bit Somewhat Not at all

D. I work hard as a caregiver but never seem to make any progress:

Completely Quite a bit Somewhat Not at all

Caregiver Role Captivity

- ❖ Here are some thoughts and feelings that people sometimes have about themselves as caregivers. For each question, please check the appropriate box.

How much does each statement describe your thoughts about your caregiving?

A. Wish you were free to lead a life of your own:

Very much Somewhat Just a little Not at all

B. Feel trapped by your relative's illness:

Very much Somewhat Just a little Not at all

C. Wish you could just run away:

Very much Somewhat Just a little Not at all

Relational Deprivation

- ❖ Caregivers sometimes feel that they lose important things in life because of their relative's illness. To what extent do you feel that you personally have lost the following? Please check the appropriate boxes.

Deprivation of Intimate Exchange

To what extent do you feel that you personally have lost:

A. Being able to confide in your relative:

Completely Quite a bit Somewhat Not at all

B. The person that you used to know:

Completely Quite a bit Somewhat Not at all

C. Having someone who really knew you well:

Completely Quite a bit Somewhat Not at all

Deprivation of Goals and Activities

To what extent do you feel that you personally have lost:

D. The practical things (he/she) used to do for you:

Completely Quite a bit Somewhat Not at all

E. A chance to do some of the things you planned:

Completely Quite a bit Somewhat Not at all

F. Contact with other people:

Completely Quite a bit Somewhat Not at all

Positive Aspects of Caregiving

- ❖ **Some caregivers say that, despite all the difficulties involved in giving care to a family member with memory or health problems, good things have come out of their caregiving experiences too. These questions deal with some of the good things reported by caregivers. I would like you to tell me how much you agree or disagree with these statements in regard to *your* caregiving situation.**

Providing Help to my relative has...	Disagree a Lot	Disagree a Little	Neither Agree or Disagree	Agree a Little	Agree a Lot
Made me feel more useful					
Made me feel good about myself					
Made me feel needed					
Made me feel appreciated					
Made me feel important					
Made me feel strong and confident					
Enabled me to appreciate life more					
Enabled me to develop a more positive attitude toward life					
Strengthened my relationship with others					

Caregiver & Care-Recipient Health

- ❖ Please indicate, by placing a check mark in the appropriate box, which illnesses *you* currently have, and which health problems *your relative* currently has.

Health Problem	Caregiver	Care-Recipient
Arthritis or rheumatism	<input type="checkbox"/>	<input type="checkbox"/>
Glaucoma	<input type="checkbox"/>	<input type="checkbox"/>
Asthma	<input type="checkbox"/>	<input type="checkbox"/>
Emphysema or chronic bronchitis	<input type="checkbox"/>	<input type="checkbox"/>
Tuberculosis	<input type="checkbox"/>	<input type="checkbox"/>
High Blood Pressure	<input type="checkbox"/>	<input type="checkbox"/>
Heart Trouble	<input type="checkbox"/>	<input type="checkbox"/>
Circulation trouble in arms or legs	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes	<input type="checkbox"/>	<input type="checkbox"/>
Ulcers	<input type="checkbox"/>	<input type="checkbox"/>
Stomach or intestinal disorders or gall bladder problems	<input type="checkbox"/>	<input type="checkbox"/>
Liver Disease	<input type="checkbox"/>	<input type="checkbox"/>
Kidney Disease	<input type="checkbox"/>	<input type="checkbox"/>
Cancer	<input type="checkbox"/>	<input type="checkbox"/>
Effects of Strokes	<input type="checkbox"/>	<input type="checkbox"/>
Parkinson's Disease	<input type="checkbox"/>	<input type="checkbox"/>
Multiple Sclerosis	<input type="checkbox"/>	<input type="checkbox"/>
Muscular Dystrophy	<input type="checkbox"/>	<input type="checkbox"/>
Effects of Polio	<input type="checkbox"/>	<input type="checkbox"/>
Alzheimer's Disease	<input type="checkbox"/>	<input type="checkbox"/>
Thyroid or other glandular disorders	<input type="checkbox"/>	<input type="checkbox"/>
Other: (please indicate)	<input type="checkbox"/>	<input type="checkbox"/>
Other: (please indicate)	<input type="checkbox"/>	<input type="checkbox"/>

Caregiver & Care-Recipient Health

❖ Please answer the following questions about your health and the health of your relative.

1. In general, would you say **your** health is:

- Excellent Very good Good Fair Poor

2. **Compared to one year ago**, how would you rate **your** health in general **now**?

- Much better than one year ago
 Somewhat better than one year ago
 About the same
 Somewhat worse now than one year ago
 Much worse than one year ago

3. In general, would you say **your relative's** health is:

- Excellent Very good Good Fair Poor

4. **Compared to one year ago**, how would you rate **your relative's** health in general **now**?

- Much better than one year ago
 Somewhat better than one year ago
 About the same
 Somewhat worse now than one year ago
 Much worse than one year ago

Appendix B:
IRB Approval Letter



Office of Research Integrity

University Veterinarian, IRB, RDRC, IACUC
315 Kinkead Hall
Lexington, KY 40506-0057
859 257-9428
fax 859 257-8995
www.research.uky.edu/ori

Initial Review

Approval Ends
June 12, 2009

Project Ends
May 30, 2009

IRB Number
08-0236-P4S

TO: Katherina A Nikzad, MSW, ABD
Gerontology
251 Chippendale Circle, Apt #1212
Lexington, KY 40517
PI phone #: (330)284-4196

FROM: Chairperson/Vice Chairperson
Non-medical Institutional Review Board (IRB)

SUBJECT: Approval of Protocol Number 08-0236-P4S

DATE: June 13, 2008

On June 13, 2008, the Non-medical Institutional Review Board approved your protocol entitled:

Dementia Caregiving Outcomes: The Impact of Caregiving Onset, Role Occupancy and Care Recipient Decline

Approval is effective from June 13, 2008 until June 12, 2009. This approval extends to any consent/assent document unless the IRB has waived the requirement for documentation of informed consent. If applicable, attached is the IRB approved consent/assent document(s) to be used when enrolling subjects. [Note, subjects can only be enrolled using consent/assent forms which have a valid "IRB Approval" stamp unless special waiver has been obtained from the IRB.] Prior to the end of this period, you will be sent a Continuation Review Report Form which must be completed and returned to the Office of Research Integrity so that the protocol can be reviewed and approved for the next period.

In implementing the research activities, you are responsible for complying with IRB decisions, conditions and requirements. The research procedures should be implemented as approved in the IRB protocol. It is the principal investigators responsibility to ensure any changes planned for the research are submitted for review and approval by the IRB prior to implementation. Protocol changes made without prior IRB approval to eliminate apparent hazards to the subject(s) should be reported in writing immediately to the IRB. Furthermore, discontinuing a study or completion of a study is considered a change in the protocol's status and therefore the IRB should be promptly notified in writing.

For information describing investigator responsibilities after obtaining IRB approval, download and read the document "PI Guidance to Responsibilities, Qualifications, Records and Documentation of Human Subjects Research" from the Office of Research Integrity's Guidance and Policy Documents web page [http://www.research.uky.edu/ori/human/guidance.htm#PIresp]. Additional information regarding IRB review, federal regulations, and institutional policies may be found through ORI's web site [http://www.research.uky.edu/ori]. If you have questions, need additional information, or would like a paper copy of the above mentioned document, contact the Office of Research Integrity at (859) 257-9428.

Maureen Van Tubingen, Ph.D./PS
Chairperson/Vice Chairperson

see blue.

An Equal Opportunity University

080236P4S

Dementia Caregiving Outcomes: The Impact of Caregiving Onset, Role Occupancy and Care Recipient Decline

			Trained:	Date:	DunnChad:	Citi:	Other Test	Degree	Role Desc
PI	Nikzad Kanikz2@uky.edu	Katherina	Y	03/23/08	Y	Y	N	MSW, AB	Unassigned
KP	Teaster pteaster@uky.edu	Pamela	Y	12/30/06	Y	Y		Ph.D.	Advisor

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- Zhang, J. Vitaliano, P., & Lin, H. (2006). Relations of caregiving stress and health depend on the health indicators used and gender. *International Journal of Behavioral Medicine*, *13*(2), 173-181.

Vita

KATHERINA A. NIKZAD-TERHUNE

Graduate Center for Gerontology
University of Kentucky
306 Wethington Health Sciences Building
900 S. Limestone
Lexington, KY 40536-0200
Born: August 30, 1981, Canton, Ohio

Phone: (859) 257-1450 ext. 80268
(859) 523-8824 (Home)
E-mail: katherina.nikzad@uky.edu
Fax: (859) 323-5747

Education

2007	University of Kentucky	Lexington, KY
	• <i>Masters of Social Work</i>	
2003	Otterbein College	Westerville, OH
	• <i>B.A. Honors Psychology (Summa Cum Laude)</i>	
	<i>Minor: American Sign Language</i>	

Research Interests

The Dementia Caregiving Career
Caregiving Transitions
Mental Health and Aging
Long-Term Care Issues

Teaching Interests

Theories in Social Work and Gerontology
Psychopathology
Assessment and Intervention
Introduction to Gerontology
Aging and Mental Health

Competitive Grants

May 2007	Awarded: John A. Hartford Doctoral Fellowship, The Gerontological Society of America
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Honors

2010	Outstanding Young Woman Award
2007-2009	Hartford Doctoral Fellow
2006	Emeriti Faculty Endowed Doctoral Fellowship
2006	National Mortar Board Graduate Fellowship
2006	Kentucky Association for Gerontology Lois E. Layne Award
2005	Keynote Student Speaker for the Southern Gerontological Society Student Mentoring Conference
2005	Donovan Scholarship in Gerontology
2005-present	The Chancellor's List, Academic Honor for Graduate Students
2004	Southern Gerontological Society Honorable Mention Poster Award
2003-2007	Kentucky Opportunity Fellowship
2003	Barbara P. Quilling National Graduate Fellowship

2003	Benua Foundation Award for Academic Excellence
2003	Maria Leonard Senior Book Award (Highest GPA), Otterbein College
2003	Outstanding Senior Honors Thesis Award for Conducted Research
2002	Marilyn Day/Joanne VanSant Book Award for Highest GPA, Otterbein College
2002	Altercare Nursing Home Umbrella Award for Service
2001	Sheila Murphy Book Award for Highest GPA, Otterbein College
2001	JoAnne J. Trow National Scholarship (Alpha Lambda Delta)
2000	Stephen Karsko Memorial Award for Psychology

Publications

Peer-reviewed articles

- Nikzad-Terhune, K. A., Anderson, K. A., Newcomer, R., & Gaugler, J. E. (2010). Do trajectories of at-home dementia caregiving account for burden after nursing home placement? A growth curve analysis. *Social Work in Health Care, 49*(8), 734-752.
- Anderson, K. A., Nikzad-Terhune, K. A., & Gaugler, J. E. (2009). A systematic evaluation of online resources for dementia caregivers. *Journal of Consumer Health on the Internet, 13*, 1-13.
- Roberto, K. A., Teaster, P. B., & Nikzad, K. A. (2007). Sexual abuse of vulnerable young and old men. *Journal of Interpersonal Violence, 22*, 1009-1023.
- Nikzad, K. (2005). The graduate school trajectory. In B. Schmid (Ed.), *Aging in Time and Place. The 16th Annual Student Mentoring Conference on Gerontology and Geriatrics*. Athens, GA: University of Georgia Gerontology Center.
- Laurie-Rose, C., Bennett-Murphy, L., Byard, L., & Nikzad, K. A. (2002). The role of the big five personality factors in vigilance and workload. *The European Journal of Personality, 16*, 185-200.

Book Chapters

- Nikzad-Terhune, K. A. (2011). Compromised family coping. In E. J. Ackley & G. B. Ladwig (Eds.), *Nursing diagnosis handbook: An evidence-based guide to planning care*. (9th Ed.). (pp. 279-284). St. Louis, MO: Elsevier, Inc.
- Gaugler, J. E., Nikzad-Terhune, K. A., & Ewen, H. H. (2010). Long-term care for families. In M. Craft-Rosenberg et al. (Eds). *Encyclopedia of family health*. Thousand Oaks, CA: Sage Publications, Inc.
- Nikzad, K. A., Anderson, K. A., & Gaugler, J. E. (2008). The potential for empowered teams in home care settings. In D. Yeatts (Ed.), *Improving resident health and employee attitudes in long term care: Why and how to create empowered nurse aid teams*. (pp. 29-38). Baltimore, MD: Health Professions Press.

- Nikzad, K. A., & Gaugler, J. E. (2008). Compromised family coping. In E. J. Ackley & G. B. Ladwig (Eds.), *Nursing diagnosis handbook: An evidence-based guide to planning care*. (8th Ed.). (pp. 261-266). St. Louis, MO: Elsevier, Inc.
- Gaugler, J. E., Nikzad, K. A., & Zarit, S. H. (2006). Respite care. In R. Schulz et al. (Eds.), *The encyclopedia of aging* (4th Ed.). New York, NY: Springer Publishing Company.
- Nikzad, K. A. (2005). Promoting family involvement in long-term care: A certified nursing Assistant's (CNA) perspective. In J. E. Gaugler (Ed.), *Promoting family involvement in long-term care settings: A guide to programs that work* (pp. 45-69). Baltimore, MD: Health Professions Press.

Presentations

- Nikzad-Terhune, K. A. (2009, February). *Dementia caregiving outcomes: The impact of caregiving onset, role occupancy, and care-recipient decline*. Poster presented at the Graduate Research Day at the Capitol, Frankfort, KY.
- Nikzad-Terhune, K. A. (2008, November). *Variations in the Onset of Dementia Caregiving: Implications for Resiliency Among Caregivers*. Paper presented at the 61st Annual Scientific Meeting of the Gerontological Society of America, National Harbor, MD.
- Nikzad, K. A. (2007, November). *The potential for empowered teams in home care settings*. Paper presented at the 60th Annual Scientific Meeting of the Gerontological Society of America, San Francisco, CA.
- Nikzad, K. A. (2007, November). *Dementia caregiving outcomes: The impact of caregiving onset, role occupancy, and care-recipient decline*. Poster presented at 60th Annual Scientific Meeting of the Gerontological Society of America, San Francisco, CA.
- Ewen, H. H., Nikzad, K. A., & Watkins, J. F. (2006, February). *Gerontology doctoral students' perceptions of interdisciplinary training*. Paper presented at the 23rd Meeting of the Association for Gerontology in Higher Education, Indianapolis, IN.
- Nikzad, K. A. (2006, November). *The onset of dementia caregiving: Implications for caregiver outcomes*. Paper presented at the 59th Annual Scientific Meeting of the Gerontological Society of America, Dallas, TX.
- Ewen, H. H., Nikzad, K. A., & Bowles, S. L. (2006, November). *Gerontology doctoral education: Students' perceptions of educational and research experience*. Poster presented at 59th Annual Scientific Meeting of the Gerontological Society of America, Dallas, TX.
- Nikzad, K. A. (2005, November). *Patterns of entry into the caregiving role and its implications for family caregivers*. Poster presentation at the Gerontological Society of America Conference, Orlando, Florida.

- Nikzad, K. A. (2004, November). *The mediational effects of care demands on sequence of onset and emotional distress in dementia caregiving*. Poster presented at the Gerontological Society of America Conference, Washington, D.C.
- Nikzad, K. A. (2004, April). *Sensory stimulation activities used as interventions for individuals with Alzheimer's disease*. Poster presented at the Southern Gerontological Society Conference, Atlanta, GA.
- Nikzad, K. A., Stimer, E., & Solt, H. (2001, May). *Cognitive failures questionnaire as a predictor of sustained attention performance*. Poster presented at the Midwestern Psychological Association Annual Conference, Chicago, IL.
- Nikzad, K. A., Solt, H., Tucci, J. & Hedrick, J. (2000, May). *Type A personality and vigilance: The effects of event rate*. Poster presented at the Midwestern Psychological Association Annual Conference, Chicago, IL, and at Otterbein College Women in Science Lecture Series.
- Byard, L., Nikzad, K. A., & Hedrick, J. (2000, May). *A closer look at personality variables in vigilance*. Poster presented at the Midwestern Psychological Association Annual Conference, Chicago, IL.
- Hedrick, J., Solt, H., Tucci, J., Byard, L. & Nikzad, K. A. (2000, May). *The influence of Mozart on vigilance performance*. Poster presented at the Midwestern Psychological Association Annual Conference, Chicago, IL.
- Invited*
- Nikzad-Terhune, K. A. (2010, October). *Remarriage after the death of a spouse*. Presented at the Seasons of Marriage Conference at Mary Queen of the Holy Rosary Catholic Church, Lexington, KY.
- Nikzad-Terhune, K. A. (2009, October). *The experience of being a certified nursing assistant*. Presented at the Sageser Annual Award Ceremony for nursing assistants in central Kentucky.
- Nikzad-Terhune, K. A. (2009, January). *Coping with holiday stress as a dementia caregiver*. Presented at monthly caregiver support group, Lexington, KY.
- Nikzad-Terhune, K. A. (2008, November). *Understanding and working with the grief process as a clinician*. Presented at Family Counseling Service, Lexington, KY.
- Nikzad, K. A. & Hosier, A. F. (2005, November). *The future of long-term care*. Presented at the Wesley Manor CCRC Advisory Board Retreat, Louisville, KY.
- Nikzad, K. A. & Lewis, R. (2005, August). *Preventing and managing falls in the elderly*. Presented at the Area Agency on Aging 10B Inc., Uniontown, OH.

Nikzad, K. A. (2005, April). *The onset of dementia caregiving: Retrospective and prospective approaches*. Presented at the Southern Gerontological Society Student Mentoring Conference, Tybee Island, GA.

Nikzad, K. A. (2004, October). *The use of nonpharmacological interventions in Alzheimer's care*. Presented at the Continuing Education Workshop on Aging, Lexington, KY.

Nikzad, K. A. (2004, March). *Successfully applying for scholarships on a national level*. Presented to Alpha Lambda Delta Honor Society, University of Kentucky, Lexington, KY.

Research Experience

- 2003-present Research Fellow, Graduate Center for Gerontology, University of Kentucky, Lexington, Kentucky
- Worked under the direction of Pamela B. Teaster & Joseph E. Gaugler
- 1999-2002 Research Assistant, Perception Research Lab, Otterbein College, Westerville, Ohio
- Worked under the direction of Cynthia Laurie-Rose & Laura Bennett-Murphy

Teaching Experience

Courses (Graduate =G, Undergraduate = U)

- 2008 University of Kentucky, Lexington, KY
GRN 770 Feminist Aspects in Gerontology* (G)
- 2006 SW 420 Human Behavior in the Social Environment (U)
- 2006-2007 A&S 300 Guest Lecturer, Aging in a Contemporary Society (U)
- 2000 Otterbein College, Westerville, OH
PSYC 260 Ethical Issues in Psychology (U)

*Denotes new courses developed

Clinical Experience

- 2007-present Therapist, Family Counseling Service, Lexington, Kentucky
- 2000-2007 Certified Nursing Assistant, Chapel Hill Community, Canal Fulton, Ohio
- 2000-2002 Certified Nursing Assistant, Altercare Nursing Home, Westerville, Ohio

Internships

- 2007 Therapy Associate, Family Counseling Service, Lexington, Kentucky

2006	Center for Geriatric Psychiatry, Affinity Medical Center, Massillon, Ohio
2005	Case Management Intern, PASSPORT Division, Area Agency on Aging 10B, Inc., Uniontown, Ohio
2002	Substance Abuse Counseling Intern, Mental and Behavioral Health Unit, Massillon Community Hospital, Massillon, Ohio
2001	Unit Coordinator Intern, Special Care Unit, Chapel Hill Community, Canal Fulton, Ohio

Specialized Training

2010	Licensed Clinical Social Worker in the State of Kentucky (#3435)
2007	Certified Social Worker in the State of Kentucky (#5235)
2004	Alzheimer's Association Lexington, KY <ul style="list-style-type: none"> • <i>Adult Daycare Volunteer Training Certificate</i>
2001	Altercare of Westerville Westerville, OH <ul style="list-style-type: none"> • <i>Alzheimer and Dementia Caregiver Training Certificate</i>
2000	Chapel Hill Community Canal Fulton, OH <ul style="list-style-type: none"> • <i>State Certified Nursing Assistant</i> • <i>CPR Certification (Updated every 2 years)</i>

Professional Activities

Current Memberships in Professional Organizations

2007-present	Society for Social Work and Research
2007-present	The Association for Gerontology Education in Social Work
2007-present	Cambridge Who's Who Among Executives & Professionals
2005-present	National Association of Social Workers
2004-present	Sigma Phi Omega Honorary Society for Gerontology
2003-present	The Gerontological Society of America
2003-present	Mortar Board National Honorary Society Alumni Member
2000-2007	American Psychological Association, Student Affiliate
2000-2007	Adult Development and Aging (Division 20 of APA)

Service to Professional Organizations

2007-present	Mental Health Expert, Rachel's Vineyard Ministries
2007-present	Clinical Committee, Family Counseling Service
2005-2006	Vice President, University of Kentucky Gamma Mu Chapter of Sigma Phi Omega (National Honorary Society for Gerontology)
2005	Search Committee, The Emerging Scholar and Professional Organization (ESPO) Division of the Gerontological Society of America
2004-2005	Secretary, The Emerging Scholar and Professional Organization (ESPO) Division of the Gerontological Society of America
2004-2005	Author of monthly newsletter articles for <i>Gerontology News</i> , a publication of the Gerontological Society of America

2001-2002 Junior and Senior Advisor, Otterbein College Chapter of Alpha
Lambda Delta (National Honorary Society for Women)
2001-2002 Treasurer, Otterbein College Chapter of Psi Chi (National Honorary
Society in Psychology)
2000-2001 Vice President, Otterbein College Chapter of Alpha Lambda Delta

Service to University Organizations

2006-2007 Faculty Search Committee, Graduate Center for Gerontology
2004-2006 Administrative Council Representative, Graduate Center for
Gerontology
2003-2005 Recruitment Committee, Graduate Center for Gerontology

Community Service

2009-present Board of Directors, Birthright, Lexington, Kentucky
2005-2007 Volunteer, Winged Women, Inc., Lexington, Kentucky
2005-2007 Volunteer, Helping Hands Adult Day Care Center, Lexington,
Kentucky
