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An Examination Of Caregiving Dyads: Community Dwelling Chronically Ill Older Adults And Their Caregivers

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AN EXAMINATION OF CAREGIVING DYADS: COMMUNITY DWELLING
CHRONICALLY ILL OLDER ADULTS AND THEIR CAREGIVERS

A Dissertation

Presented to

Faculty of the Graduate School of Social Work

University of Denver

In Partial Fulfillment

of the Requirements for the Degree

Doctor of Philosophy

by

Jessica E. Haxton

June 2010

Advisor: Jeffrey M. Jenson, Ph.D.

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Abstract

Increases in life expectancy among older adults raise important concerns about the availability of resources for an aging population living with chronic and debilitating illnesses. Living longer is complicated by the fact that many elders prefer to reside in their homes until medical or other conditions require an alternative living arrangement. The strong desire to remain at home expressed by older persons in the United States has in turn created an increased demand on informal caregiving. Consequently, adult children often bear the burden of providing care to their aging parents. In view of this demand it is critical that research be conducted to identify the conditions that may threaten the stability of long-term caregiving arrangements. The purpose of this study was to examine the nature of interpersonal dynamics between caregivers and care-receivers during the care process. Specifically, the study aimed to investigate the relationship between role engagement and quality of commitment among caregivers and care-receivers and to assess how these two processes impact the psychological well-being of such dyads. A sample of caregiver and care-receiver dyads as well as additional caregivers were identified through Colorado agencies that administer home and community-based Medicaid programs and used to evaluate relationships between dyad members. Higher caregiver personal commitment to their care-receiver was related to care-receivers' experience of dyad strain. Caregiver perception of care-receiver competence had a negative relationship with care-receiver depression. Higher personal

commitment in care-receivers was positively related to caregiver autonomy. Higher care-receiver relational coping was related to lower levels of caregiver dyad strain and depression. Personal commitment and perceived role competence of the care-receiver were significantly related to depression in caregivers. Like care-receivers, caregivers with higher levels of personal commitment also had lower levels of depression and lower dyad strain, higher positive interaction, and higher perception of care-receiver competence. Caregiver personal commitment and perceived role competence of care-receivers were significantly associated with depression in caregivers. Results indicate that personal and moral commitment may be important predictors of psychological well-being. Study findings that inform existing practice and policy strategies for older adults and their caregivers are discussed.

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Chapter 1: Introduction

Increases in life expectancy among older adults raise important concerns about the availability of resources for older persons living with chronic and debilitating illnesses. The opportunity for older adults to remain in their homes with assistance has become an important alternative to institutionalized care. The concept of older adults remaining in their homes, often called “aging in place,” was established due to preferences of people later in their life, physical and mental health benefits for older adults to remain in their own homes, and the significant cost savings that occur for individuals, families and public health care systems (MacLaren, Landberg & Schwartz, 2007; Bookman, 2008). The national distress related to limited resources and a strong desire to remain at home expressed by older persons in the United States has in turn created an increased demand for informal caregiving. Consequently, adult children often bear the responsibility of providing care to their aging parents.

The number of older adults with chronic illness who engage in caregiving dyads has increased drastically in the last two decades (McKune, Andresen, Zhang, & Neugaard, 2006). Dyadic interactions have substantial effects on both parties’ mental health and ability to function in society (McKune, et al., 2006; Wolff & Kasper, 2006). Such interactions between caregivers and care-receivers also play a critical role in the adequate management of older adults’ needs (McKune, et al., 2006). For example, many community dwelling older adults’ success or failure in caregiving relationships may

influence whether they remain in a community setting or are forced to consider more restrictive and expensive skilled care residency (Dorothy, 2003; Spruytte, Van Audenhove, & Lammertyn, 2001).

In view of the societal trends mentioned above it is critical that research be conducted to identify the conditions that may bolster or threaten the stability of long-term, informal caregiving arrangements. Therefore, finding a useful way to measure and examine the caregiver and care-receiver as a dyad is an important next step in caregiving research. A fundamental aspect of informal caregiving arrangements is the unique relationship that exists between each person in this dyad. Thus, this relationship is important to study as part of an ongoing effort to improve conditions for older adults.

This study examined the interpersonal dynamics that exist between caregivers and the older parents they care for. The specific relationship components investigated included role engagement and commitment, and how these two components impact psychological well-being outcomes of older adults and their caregivers. A sample of caregivers and care-receivers identified through non-profit and state contracted agencies in Colorado was used to evaluate relationships between dyad members. Implications for practice and policy strategies for support of older persons and their caregivers are noted. In this chapter I provide a brief review of major concepts and their definitions as well as important problems and trends that impact older care-receivers and their caregivers.

Conceptual and Operational Definitions

Caregiver

A caregiver is “a person, either paid or voluntary, who helps an older person who assumes the role of care-receiver. Caregivers assist care-receivers with the activities of daily living, health care, financial matters, guidance, companionship and social interaction. A caregiver can provide more than one aspect of care” (Elder-care.net, 2009). Aspects of care are dependent upon the types and severity of needs of the care-receiver. The amount of need of care-receivers is often a factor in outcomes for caregivers (Greenberg, Seltzer, & Brewer, 2006). In many cases the role of caregiving is a progressive one that starts with assisting with minor tasks and over time increases in intricacy and frequency. This study examined the later stages of caregiving during which the amount of need of the care-receiver, in order to remain at home, was over ten hours per week.

Care-Receiver

The ways in which care-receivers engage in their role in the care process has been overlooked in caregiving research (Gaugler, Kane & Kane, 2002). As a result, the call for more research on care-receivers’ contributions to the care process has grown stronger over the last few decades. As defined in this study, a care-receiver is an older adult over the age of 60 who lives with debilitating health issues and requires assistance in daily living. The tasks associated with being a care-receiver have strong links to their well-being (Liang, Krause & Bennett, 2001; Tetz, Archbold, Stewart, Messecar, Hombrook, & Lucas, 2006; Sebern & Whitlatch, 2007). The salience of these tasks have been

established in several studies (Cox & Dooley, 1996; Cox, Green, Seo, Inaba, & Quillen, 2006; Gallo, Rebok, Tennstedt, Wadley, & Horgas, 2003, Hollis-Sawyer, 2003). They include cooperating (or not) with assistance provided, showing consideration of and respect towards the caregiver, providing emotional support to the caregiver, and participating (or not) in decisions being made about their own health. These are all tasks of how a care-receiver can engage in their role and be an active participant in their own care.

Care Dyad

A care dyad is a group consisting of two members participating in a process in which an older adult performs as the care-receiver and another person performs as the caregiver. Although caregiving dyads often vary in membership type, for this study it is always the case that the caregiver is a child caring for an older parent who is the care-receiver. This parent-child care dyad relationship has inherently different characteristics than other types of dyads, such as caregiving and care-receiving spouses, because of the complex implications of the nature of the dyad's relationship prior to the need of care. For example, if an older adult is receiving care from her life partner the interactions in the care process stand to be impacted by the level of intimacy or devotion based on the shared history and relationship development that typically happens in romantic relationships. If, on the other hand, an informal caregiver shares limited or no history with her care-receiver, the interactions in this dyad are more likely to be influenced by personal factors unrelated to family history. Parent-child dyads share a unique history and therefore must be examined as a different population of dyads when aspects of the

interpersonal relationship are the target of inquiry. Care process refers to the interactions that take place between a care-receiver and caregiver as support is produced by both members. Although this care process includes participation by two members, the physical assistance and personal care is most often provided to an older adult with chronic illness by the caregiver.

Role Engagement

Role engagement refers to the way caregivers and care-receivers perceive and participate in their respective roles. The term role engagement conceptualizes an understanding of what it means to engage in caregiving and care-receiving roles in an interactive way. It is measured by how one performs the tasks associated with being a caregiver or care-receiver. How one engages in a role as a caregiver is extremely different than how one engages in a care-receiver role. Therefore, these two roles require unique conceptualizations and definitions in terms of role engagement, which will be described in the following chapter.

Commitment

Commitment refers to the motivation experienced by one dyad member of why one engages in their role with the other dyad member. These are motivations behind an actor's behavior that are related to that actor's outcomes as well as their partner's outcomes (Rusbult & Buunk, 1993, Rusbult & Van Lange, 2003). These motivations have been conceptualized in research of human relationships as interpersonal commitment. It is hypothesized in this study that motivations for committing to be

someone's caregiver or agreeing to be in a care-receiving arrangement are important in determining how one experiences these roles.

Home and Community-Based Services

Home and Community Based Services (HCBS) are services provided to individuals and families with limited resources to manage mental and physical disabilities while they remain living in a community setting. The HCBS agencies and other non-profits serving older adults who need assistance to remain independent at home were accessed in order to recruit participants for the current study. The types of services provided by these agencies include health maintenance activities, personal care, and homemaker services. The client or authorized representative may often self-direct these services.

Chronic Illness

Chronic illness refers to any illness, disease or health condition that lasts longer than three months. It often refers to an illness that persists over a very long period of time and that causes a progressive decline. Assisting older adults in managing debilitating chronic illness is identified as a complex and looming challenge to be faced by gerontological social workers (Berkman, Gardner, Zodikoff, & Harootyan, 2006). The research community has begun to examine the dynamics between two people in informal caregiving relationships in order to address why some older adults living with chronic illness and their caregivers thrive and others living with the same health conditions have poorer outcomes.

Recent Trends in the Aging Population

Older adults comprise the fastest growing segment of the population in the United States (United States Census Bureau, 2000). Older adults are living longer than in past years and elders with chronic illness account for nearly one-third of national healthcare spending (Gerberding, 2007). Eighty percent of older adults have at least one chronic health condition, 50% have two or more conditions, and those who are advancing toward the debilitating stages of their chronic illness will require late life caregiving assistance. Sixteen percent of Americans provide regular informal care for these older adults (McKune, et al., 2006). The intersections of these trends have resulted in increased demand for families to care for their elders.

Fifty years ago this demand was typically anticipated by families, however, the traditional structure of the family has transformed in ways that cater to an industrial and independent society. The traditional infrastructure of families caring for aging relatives without external support is no longer the norm (Hooyman & Gonyea, 1995). Hooyman and Gonyea (1995) highlight the critical issues related to family caregiving that should be reflected in social policies in order to protect and support informal caregiving. The current study is highly relevant at a time when resources for older adults are predicted to be limited. The growth of an aging population and a plateau in the amount of affordable out-of-home care have increasingly shifted the attention of health and social services towards the needs of older adults who are living at home (Fortinsky, Fenster, & Judge, 2004). Additionally, elders who receive care from others to maintain daily life are more

vulnerable than those who are independent in the community (Dent, et al., 1999; Gallo, et al., 2003).

Finding policy solutions and effective strategies to bolster informal caregivers and elder care-receivers is essential in the effort to improve the country's long-term system of care. Trends in life expectancy and in-home care, where there is a 20% likelihood that caregivers live with care-receivers, place significant demands on informal caregivers (National Alliance of Caregiving [NAC] & American Association of Retired Persons [AARP], 2009). Thus, it is important that research be aimed at understanding the conditions and characteristics associated with positive and negative outcomes among community-dwelling older adults and their caregivers.

Circumstances of Caregiving

In light of the current continuum of care available for older adults, informal caregiving is considered the backbone of the long-term care system (NAC & AARP, 2004; Wolff & Kasper, 2006). This type of caregiving in the United States, where there are now 49.5 million people caring for someone 50 years and older, is considered an augmentation of the current formal health care system (Link, Dize, Filkemer, & Curran, 2006; National Alliance of Caregiving [NAC] & American Association of Retired Persons [AARP], 2009). It is vital, then, that society supports older adults and their informal caregivers in light of the challenges they face.

Older adults and their informal caregivers are better supported in part through increased understanding of the care process. Care processes have a substantial impact on mental health and functioning among older adults and caregivers (Wolff & Kasper,

2006). Studies show that the quality of interactions between dyad members plays a critical role in adequate management of the needs of older adults (McKune, et al., 2006). Success or failure of these interactions may even determine whether older adults remain in a community setting or are forced to consider more restrictive and expensive skilled care residency (Dorothy, 2003; Spruytte, Van Audenhove, & Lammertyn, 2001). Lechner and Gupta (1996) found that the relationship between the caregiver child and care-receiving parent was the best predictor of the persistence or discontinuance of the caregiving arrangement. The connection between quality of caregiver/ care-receiver relationships and the stability of long-term caregiving arrangements is apparent.

Predominantly, when older adults begin to receive informal care, a primary caregiver emerges as the main source of that care. Based on current profiles of the number of older adults who receive care, 44% of the time this primary caregiver will be an adult child (Mack, Thompson, & Friedland, 2005). The difficulties associated with primary caregiving include stress, burn out, poor health and mental health, including depression (Greenberg, et al., 2006; Parrish & Adams, 2003; Pinquart & Sorensen, 2004; Wolff & Kasper, 2006). In addition, numerous studies and reports have found that, when compared to their non-caregiving counterparts, caregivers have lower life satisfaction (Borg & Hallberg, 2006).

There is a limited understanding in contemporary social services about the specific elements that sustain healthy dyad relationships between elders and their adult child caregivers. Social workers are well positioned to create interventions that adequately support these relationships so as to prevent unnecessary poor mental and

physical health outcomes and premature institutional placement. Therefore, measuring and examining the dyad relationship is an important next step in caregiving research (Lyons, Sayer, Archbold, Hornbrook & Stewart, 2007).

Research to date regarding dyad relationships has examined romantic partnerships, young parent and child relationships, and friendships. These studies have been conducted for the purpose of discovering and measuring the potential impact on peoples' health, mental health and social functioning (Reinardy, Kane, Huck, Call & Shen, 1999; Rusbult & Buunk, 1993; Rusbult & VanLange, 2003; Gayle & Preiss, 2002b). However, the relationship between older adults with chronic illness and their informal caregivers is rarely the focus of dyad research. Because this type of caregiving relationship is occurring more frequently, it is necessary to better understand it for its outcomes on both parties.

Furthermore, recent social policy creation that resulted in the National Family Caregiver Support Program (NFCSP) provide important context to the need to study caregiver and care-receiver issues. The effectiveness of these policy reforms has come under some scrutiny due to lack of meeting enough needs of caregivers (NAC & AARP, 2004). Therefore, learning more about the care process is necessary to inform and support policy changes that better meet the needs of the older adult population. The current study is strongly aligned with the national gerontological social work research priorities identified by Burnette, Morrow-Howell and Chen (2003). These research priorities were established by surveying accomplished social work scholars in gerontology. These experts contributed to the identification of the most pressing needs

for further research. One of these priorities is to better understand the specific sub-group of family caregivers as well as to address the mental health needs of older adults (Burnette, et al., 2003).

Study Purpose

There are growing concerns about trends in the aging population and their related implications for caregivers' and older care-receivers' health and mental health outcomes. Although many important strides have been made to understand caregiving and care-receiving, there is still a limited understanding in contemporary social services about the specific elements that sustain healthy care dyad relationships. This study examined a crucial aspect of the care process, the nature of the interpersonal dynamics between chronically ill older adults and child caregivers during the care process. The current study collected data from caregivers and their respective care-receivers. This strategy provided a valuable dual perspective that is seldom found in caregiving research or intervention studies (Martire, et al., 2004).

How one engages in either a caregiver or care-receiver role has consequences. Commitment to a relationship has been established as an important aspect of dyads, yet our understanding of commitment in the context of caregiver care-receiver relationships is limited. The current study looks at commitment and role engagement in order to contribute to a more contemporary understanding of this important aspect of caregiving. It also claims to improve our understanding of how these two processes, commitment and role engagement, impact the psychological well-being of dyad partners. Finally, by recognizing the important contributions of care-receivers, the study's purpose

acknowledges a strengths-based conceptualization of the care process (Chapin, Nelson-Becker, & MacMillan, 2006), that creates a positive shift away from the deficit and burden based caregiving paradigm.

Information from this study is intended to provide knowledge that may lead to improved assessments and interventions for older persons and caregivers. The social work profession has considerable potential to effectively address problems experienced by care dyads. A more sophisticated understanding of care dyads may lead to improved assessments and interventions that are applicable to in-home settings. Findings from the proposed study may have useful applications for geriatric case management, counseling, and therapy. Results may also contribute to increasing our understanding of efficacious ways to impact advocacy efforts and policies aimed at improving conditions for older adults and their caregiving family members. Finally, this study attempts to make a positive shift away from the deficit and burden based caregiving paradigm in which it is strongly aligned with the movement towards a strengths-based approach in social work and other disciplines (Chapin, et al., 2006).

Chapter Summary

The current study examines commitment and role engagement and its relationship to the psychological well-being within and between caregivers and care-receivers. The ability to assess caregivers and care-receiving parents as dyadic partners is an important next step in improving social services that attempt to assist and support dyads. The following chapter provides a review of theoretical frameworks and a discussion of current knowledge about older adults, their caregivers, and caregiving dyads.

Chapter 2: Review of the Literature

This chapter examines the theoretical models of social interdependence and role theories that provide the framework for this investigation of the relationship between care-receiving parents and their caregivers. The literature review that follows will discuss research that has improved our understanding of the nature of such relationships and their related outcomes, and that has contributed to the conceptualization of caregiving, care-receiving, and social interactions within dyads. Gaps in current knowledge about these concepts and their impact on caregivers and care-receivers are explained. Finally, this review will address the empirical basis that guides the measurement of these concepts in the current study.

Theoretical Model

There is an extensive history in the social sciences that has contributed to our understanding of individuals in relationships. Theory serves an integral role in our understanding of the relationship between family members and specifically between caregivers and care-receivers. Social interdependence and role theories (Holmes, 2002; Rusbult & VanLange, 2003, Marks, 1977, Burr, Leigh, Day & Constantine, 1979; Turner, 1962; Schumacher, Stewart, Archbold, Caparro, Mutale & Agrawal, 2008) contribute to the conceptualization of the interpersonal dynamics between caregivers and care-receivers used in the current study. These theoretical approaches serve as the platform to explore the components of such complex roles and relationships as found in care dyads.

Social science research often examines dyad relationships--romantic partnerships, parent to child relationships, and friendships--for the purpose of identifying and measuring the potential impact these relationships have on peoples' health, mental health and social functioning. The application of dyad research to older and their caregivers is less common.

Though the most popular subject of dyad research is the marital relationship, social scientists have also studied relationship dynamics beyond the typical spousal or romantic dyad. For example, Oswald, Clark and Kelly (2004) conducted three studies on friendship dyads to better understand friendship maintenance behaviors. They found that each member of the dyad's satisfaction and commitment to the relationship could be predicted by their perception of the other member's efforts to maintain equality and to see things the same way. These researchers addressed components of dyad member relationships using a theoretical orientation called The Investment Model, which is embedded in Interdependency Theory. They purport that satisfaction is a function of commitment and concluded by identifying factors that contribute to relationship maintenance in friendships (Oswald, Clark & Kelly, 2004). Friendship dyads are only one example of how dyad studies have pursued a better understanding of functions in seminal relationships beyond the traditional marriage dyad. The research community has recently begun examining the nature and outcomes related to the dyad process in caregiving relationships.

The conceptual models developed from the previous dyad research are useful when examining the specific characteristics of the caregiving dyad. Caregiving dyad

studies to date have examined perception of role (Li & Seltzer, 2005; Piercy & Chapman, 2001; Russell, Bunting & Gregory, 1997; Tetz, et al., 2006; Cox, & Dooley, 1996), relationship quality (Horowitz, Goodman, & Reinhardt, 2004; Lyons, Zarit, Sayer, & Whitlatch, 2002; Martini, Grusec, & Bernardini, 2001; Synder, 2000), commitment (Pohl, Boyd, Liang, & Given, 1995; Pierce, Lydon, & Yang, 2001; Piercy, 2007) and psychological well-being in the pursuit of understanding physical and mental health outcomes among caregivers and older adult care-receivers. In the section that follows I explain the theoretical frameworks used to guide the current investigation and relevant findings from previous research.

Commitment in caregiving relationships

Social interdependence theory assumes that people in intense social relationships depend on one another for social functioning (Holmes, 2002). Social interdependence theory was originally developed through the group work of an early pioneer of social psychology, Kurt Lewin. Lewin's equation for behavior, $B=f(P,E)$, is a heuristic that provides a theoretical explanation of human behavior through one's psychological interactions with the environment (1946). The assumptions of interdependence theory imply that people have intrinsic motivations to collaborate with each other in order to achieve goals they both find important (Holmes, 2002; Rusbult & VanLange, 2003). Key theoretical elements include an understanding of mutual dependence, motivation, mutuality of expectations, and contextual influence. When considering dyad interactions, interdependence theory alleges to explain each person's needs, thoughts, and motivations behind behavior within the context in which the interactions occur. An important

strength of interdependence theory in the study of caregiver and care-receiver relationships is that abstract social-psychological needs and more tangible physical needs are both considered important. Using the interdependence structure, whether or not caregivers' social-psychological needs are being met by their care-receiver will impact the relationship and the individuals.

Interdependence theory does not assume that there is one overarching need that explains a person's behavior within a close relationship (Rusbult & Van Lange, 2003). Rather, it assumes that there is a wide variety of instrumental and social-emotional needs that every human has that are rooted in biology, emotions, learned behavior, etc. Some of these needs are only served in a dyad relationship. These needs are most often unique to the context of where a person is in life and the nature of the partnership or relationship they have with the other person. By examining the situational structure one can identify the individual outcomes related to whether or not the needs of the partner are satisfied (or not) by the actor. Understanding the structure allows for clarification of the extent to which outcomes for each member of the dyad are positively or negatively correlated. The "basic components of influence and covariation" (Rusbult & Van Lange, 2003, p. 345) in relationships are the level of dependence, mutuality of dependence, basis of dependence, and covariation of interests.

Relationships in caregiver research are often conceptualized as unbalanced based on the notion that care-receivers have little to offer the relationship because of their decline in health and overall well-being (Whitlach, Judge, Zarit & Femia, 2006). However, this perspective fails to consider the healthy, balanced, and satisfactory caregiver/ care-

receiver relationships that do exist. Therefore, it is important to acknowledge an interdependence structure that recognizes both dyad members' interactions.

Another key aspect related to the structure of interdependency is that of expectations from both persons in the relationship (Rusbult & Van Lange, 2003). These expectations are often internalized social norms learned throughout one's life about what one should expect from an older parent in need of assistance or adult child caregiver. Interdependence is a "grand theory" that supports the structure in which motivations behind an actor's behavior are related to that actor's outcomes as well as their partner's outcomes (Rusbult & Buunk, 1993, Rusbult & Van Lange, 2003). These motivations have been conceptualized in research of human relationships as interpersonal commitment. Commitment is a central construct of interdependency theory and has traditionally been viewed as a measure of relationship stability and a predictor of relationship quality and longevity. Lastly, two important components of interdependence structure are 1) these phenomena of relationship interactions typically evolve over time and 2) the availability of information to one or both of the dyad members also influences the structure. For example, if a caregiver was not aware of how much their care-receiver really appreciated what they provided for them, the caregiver's outcomes could vary between the time before and after such knowledge was obtained (Rusbult & Van Lange, 2003).

A comparable theory in regard to the relationship between caregivers and care-receivers is based on principles of attachment. There are interesting implications of family caregiving for the provider and the recipient that relate to attachment. Attachment

and its connection to empathy and altruistic behaviors has been investigated by several researchers (Britton & Fuendeling, 2005; Mikulincer, Shaver, Gillath & Nitzberg, 2005). Mikulincer, Shaver, Gillath and Nitzberg (2005) who found that having a high level of secure attachment resulted in less expenditure of personal resources towards self-protection, which allowed the option of reallocation to others. The authors concluded that reallocation is mediated by level of interdependence with the care-receiver and priming of feelings of security yielding higher levels of confidence and perceived control for the provider (Mikulincer, et al., 2005). In addition to attachment, interdependence may also be an important component in the caregiver and care-receiver dyad interaction process.

An extension of interdependence theory is the assertion that dependence on a relationship is “subjectively represented and experienced as feelings of commitment” (Rusbult & Buunk, 1993, p. 180). Commitment plays a large role for individuals within care dyads. Regardless of dyad composition, commitment is fundamental to any close relationship. Commitment has traditionally been viewed as a predictor of relationship quality and longevity (Adams & Jones, 1999; Rusbult & Buunk, 1993). Therefore, commitment plays a role in how long a relationship endures over time. Commitment is also viewed frequently as adaptation to difficult challenges such as personal sacrifice or as a characteristic that promotes positive adaptive behaviors in the relationships (Rusbult & Buunk, 1993). Commitment is a complex construct with multiple domains that cannot be examined in global terms (Johnson, 1999), but can be used to discern the different types of motivations behind caregiving and care-receiving. For example, commitment

motivated by love or personal affection is quite different than commitment motivated by moral obligation or perceived absence of alternatives.

Caregiving requires a great deal of responsibility and can be taxing on a person's emotional, financial, and cognitive resources (Feeney & Collins, 2003). Understanding the motivations and mechanisms behind a family member's choice to help an aging parent may prepare us to respond to the future needs of older adults and their families. It is evident that the mechanisms behind caregiving behavior are complex and require intricate investigation if one wants to understand them accurately. Feeney and Collins examined motivations behind the commitment to caregiving for an intimate partner (2003, 2001). These authors measured quality of past relationships with parents and romantic relationships and chronic personality styles. They purport that these two factors, personality and quality of past relationships, impact whether one's motivation to provide care is based in altruism or egoism. Based on these findings, the authors established caregiving motivations. Some of the domains established to this research indicate a desire to fulfill an obligation which introduces the interplay of social norms around a family member's role, linking motivation to self promotion and protection from unpleasant feedback from a social group (2003, 2001).

Commitment as it relates to the dynamic process between caregivers and care-receivers has also been examined in previous research. The act of caregiving has been dubbed the behavioral expression of a commitment to another person's welfare (Pearlin, Mullan, Semple, & Skaff, 1990). The caregiving role and the motivation behind making a commitment to fulfill that role were investigated in a study involving 50 caregivers of a

relative who suffered from dementia. In this study Pierce, Lydon, and Yang (2001) explored commitment and internalization and their connection to well-being. A significant positive correlation was found between internalization of caregiver role and well-being. In another study, Lechner and Gupta (1996) found that the relationship between the caregiver child and care-receiving parent was the best predictor of commitment to the caregiving role. This study determined that level of participation, tensions between the parent and child-caregiver, and caregiver attributes are factors in relationship longevity (Lechner & Gupta, 1996). Pohl, Boyd, Liang, & Given (1995) tested a model to understand commitment in mother-daughter relationships within the first three months of a transition into a care-receiver or caregiver role. Commitment to caregiving was significantly related to the quality of the relationship. Higher levels of commitment and relationship quality predicted willingness to move their mothers into their homes and care for them long-term (Pohl, et al, 1995). A recent study of caregivers of bone marrow transplant patients recognized commitment as a crucial factor in sustaining informal caregivers in their difficult role (Williams, 2007). Additionally, Piercy (2007) discovered that strong moral and personal commitment impacted coping in adult child caregivers and suggested a need for further investigation of commitment as it applies to the caregiving experience.

Although strides have been made, there is much more to be understood about how commitment impacts parent/child care dyads. Further investigation of commitment and engagement in the caregiver/ care-receiver role expands our understanding of the positive and negative outcomes for caregivers and care-receivers (Bartsch, 2006; Piercy, 2007).

Motivations underlying commitments such as personal affection, moral obligation, and structural influence to the care process are central to the current study and are discussed in the following paragraphs.

This study incorporates three types of commitment: personal, moral, and structural. These three types of commitment exist interdependently within an individual and offer a way to examine the complexity of caregiver and care-receiver relationships, illuminating how relationship quality and commitment contribute to variation in the positive and negative outcomes for care dyads. Personal commitment refers to one's personal desire and attraction to be in the relationship and incorporate it into one's identity. Although many caregiving partnerships occur between people who are not or have not been intimate life partners, there is still a level of attraction and self identification a caregiver can feel towards their care-receiver and the care-receiver towards their caregiver (Coeling, Biordi, & Theis, 2003). Personal commitment is driven by how much someone cares about someone else and truly enjoys interactions with them, benefiting from such affection. Another component of commitment found to be relevant in care dyads is moral commitment, where one feels a sense of duty towards another. This sense of duty could be felt by either the caregiver or the care-receiver and come from past promises made (Groger & Mayberry, 2001), family role identity (Li & Seltzer, 2005), a need to protect someone else from the burden of the role (Russell, et al., 1997), or for the sake of continuity. For example, normative cultural values may motivate someone to care for their aging parent or accept care from their family. In a recent study, Piercy, during an investigation into intergenerational commitment in caregiving (2007),

reframed what were considered challenges to caregiver into affection, morality, and religiosity, which form the basis for strong commitment.

Structural commitment is the sense of obligation to stay in a relationship regardless of personal or moral commitment (Johnson, Caughlin, & Huston, 1999). This type of commitment does not compete with personal or moral commitment and differs from these other two types of commitment in that it is external to the individual. In other words, there is an ultimatum or a perceived message that there is no other alternative caregiving arrangement possible. This aspect of commitment and how it might apply to a caregiver/care-receiver relationship has not yet been investigated. If this concept were to be applied to a caregiving dyad relationship, the caregiver and/or the care-receiver would hold the perception that there were no other possible arrangements or person that would meet the needs of the care-receiver. This sense of constraint may come in the form of limited financial and support resources.

Measures of structural commitment have not been previously developed in the caregiving literature. However, based on HCBS program requirements, I anticipated that the population of seniors targeted in this study (older adults who are eligible for services due to low income status) and their informal caregivers would have limited financial resources. Structural commitment could conceivably be experienced as a result of limited options for elders who require long-term care. Thus, the structural type of commitment, operationalized in the current study, is relevant to caregiver/care-receiver dyads because it is often the case that older adults lack the resources for alternative care.

The creation of the structural commitment measure used in the current study is addressed in the next chapter.

Marks (1977) postulated that whether or not one feels strain or stress from performing a role is closely linked to one's motivations to perform the role and feelings about how the role is (or isn't) performed. Correspondingly, one can experience a higher level of energy or satisfaction from performing a role for similar reasons (Marks, 1977). These elements are similarly categorized as compared to the personal, moral and structural components of commitment. Furthermore, the results of Piercy's study (2007) suggest that strongly committed intergenerational caregivers will need resources from informal supports and family as well as formal supports in order to maintain their commitment to caregiving. Piercy (2007) recommends the future development of caregiver commitment measures, as commitment level has been linked to outcomes for the individual. Silverstein, Gans, and Yang (2006) examined the normative commitments that lead adult children to take on the role of caring for their parents in need. This study found support that although the lives of intergenerational affiliations were in many cases lived separately, the norm of children providing supportive care emerged when the needs of the parent arose (Silverstein, Gans, & Yang, 2006). Like commitment, engagement in a role as caregiver or care-receiver is another essential component of the current study. The following section examines how engaging in one's role is closely linked to outcomes for caregivers and care-receivers.

Roles of caregiving and care-receiving

Caregiver and care-receiver are roles that most individuals will perform at least once, if not multiple times, during the lifetime (Carter & McGoldrick, 1999). The concept of role engagement is rooted in role theory and refers to the way caregivers and care-receivers perceive and participate in their respective roles. The following section examines role theory and why it is a functional approach frequently examined in caregiving and dyad research.

Role theory is embedded in the disciplines of sociology and social psychology and is a renowned concept of social behavior predicted by social norm expectations of how one interacts and serves a purpose living in social groups (Bertrand, 1972; Biddle, 1979; Sarbin & Allen, 1968). Role theory recognizes that people perform tasks and enact behaviors based on internal and social expectations and are constantly negotiated between individuals (Burr, Leigh, Day & Constantine, 1979; Turner, 1962; Schumacher, et al., 2008). How roles impact people's lives is found in the more specific concepts of role salience, role adequacy, and role perception (Biddle, 1986). Perception of role performance is defined as confidence in one's own and their partner's ability to perform the tasks associated with their role. Role perception has been measured subjectively and objectively as an indicator of quality of care in caregiving dyads (Cox & Dooley, 1996; Tetz et al., 2006).

It is important to examine roles unique to older adult caregiving and care-receiving dyads, since they are very different from other dyad relationships. Role expectations in terms of role performance within the caregiving dyad has been examined

and associated with the well-being of the care-receiver and caregiver (Izal, Montorio, Marquez, & Losada, 2005; Lyons, et al., 2002; Synder, 2000). Montgomery & Kosloski (2000) established a comprehensive understanding of caregiver role identity development, which is that the caregiver role often emerges out of an existing role within the family such as spouse or child of an elder who is experiencing decline. The role of the care recipient in the caregiver/ care-receiver relationship has also been established in the literature, although not as extensively as the role of the caregiver (Russell, et al., 1997; Cox, Green, Hobart, Jang, & Seo, 2007). The following section describes how caregiver and the care-receiver roles are conceptualized in the current investigation.

Caregiving

Role theory is useful in examining the role of caregiving, which has traditionally been studied through stress process models (Pearlin, et al., 1990; Greenberg, et al., 2006). This is because of the multitude of tasks that have been associated with this role. The burden of caregiving has been associated with negative health and mental health outcomes for caregivers. Caregiver burden became a very common abstraction of the caregiver experience in early caregiving research (Zarit, Reever, & Bach-Peterson, 1980). Caring for an elder parent can often compete with other priorities such as parenting and being a supportive partner/ spouse. Litvin, Albert, Brody, & Hoffman (1995) discovered that holding care for an older parent as the highest priority typically only happens for caregivers who do not have partners or children to consider. Although caregiver burden has become a popular way to measure and conceptualize caregiving, other research has sought to identify a less deficit-based conceptualization. For example, Townsend,

Noelker, Deimling, and Bass (1989) found, contrary to their hypothesis, that intensity and longevity of caregiving tasks did not predict caregiver stress and depression. They found that adaptability of adult child caregivers appeared to be related to other factors (Townsend, Noelker, Deimling & Bass 1989). Kramer's (1997) review of literature that focused on caregiver gains established a stark need for further attention paid to the positive aspects of caregiving in order to advance the understanding of positive caregiving adaptations. Pinquart and Sorensen (2004) believed that there were not only negative outcomes associated with the role of caregiving but that there could be benefits as well. They sought to identify the positive aspects of caregiving, which they called "uplifts," and were able to associate these uplifts with higher well-being outcomes for caregivers (Pinquart & Sorensen, 2004).

There are many aspects, such as physical and emotional stress, of caregiving that can contribute to negative and positive outcomes for caregivers. Caregivers for elder relatives are at higher risk of physical and psychological morbidity and social functioning (Fortinsky, Tennen, Frank, & Affleck, 2007). The aims of the current study are predicated on the findings that the relationship between the caregiver and care-receiver is a factor in the outcomes for both dyad members (Greenberg, et al., 2006; Horowitz, et al., 2004; Snyder, 2000). Yates, Tennstedt, and Chang (1999) found that the quality of the relationship between the informal caregiver and care-receiver mediated the occurrence of depression caregiver strain, and overload. This finding demonstrates the importance of considering the relationship as it relates to outcomes. Caregivers for chronically ill

parents have been found to experience negative and/or positive adjustment to performing as a caregiver (Piercy & Chapman, 2001; Li & Seltzer, 2005).

The way in which a caregiver perceives personal competence in her role is associated with positive appraisal of the caregiving experience. Interestingly, high levels of perceived caregiver competence have been found to be both positively and negatively correlated with caregiver burden in previous studies (Pearlin, et al, 1990; Greenberger & Litwin, 2003; Halm, Treat-Jacobson, Lindquist & Savik, 2006). Researchers suggest that competence may be a measure of positive appraisal but is not necessarily a protective factor against caregiver burden and may serve as more of a measure of how hard one works to engage in the role (Greenberger & Litwin, 2003). Perception of caregiver preparedness is defined as one's perception of how prepared one is to take on all the responsibilities related to caregiving, such as setting up needed in-home supports, and providing physical care and emotional support (Archbold, et al., 1990; Schumacher, et al., 2008). Archbold et al. (1990) found preparedness to be associated with lower caregiver strain. Higher caregiver preparedness has also been associated with better psychological well-being outcomes (Schumacher, et al., 2008).

Preparedness is similar to perceived competence because they are both appraisals of one's ability to perform. There are a limited number of studies that examine caregivers' perceived competence in their role and how that might influence their psychological well-being (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Pearlin, et al., 1990). Fewer still investigate the relationship between perceptions of caregiver competence and care-receiver's well-being. The current study investigates these

relationships further. Perceived competence in one's role is a measure of how one believes someone else has engaged in that role. Additionally, caregiver competence can change over time as the circumstances of the caring arrangement change. Therefore a conceptualization of role engagement for a caregiver serves as a measure of how much one has accomplished in this role. Since that component cannot necessarily be measured by the length of time one has been the caregiver in the caregiver/care-receiver dyad, perceived competence will be examined. This is due to the variations in care-receiver level of need and other contextual factors. The level of engagement into one's role as caregiver or care-receiver is understood through one's perception of their competence in the role and the immediate tasks associated with it.

Care-receiving

Care-receivers have been neglected in much of the caregiving research (Gaugler, et al., 2002). A care-receiver is an individual who requires assistance from others to remain physically and socially functional, and because of disability and dependency, often experiences depression and lower life satisfaction (Putnam & Stark, 2006), so it is important to look at their the perception of their role and their caregiver's role. Perception of role is recognized as salient in the care-receiving process (Cox & Dooley, 1996; Cox, et al., 2006; Hollis-Sawyer, 2003). Several studies have examined difficulties in adaptation from independence to the receipt of care from others due to challenges related to disability (Cox & Dooley, 1996; Cox, et al., 2006; Gallo, et al., 2003). Cox and Dooley (1996) found that it is important to concentrate on care-receiver roles that relate to the adoption of optimistic attitudes, the learning of new behaviors, and the preservation

of psychological well-being. Aspects of self-efficacy as they relate to activities of daily living were found to impact the quality of the care-receiver's own psychological and physical well-being in late life (Callaghan, 2005; Joeke, van Eldern, & Schreurs, 2007; Kreitler, Peleg, & Ehrenfeld, 2007). These components of self-efficacy in role performance are important to the conceptualization of care-receiver role engagement in the current study.

Several researchers have found that a care-receiver's well-being can be impacted by providing assistance to their caregiver during the caregiving process. In a study of 570 community-dwelling elders with chronic vision impairment it was found that higher life satisfaction was associated with receiving and providing positive support to informal caregivers (Reinhardt, 2001). Being an older care-receiver consists of, among other things, providing assistance in the provision of their own care, providing emotional support to the caregiver, and participating (or not) in decisions being made about their own health. In the past few decades, through the lens of formal nursing care provisions, the crucial role of the care recipient in the quality of care gained momentum (Russell, et al., 1997). The recognition of the care-receiver's role in informal caregiving has recently gained significant ground (Cox & Dooley, 1996; Cox, Green, Hobart, Jang, & Seo, 2007). Cox and Dooley (1997) found three different styles of care receiver participation: 1) interacting with the caregiver using personal caregiver-oriented strategies; 2) acknowledging caregiver needs, and 3) providing emotional support to the caregiver. Care-receivers also participated by providing child-care or financial assistance, and by being flexible to the caregiver's schedule and not overly demanding. Positive proactive,

passive accepting, and negative styles of coping were also observed in care-receivers and how they play out their role as a care-receiver (Cox & Dooley, 1996; Cox, et al., 2007). Newsome reviewed literature regarding negative reactions to care-receiving (1999), and found that two of the major factors that contribute to negative reactions, outside of inadequate care, are the relationship between the caregiver and care-recipient and the individual differences between the caregiver and care-recipient (Newsome, 1999).

There are a limited number of additional caregiving studies that have analyzed a care-receiver's contribution to the caregiving process. One study measured the care-receiver's perceptions of their own contributions (Walker, Pratt & Oppy, 1992). A second obtained both the caregivers' perception of the care-receivers' contributions (Reid, Moss, & Hyman, 2005). In a study of mother-daughter caregiving dyads, care-receiving mothers reflected that as their condition changed and they required more care, their roles often changed from providing instrumental support to their daughters to a new important role of providing emotional support (Donorfio & Kellett, 2006). Russell, Bunting and Gregory (1997) present evidence from three studies of how care-receivers self-protected as well as protected caregivers from the potential negative aspects of the care process, dubbing these activities as "protective care-receiving". Tetz, Archbold, Stewart, Messecar, Hombrook, and Lucas (2006) examined care-receiver perceptions in order to understand how they believed the caregiver was performing their role. The care-receiver's rating of care quality was positively correlated to the care-receiver's positive affect, better caregiver physical health, and lower caregiver role strain. Research on care-receivers' contributions to the caregiving process and potential impact of those

contributions on both members of the caregiving relationship is an important next step in caregiving research (Tetz et al., 2006).

The tasks associated with being a care-receiver have strong links to the well-being of that care-receiver (Tetz, et al., 2006, Sebern & Whitlatch, 2007, Liang, Krause & Bennett, 2001). Several studies have identified specific salient activities related to the role of care-receiving (Cox & Dooley, 1996; Cox, et al., 2006; Gallo, et al., 2003, Hollis-Sawyer, 2003). Liang, Krause & Bennett (2001) found that care-receivers who provided support to their caregivers experienced higher levels of well-being. According to theories related to adaptation and family roles, an elder who faces chronic and debilitating illness encounters a new role as one who must become more dependent on others for tasks they have been able to complete independently in the past (Cox & Dooley, 1996). Although such changes have been associated with negative outcomes for older adults, Crist (2005) found that receiving care from family can have positive meaning for older adults. This was especially true within relationships considered to be positive to the older adult (Crist, 2005). It is important to continue to examine what potential psychological implications exist for care-receivers if we are to pursue a better understanding of the caregiver/care-receiver dyad relationship. Based upon the current literature that contributes to the conceptualization of role engagement, the current investigation considers care-receiver perceptions to the extent of which they engage in the defined role.

The caregiving dyad

Measuring and examining caregivers and care-receivers as dyad units instead of individuals is an important next step in caregiving research. In addition to examining

how relationship components may impact an individual, a dual perspective provides for a more in-depth approach towards a social system than the traditional approach of using only the individual as the unit of analysis. Compared to dyad research on other relationship types, little is known about how giving and receiving care impacts outcomes for both dyad members (Reinardy, et al., 1999). As mentioned in previous sections, there are positive and negative outcomes related to both roles. In pursuit of the accurate understanding of dyadic interactions, it is important to examine outcomes relevant to both members of the dyad.

Psychological well-being is a dynamic and multi-dimensional mental health paradigm that is central to caregiving research. Measures of positive psychological well-being and depression serve as important and relevant outcomes for both older adults and their caregivers and are strong indicators of quality of life for older adults and caregivers. Ryff's theoretically grounded concept of psychological well-being which features subjective, social, and psychological dimensions as well as health-related behaviors has been found relevant to understanding successful and healthy aging processes in later life (Ryff, 1989; Seifert, 2005). The six factors of this conceptual model are autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance. Ryff's model and measures demonstrate positive psychological well-being outcomes of caregivers and care-receivers. Another important and widely recognized indicator of psychological well-being is depression.

Depression is a widely used measure of psychological well-being with high relevancy in the lives of caregivers and care-receivers. Depression is associated with the

strain and burden of informal care provision (Langa, Valenstein, Mark Fendrick, Kabeto, & Vijan, 2004; Pinquart & Sorensen, 2003). Older adults living with debilitating chronic illness are an important focus for study because they are at risk for depression (Bishop, 2005; Putnam & Stark, 2006). Additionally, depressive symptomology has been examined in dyads and found to be an important component in understanding that symptom levels can co-vary in close relationships (Townsend, Miller, & Guo, 2001). Townsend, Miller and Guo (2001) examined the relationship between each spouse's depressive symptomology and found moderate correlations. Thus, levels of depression experienced by caregivers and care-receivers will be appropriate outcomes to examine within the realm of psychological well-being.

It is important to investigate how individual outcomes are influenced by dyad interactions, but it is not enough to compare just individual level independent variables in this pursuit. Dyadic components must be considered. Examples of studies that consider dyad interactions include a longitudinal study of 2237 elder parent-caregiver dyads which found, among other important results, that relationship quality predicted level of depression (Davey & Eggebeen, 1998). In a different study depression in the caregiver was associated with their incongruence with the care-receiver's perception of the adaptation to illness (Horowitz, et al., 2004). A dyad approach to caregiving embraces the notion that individual psychology and behavior exist in the context of social relationships. For example, it is often found in the caregiver literature that, measured by the caregiver's outcomes, a care-recipient is a stressor for a caregiver. However, this one-sided approach lacks consideration for the potential benefits of caregiving and care-

receiving and as well denies that there are two individuals influencing the context of each others' experience. To study the mutual influence of care dyad members, researchers have recommended collecting data from both members, and developing and testing constructs through psychometrically sound methods (Kenny, Kashy & Cook, 2006; Kramer, 1997; Sebern & Whitlach, 2007; Whitlach Feinberg & Tucke, 2005). The following section addresses important aspects of dyadic analysis, how these apply to the caregiving dyad, and how they are relevant to caregiver dyad research to date. Additionally, a review of the general aspects important to examining psychological outcomes in dyads is presented.

Becker and Useem (1942) were among the early sociological scholars to put forth conceptual and methodological issues important to consider when examining the dyad as a unit. Dyads are constituted by two individuals who have social interactions over time identified as having patterns (Becker & Useem, 1942, p). They state that although there are very unique aspects for each type of dyad--marital, friendship or parent-child--there are universal aspects true for every dyad. This conceptualization of the personal relationship emphasizes the importance of the dynamics related to level of intimacy, external factors, and roles of each member in studying dyads (Becker & Useem, 1942). Thompson and Walker (1982) further explored the conceptual and methodological issues involved with studying the dyad as the unit of analysis and present a conclusive outline of considerations: a distinction between individual and relationship properties, a clear conceptualization about the pattern between two people, a consistency of dyad as the unit of analysis throughout the research process, conceptual underpinnings of dyad scores,

and a honing of the advantages of using the data collected from both members (Thompson & Walker, 1982). The current study used these points as a guide in its design. There are both individual and relationship properties examined within the current research study but they are kept distinct by using conceptualizations of interactions to determine the dyad related measures. Each question related to the dyad as the unit of the analysis is addressed consistently from the measurement to the analysis. Both members of the dyad provided data for analysis and reported perspectives they have about themselves as well as the other member of the dyad.

The premise that each person in a dyad affects and is affected by the other is the basis of dyadic processes (Gayle & Preiss, 2002b). Many studies illustrate how care dyad approaches have brought new insights into the caregiving relationship. Lyons, Zarit, Sayer, and Whitlatch (2002) examined 63 caregiver/ care-receiver dyads to see if one member influenced the well-being outcomes of the other member. Results indicated no significant relationship between caregiver and care-recipient outcomes. However, caregivers and care-receivers appeared to agree on patient needs but disagreed on caregiving difficulty estimation. Researchers found a significant relationship between the caregiver's relationship strain and disagreement with their care-receiver's perceptions of the level of difficulties in that caregiving process. Two major implications of this study are the importance of relationship quality and the need to understand both perspectives in caregiving interventions and research (Lyons, et al., 2002). Another illustration of the examination of how dyad interactions impact individual outcomes was when Sarna et al. (2006) examined women with lung cancer and correlates between quality of life and

health status and family member quality of life. Data from a sample of 51 dyads were analyzed. Patient QOL and/or health were not associated with family member QOL. However, younger non-spouse caregivers had considerably lower emotional QOL scores. This group as made up with mostly adult children. A main conclusion was that family members with lower physical QOL were older, had more co-morbid conditions and a lower level of education (Sarna et al., 2006).

When analyzing dyads as opposed to individuals as the unit of analysis the focus of inquiry must shift from individual processes to more dynamic interpersonal interactions. The study of dyads is relatively new but much research has established precedence for effective ways to conceptualize and measure the interactions between caregivers and care-receivers during the caregiving process. Within the framework of dyadic analysis, relationship quality, and congruence and reciprocity between caregiver/care-receiver dyad members have been examined to determine how these dyadic findings influenced individual well-being outcomes. The following describes how relationships have been conceptualized and examined in previous research in order to generate hypotheses of mutual influence. This description presents a myriad of alternatives that have been explored in care dyad examination and provides the context in which the current study was designed.

Reciprocity.

Although reciprocity is a concept that appears less relevant in caregiver literature, its importance in relationships becomes more apparent when considering the care-receiving role and it is actually a recognized component of interdependency theory

(Holmes, 2002). Reciprocity is defined as partnership, empathy, listening when exchanging advice, and aid and emotional support. Reid, Moss and Hyman (2005) examined the relationship between caregiver reciprocity and the experience of caregiver burden among 56 primary caregivers. Results indicated that reciprocity decreased burden for caregivers (Reid, et al., 2005). Reciprocity has also been found as an important factor for care-receivers' psychological well-being. Wolff and Agree (2004) analyzed data from a sample of 420 community-dwelling care-receivers. Results indicated that those participants who felt a high level of reciprocity in their informal caregiving arrangements were less likely to be depressed (Wolff & Agree, 2004). Recent research has established reciprocity as an important component not only for individual outcomes but also in caregiver dyad relationship outcomes. Both Seburn (1996) and Archbold (1990, 1992) postulated that reciprocity was an important component of family caregiving relationships.

Researchers who studied reciprocity within dyads found that the opportunity to provide assistance and reciprocate within a family bolstered well-being for both members of the dyad (Archbold, et al., 1992; Beach, Schulz, Williamson, Miller, Weiner, & Lance, 2000; Davey & Eggebeen, 1998; Liang et al., 2001; Lyons, et al., 2002). It is important to understand that reciprocity plays an important role in personal relationships. Although reciprocity has been used to examine caregiving dyads and is recognized as an important aspect of this relationship, the current study does not use it as the central factor for caregiver and care-receiver interactions and related outcomes. Due to the difficulty in applying this concept to the complex dynamics of potential reciprocation of emotional

and physical reciprocity within care dyads it is not utilized. Other viable approaches to dyadic interactions were explored in the current study.

Relationship Quality.

The quality of the caregiving situation for both the caregiver and the care-receiver is also important. Relationship quality has been examined and found to be associated with health and mental health outcomes for caregivers and care-receivers. For example, caregiver and care-receiver relationship quality was found to be related to stress and well-being of the care-receiver (Cox & Dooley, 1996; Spaid & Barusch, 1994; Tetz et al., 2006) and caregiver (Greenberg, et al., 2006; Horowitz, et al., 2004; Snyder, 2000). Numerous studies have identified interpersonal emotional factors that highly contribute to the overall quality of caregiving (Spaid & Barusch, 1994; Wright & Aquilino, 1998). Martini, Grusec, and Bernardini (2001) found that perception of physical care was strongly associated with how care-receiving mothers, and their caregiving adult daughters viewed relationship quality. Relationship quality is a partial indicator of the overall quality of caregiving and care-receiving (Lawrence, Tennstedt, & Assmann, 1998; Lyons, et al., 2002).

Lawrence, Tennstedt, and Assman (1998) studied 118 caregivers to determine whether relationship quality mediated or moderated (or both) the relationship between caregiver stressors and negative well-being outcomes (role captivity, overload, and depression). Relationship quality was measured in four ways: how close the caregiver felt towards the patient, communication with patient, similarity about views, and degree of getting along. Relationship quality was found to play an important role but didn't

moderate any outcome variables. It was only found to mediate the stresses of behavior and role captivity, which is related to the fact that relationship quality suffers when disability increases (Lawrence, et al., 1998). Quality of relationship plays an important role but as in this case it may not have a moderating or mediating effect on outcome variables. Similar concepts related to the context and quality of interactions that occur within a dyad have been measured in studies with caregivers and care-receivers that examined congruence and dyad member mutual influence (Horowitz, et al., 2004; Lyons, et al., 2002).

Congruence.

Congruence between dyad members has also been used to examine interactions between people in dyad settings. Interactions between older adults and their caregivers play an important role in individual outcomes but remain hidden without understanding both of their perspectives (Lyons, et al., 2002; Sebern & Whitlach, 2007). Researchers have found utility in measures of congruence between older adults and their caregivers. For example, Horowitz and colleagues (2004) associated caregiver strain, depression and report of negative relationship with congruence across certain domains including functional disability, family over-protectiveness, understanding of illness and vision impairment related to elder adaptation. The study also examined what caregiver and care-receiver characteristics are linked to greater incongruence on the issues listed above. The results reveal three significant relationships; incongruence was negatively correlated with elder health self-rating and elder report of their caregiver's level of understanding of their situation. Higher incongruence was associated with being a friend instead of relative.

Additionally it was found that the greater the caregiver depression score, the greater the incongruence regarding elder's level of adaptation. Disagreement contributed to both dyad members' depression scores. Results indicate variation in levels of congruence across dyads but also between dyad members about different issues. For example, depression was associated with higher levels of incongruence on perception of adaptation, but not on other categories of incongruence. These researchers concluded that although congruence appears to be salient, global congruence will not adequately identify predictors of caregiver and care-receiver outcomes and recommended a more targeted approach (Horowitz, et al., 2004).

Izal, Montorio, Marquez, & Losada (2005) found higher levels of congruence about role expectations and role performance within the caregiving dyads. Researchers studied dyads (N= 33) consisting of community-dwelling elders. The caregivers' assessment and care-receivers' self-assessment of care-receiver functional capacity were compared. Izal et al. (2005) examined the degree of adjustment (congruence) between care-receivers' and caregivers' assessments of the care-receiver's functional ability. It was found that the group that had congruent scores in assessment of functional ability had higher levels of self-efficacy and life satisfaction in the care-receivers. Findings indicated psychological benefits of more equilibrium between expectations of caregivers and competence of care-receivers (Izal, et al., 2005). Similar findings were found in other studies that associated congruence between dyad members with the higher well-being of the care-receiver and caregiver (Izal, et al., 2005; Lyons, et al., 2002; Synder, 2000).

Hollis-Sawyer (2003) explored the issue of congruence between caregiving daughters and care-receiving mothers (N= 122 dyads) who were living together. In this study the mothers required assistance with activities of daily living, but were receiving no supplemental formal support services. The outcomes examined in the study were congruence in role expectations, perceived personal growth, and enhanced understanding of personal aging for self and other. The independent variables consisted of role related factors and individual difference factors. Findings suggest there is a need to focus more on communication role expectations between the caregiver and care-receiver (Hollis-Sawyer, 2003). Congruence between caregivers and care-receivers appears to be an important component of the dyad relationship. The current study targets congruence between how older adults and their adult child caregiver report their role engagement and commitment to the care process.

Further development of the care dyad concept

The complexity within the relationship between caregivers and care-receivers and related implications for older adults and their family members is not widely understood, as the care dyad has been studied by only a select few researchers in the past decade. Coeling, Biordi, and Theis (2003) conducted a qualitative study that examined how caregivers and care-receivers negotiate their roles in order for them to fit in their lives. The researchers dubbed these negotiations “dyadic rules” and discovered that failure to agree upon them often resulted in strain. They proposed a theory of caregiver and care-receiver dyadic identity development in which negotiation is an important aspect to consider when working with caregivers and care-receivers. They suggest a need for

further research on informal caregiving as the unit of analysis and interventions that provide education to develop negotiation skills (Coeling, et al., 2003).

Sebern (2005) performed an extensive literature review that furthered the development of a care dyad construct called “shared care decision-making,” which was initially created by Sebern in 1996. Shared care decision-making is characterized by an elder intentionally looking for information about their health and participating in decisions about his/her care. Components of shared care are communication, decision-making and reciprocity. This review suggested that shared care is able to modify the effects of providing and receiving assistance. Sebern (1996) analyzed relevant literature to look at the effects of these components and what contextual factors needed to be in place for them to happen. She concluded that higher quality of relationships and higher level of agreement seemed to result in more interaction and communication between family members. Sebern also professed that there was a benefit for both dyad members when assistance was exchanged within a positive context of family care and that the roles and quality of the relationship very often affects depression outcomes. Sebern (2005) eventually established what she called the requirements for dyad shared care to occur. These pre-requisites are cognitive ability, personal judgments, chronic illness in the older person, a family history of interdependence, and the existence of the goal of the dyad to stay in control and maintain membership (Sebern, 2005).

Whitlatch, Judge, Zarit, and Femia (2006) furthered the pursuit of care dyad relationship research by testing a dyadic intervention with 31 caregiver/ care-receiver dyads. It was found that caregivers and early stage dementia patients are capable of

participating and benefiting from this intervention of care planning for future needs (Whitlatch, Judge, Zarit, & Femia, 2006). Sebern and Whitlatch (2007) created and validated the Dyadic Relationship Scale (DRS) based upon previous dyad research performed by Sebern in 2005. The DRS measures positive and negative aspects of the interactions from perspectives of caregivers and care-receivers. This investigation found that DRS explained 23% in the variance in patient depressive symptoms and 21% if the variance in caregiver depressive symptoms. Dyadic strain was significantly associated with depressive symptoms for caregivers and care-receivers. Sebern and Whitlatch (2007) also concluded that positive interactions could be associated with care-receiver depressive symptoms if care-receivers perceive they are benefiting more than the caregiver because of their inability to reciprocate the care provision. These results suggest the need for an intervention that assists the care-receiver in identifying ways to provide support to the caregiver that is within their ability.

Lyons and Sayer (2005) discuss the advantages of using multilevel modeling in caregiving research that allows for expansion beyond simply congruence in dyad perceptions. It is important to recognize the limitations of congruence. Although the outcome of congruence is important it is really only a component of the larger issue that dyad members strive for balance in needs and well-being (Lyons & Sayer, 2005). These researchers emphasize that it is advantageous to consider alternative aspects of dyads that determine balance within relationships as opposed to whether or not congruence in perception exists (Lyons & Sayer, 2005). Lyons, Sayer, Archbold, Hornbrook and Stewart (2007) studied the enduring and context effects of physical health and depression

on mutuality in care dyads. Researchers defined mutuality as the positive quality of care relationship and considered it to be a protective factor for caregivers of older adults.

Wolff and Agree (2004) looked at 420 women over 65 years old in informal long-term care and examined the relationship between perceived quality of care and depression.

Using six different time points and after controlling for socio-economic status variables, those who perceived disrespect from their caregiver were more likely (33-60%) to be depressed and those who felt like they were valued by their informal caregiver were less likely (70%) to be depressed.

Care-receiving older parent- Caregiving child dyads

The nature of the relationship between caregivers and care-receivers is often important to consider when examining these relationships and their related outcomes (Greenberg, et al., 2006). A clear distinction has been made in the literature between the experiences of caregivers of aging parents and other types of caregivers. Kenny, Kashy and Cook (2006) present important considerations when examining dyads that relate to several categories of dyad typologies. Included within these is the fact that dyads can be in their relationship due to voluntary or obligatory reasons based upon a familial history. Older adults and their child caregivers have a unique combination where the relationship is voluntary in nature but also possesses a family history. This can complicate the dynamics of the dyad and further constitutes the importance of studying caregiving children and care-receiver parents as a unique dyad population (Kenny, et al., 2006). The following research studies are presented as an illustration of why it is not enough to just

study caregivers and care-receivers regardless of age and the nature of the care relationship, as many caregiving studies have done in the past.

In an examination of spouse and non-spouse caregivers, Pierce, et al. (2001) found that adult child primary caregivers had quite different interpersonal expectations than the care-receiver, which impacted their level of enthusiasm and affected their well-being. Bekelman, Nowels, and Haxton (2008) studied the experiences and palliative care preferences of people with severe chronic heart failure and their caregivers. Data from the individual testimonies of patients suffering from Heart Failure (HF) and their spouse/partner or adult child caregiver were examined and analyzed. The study examines how the individuals within these dyads are coping with physical symptoms, emotional issues, and psychosocial challenges of living with HF. Separate accounts of care-receivers' and caregivers' experiences were collected. Findings of this investigation suggest there are important distinctions between parent-child and spouse dyads (Bekelman, et al., 2008).

Donorfio and Kellett (2006) examined caregiving daughters and care-receiving mothers and found a unique process of role negotiation between each member of the dyad. This study illustrated the interactive process between dyad members, and it was discovered that this process involved role definition, subsequently re-defining the relationship (Donorfio & Kellett, 2006). Hollis-Sawyer (2003) studied 122 mother-daughter caregiving dyads and found that certain aspects of the caregiving experience had very different characteristics than those of care-receiver experiences. This establishes the importance of considering the two members of the dyad, but also emphasizes that it is

vital to consider that the two roles of care-receiver parent and caregiving child. It is plausible that these differences between role expectations and perceptions subsequently have different needs associated with them (Hollis-Sawyer, 2003). Martini, Grusec, and Bernardini (2001) examined 44 mother-daughter dyads by interviewing each member separately to measure feelings of interpersonal control, perspective-taking abilities, and attributions made about self and other during negative encounters. This was done to understand the potential influences these measurements might have on care-receiving mothers' satisfaction. Results indicate that the most important predictor was accuracy in interpreting the other's feeling about the care relationship and interpersonal control (Martini, et al., 2001). The nature of one's relationship and differences between tasks associated with each role are not the only contextual influences that are important to consider when studying care dyads. The following section briefly summarizes other respondent characteristics pertinent to the current study.

Contextual influences

Caregiving dyads function within larger systems and within environments that impact their functioning. The caregiving context—including the relationship with the care-receiver; the caregiver age, gender, race, and socioeconomic status; the living arrangements with the care-receiver; and care-receiver illness diagnosis—is often important to consider when understanding caregiver care-receiver relationships (Greenberg, et al., 2006). It is well known that factors unrelated to the caregiving relationship, such as health conditions and environmental factors like availability of formal services and additional family supports, significantly impact the caregiving

process. In order to account for the caregiving context, environmental factors that impact the partnership were assessed in the current study.

Type of illness among aging adults is also important to consider. For example, Bertrand, Fredman and Saczynski (2006) found different levels of stress and appraisal of the situation to be different for dementia vs. non-dementia caregivers. Other research found the following factors to be important: level of care-receiver need, type of diagnosis, socioeconomic status of the aging parent, caregiving living arrangement, and specific child-parent caregiver/care-receiver relationship (Keeling, Dolbin-Macnab, Hudgins, & Ford, 2008; Lyons, et al., 2007). Issues that have the potential to create difficulty for both the caregiver and the care-receiver, called the appraisal on caregiving context, have been combined into measures of contextual influence for care dyads (Lyons, et al., 2002; Noelker, Townsend, & Deimling, 1984).

The Current Study

The National Commission for Quality Long Term Care [NCQLTC] encourages researchers to target Home and Community-Based Services (HCBS) to identify needs and develop supportive interventions as a strategy critical to improving outcomes for elders living with disabilities (2007). The NCQLTC report concludes that informal caregivers are crucial to helping older adults stay in a home setting and should be considered in HCBS service plans (Magan, 2007). The HCBS population is an at-risk group based on their age, level of disability, and socioeconomic status. Therefore, the population that was targeted to participate in the current study consisted of the older clients of Colorado HCBS and similar programs and their caregivers.

Previous research guides our current understanding of care dyads composed of older adults and children who care for them. Prior studies have found that the quality of the relationship and the roles associated with the care process are closely related to outcomes for both caregivers and care-receivers. However, specific aspects of the relationship between caregivers and care-receivers that predict individual outcomes for both partners have not been specified. Research suggests that commitment and role engagement are important factors in the health and mental health of older adults and their caregivers. However, little is known about the specific elements that sustain healthy care dyad relationships specific to elders and adult children. We understand that caregivers are responsible for a certain portion of their care-receiver's physical and emotional needs and therefore impact physical and mental health outcomes for the care-receiver. Care-receivers may impact a caregiver's health and mental health by the way they behave physically and emotionally toward the caregiver. Previous research supports the pursuit of a more detailed understanding of the complexities of the care dyad relationship and the implications for both caregivers and care-receivers.

Summary and Application of Concepts

A review of the literature found in caregiving, care-receiving, and dyad relationship research was the impetus behind the concepts chosen in the current investigation. The concepts central to this study are role engagement and commitment within a caregiving relationship between a care-receiving older adult and their cohabitating caregiver who is an adult child (daughter, son, daughter-in-law, son-in-law, step-child, etc.). Role engagement refers to the "what" of caregiving and care-receiving

and how the tasks of these roles are performed. Conversely, commitment represents the “why” of engaging in caregiving and care-receiving. Motivations behind one’s commitment to a caregiving arrangement are proposed as another crucial aspect of the caregiving dyad experience.

It is hypothesized that these two aspects of the caregiving relationship, role engagement and commitment, are related to psychological well-being. Figure 1 below depicts how these concepts are applied in the study. It is proposed that the older care-receiving parent commitment and role engagement impacts the caregiver’s psychological well-being. Similarly, caregiver commitment and role engagement is hypothesized to have an impact on care-receiver psychological well-being. The arrows between the circles labeled ‘older parent’ and ‘caregiver’ represent this interpersonal influence. Concurrently, it is also hypothesized on an individual level that one’s commitment and role engagement toward another is associated with their psychological well-being. Arrows found on each individual circle represent this level of impact.

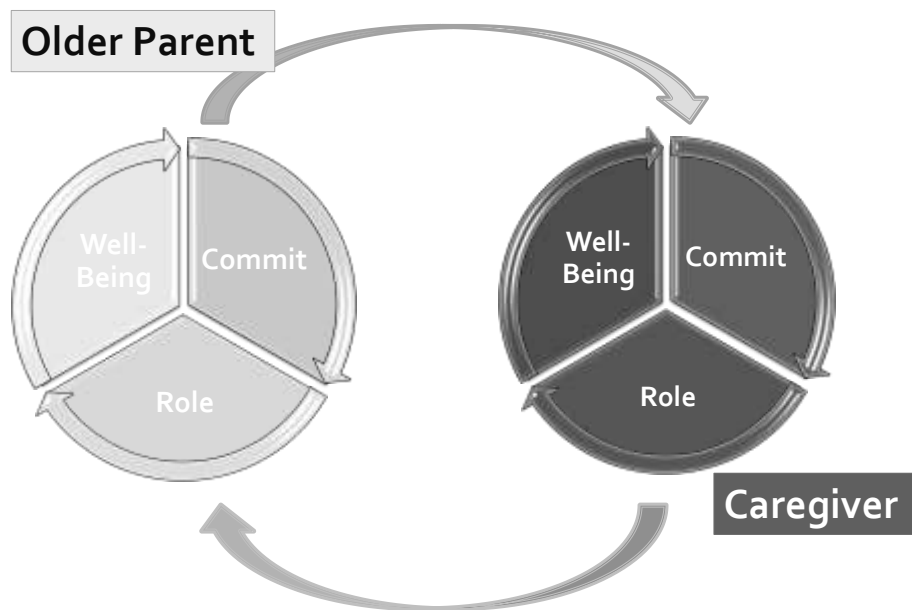


Figure 1. The Caregiving Dyad

Advancements in care dyad research have brought new insights into the relationship between caregivers and care-receivers, but they are still in the early stages of development. When examining care dyads it is important to identify variation in both members' experiences concurrently in order to understand more than just the sum of two separate experiences. The current study amalgamates evidence suggesting that the quality of commitment within relationships and the engagement in these unique roles are vital to understanding outcomes for dyad members of caregiver/ care-receiver relationship. It further hypothesizes that the basic caregiving components of commitment and role engagement in the care process will be associated with the psychological well-being of caregiver and care-receiver dyads. Additionally, it is hypothesized that commitment and role engagement in the care process, and the congruence between

members on these facets, will be associated with individual levels of psychological well-being and depression among caregivers and care receivers. The questions below serve as a guide to examining relationships within and between dyad members in the current study.

Research Questions and Hypotheses

1. Is commitment to the care process, role engagement, and psychological well-being of one dyad member associated with commitment to the care process, role engagement, and psychological well-being of the second dyad member? **H1:** **T**ypes of commitment to the care process, role engagement, and psychological well-being of one dyad member will explain a significant amount of variation in individual outcomes of psychological well-being in the second dyad member.
2. Are aspects between dyad members including commitment to the care process, role engagement and congruence on these variables associated with the psychological well-being of dyad members? **H2:** Commitment to the care process, role engagement, and congruence between care receivers and caregivers on these variables will explain a significant amount of variation in psychological well-being.
- 3a. What is the relationship among role engagement, commitment to the care process, and psychological well-being in elder care-receivers? **H3a:** Role engagement and commitment to the care process will be significantly related to psychological well-being in elder care receivers.
- 3b. What is the relationship among role engagement, commitment to the care process, and psychological well-being in caregivers? **H3b:** Role engagement and commitment to the care process will be significantly related to psychological well-being in caregivers.

Chapter Summary

This chapter reviewed the theoretical foundations, previous research, and remaining questions that guide the current study. Interdependency theory as it relates to commitment, role theories related to the caregiver and care-receiver roles, and the highly relevant outcomes of psychological well-being informed the current inquiry of the interpersonal dynamics between care dyads. Previous research as it relates to the unique

roles of caregiving and care-receiving and how these populations have been studied separately as individual groups was outlined. Empirical investigations into the conceptualizations of the care dyad relationship were also presented. Finally, the important aspects of the care dyad that have been utilized to pose questions intended to advance research on caregiving of older parents in social research were stated. The following chapter describes the methodology used in the present study.

Chapter 3: Methodology

The focus of the current study is to examine the relationship among commitment, role engagement, and psychological well-being. The way in which interactions between dyad members, a caregiver and a care-receiver, impact psychological well-being is of particular interest in this investigation. This chapter presents the research design and analytic approaches used in the study. Human Subjects and logistical considerations are also noted.

Sampling Approach

As mentioned in the previous chapter, the Colorado HCBS and similar programs were targeted for recruitment to participate. In Colorado, HCBS services for older adults are implemented through Single Entry Point (SEP) agencies. The governing body at the state level for SEPs is the Colorado Department of Health Care Policy and Financing (CDHCF). I consulted with CDHCF to request approval for access to SEP agencies. The response from this department was supportive with regard to working with the SEP agencies. However, they would not allow access to information about clients, even for screening purposes, unless a formal full data information request and justification for access to detailed information was filed. Based on the fact that minimum information was required for screening, I chose to collaborate with agencies for initial eligibility screening and notification about the study opportunity with no direct access to the population.

In June 2008, a preliminary feasibility inquiry was performed with supervisors and case managers of Long Term Care Options (LTCO) who managed cases for the Elderly, Blind and Disabled and Home Care Allowance Medicaid Waiver programs. Based on client sampling criteria (living with adult child caregiver, age 60+, English speaking, requiring ten or more hours of care each week) and a screening protocol I estimated the number of LTCO clients who would meet the study criteria. It was reported by case management supervisors that LTCO at that time was serving over 800 clients who met basic eligibility criteria used in the current investigation. Based on this assessment it was then decided that a large sample size for this study could be obtained by following targeted recruitment components that included: 1) collaboration with case managers in recruitment of clients, 2) incentives for participation of both case managers and participants, 3) letters sent to both the older adult and the adult child, and 4) large assessed potential participant pool. However, after recruitment efforts began several barriers occurred that limited access and recruitment of clients. These problems included lack of ability to confirm how and whether or not clients and their caregivers were actually notified about the study. A second issue that arose was the overestimation case managers reported regarding the actual number of older competent clients living with their child(ren). Lastly, inconsistent participation of case managers at the agency caused a reduction in how many clients were informed of the study. Consequently, a much smaller number of eligible clients were identified and invited to participate (n=203) than originally estimated. Due to this problem, other SEP sites and similar non-profit agencies were identified as recruitment sources.

Recruitment efforts for the current study targeted HCBS agencies above all other organizations because of the similarities between the qualifying criteria for older adults to receive the services and the study criteria. A uniform client screening process is performed at all SEP agencies and therefore a uniform eligibility screening process was easily implemented. The other agencies invited to participate in the study serve similar populations as those served by HCBS and performed similar assessments with their clients. These agencies were therefore asked to use similar selection criteria as those used by the HCBS agencies.

Improved and updated sampling procedures for the study involved collaboration with multiple agencies. Nine HCBS SEP agencies, five senior centers, and five other non-profit private social service or health care agencies were invited to participate in the study. Of those agencies invited, only six HCBS SEP agencies, two senior centers, and three other non-profit agencies serving older adults and their families agreed to participate. The main role of these agencies was to assist in participant recruitment, identifying eligible clients. I worked with the supervising staff, with the exception of a few cases where I spoke directly to groups of case managers. The specific protocol for the communication process was commanded by the particular agency based on this researcher's recommendations and on the agency's organizational structure. Incentives such as small snacks and grocery store gift cards were offered and given to staff of these agencies to encourage participation. What and how incentives given were determined by each individual agency.

Each agency followed the following participant recruitment protocol. First, I instructed designated supervisory staff at these agencies to have relevant case managers identify all clients who met the study criteria and report this list to the supervisor. Case manager understanding of physical limitations and financial income of the older adults is well established because the physical limitation requirements for receiving services from HCBS and similar programs have been standardized. Each case manager was instructed to review their client caseload, and then to report the names of the clients and caregivers who met the initial screening eligibility requirements to their supervisor. Although they were instructed to participate, not all case managers participated in the client identification process because it was a voluntary activity. Clients and caregivers selected by case managers were mailed a form letter that explained the study (sample letter in Appendix A), which was approved by agency supervisors prior to being mailed. Once I delivered the letters to each agency, the envelopes were addressed and mailed by the agencies. Clients were told that their decision to participate had no influence on their services received through that agency. They were also instructed about how to contact the principal investigator to inquire about participation. The letters instructed clients and their adult child caregivers about the purpose of the study, how to become involved in the study, and explained that there was a \$15 grocery store gift certificate incentive offered for their participation. Elders and their caregivers who responded to the invitation via a phone call or email were screened over the phone to confirm that they met the requirements of the study.

Eligibility criteria

Eligible caregivers in the current study were primary caregivers to an older parent including step-parents or parents-in-law. The older parent must have been over the age of 60 and be 1) suffering from a chronic illness, 2) in need of over 10 hours per week of activities of daily living assistance, 3) residing with the caregiver, and 4) able to speak and understand English. Level of care criteria was determined by eliminating older adults requiring less than 10 hours of care per week. The rationale for this number of hours was informed by the standardized assessment used by SEP agencies. Caregivers who owned or rented a separate home but spent more than 15 hours each week and frequently slept at their parent's home were also included in the study. Older care-receivers participating in the study must have met the criteria listed above and had to have a caregiver willing to complete a questionnaire as the other dyad member. Caregivers who were interested in the opportunity to participate but whose parents were cognitively incapable or unwilling to participate were invited to complete the caregiver questionnaire. The total number of letters sent to eligible older clients of all agencies and their caregivers was 538. The number of responses to the invitation to participate in the study included 95 caregivers and 41 care-receivers, approximately a 25% response rate to invitation letters. After phone screenings, the total number of eligible participants in the study who completed questionnaires was 81 caregivers and 35 older parent care-receivers (35 dyads, N=116). Four caregiver questionnaires and five care-receiver questionnaires were subsequently eliminated from the analysis because of incompleteness. Demographic characteristics of the final sample are presented in the next chapter.

Data Collection

Participants were enrolled in the study over a span of 11 months, between January 20, 2009 and December 20, 2009. All elders who volunteered to participate received a home visit to complete the hardcopy questionnaire with the assistance of the researcher or other trained data collection staff. Data collection staff consisted of me and five graduate level social work students who had received specialized training in gerontology and who currently had internships working with older adults. Prior to protocol instruction and weekly supervision, all data collectors received training pertinent to working with a uniform data collection protocol. Participating caregivers were instructed on the completion of the questionnaire, and offered the opportunity to complete a hard copy or online version of the questionnaire unsupervised by the research team. In the cases where parent care-receivers completed the questionnaires, caregivers were asked to leave the room to give parents privacy and reassure confidentiality of their answers. Older adults enrolled in the were identified and associated with their caregiver forming 35 dyads during the data collection process

Study measures rely on accurate self-report. Therefore, older adults and their adult child caregivers were screened in order to determine cognitive competence. All older adults and their caregivers forming a dyad who completed the questionnaire were given a Callahan six-item screener score; a copy of this instrument can be found in Appendix B (Callahan, Unverzagt, Hui, Perkins, & Hendrie, 2002). Study subjects were also given a \$15 gift certificate to a local grocery store for participation in the study.

Considerations for protection of human subjects

During the data collector training, the research team learned ways to identify and respond to emotional or physical circumstances that may arise during interviews, and were instructed about ways to assist participants with low literacy or those who were confused about certain questions. When data collectors disseminated questionnaires informed consent was obtained from each participant. The participants were informed of all the potential benefits and any potential risks related to participation in the study prior to completing the questionnaire. Participants were informed in writing of how to contact the University of Denver Institutional Review Board to report any concerns about their treatment during the study (see full document in Appendix C). In order to address potential consent issues for older adults who are considered vulnerable, all older adults participating in the study were given the consent form, which was explained to them verbally prior to signing the form. This consent included information about confidentiality and emphasized that any information provided would not be shared with the other member of the dyad. Participants' cognitive awareness to sign the consent was confirmed through an initial screening of their cognition and memory capacity performed by trained staff. After the study was explained and consents were signed, the older adult and adult child caregiver were asked to complete the survey separately. Data collectors assisted with the completion of the questionnaire by either sitting with the older parent as they completed it or by reading the items aloud for the care-receivers to answer.

Measures

Items used in this study assessed role engagement; personal, moral and structural commitment; and psychological well-being among caregivers and care-receiving older parents. Selected measures used in previous studies were implemented here in their original or adapted form. The next section describes the instruments used to measure the independent, dependent, and respondent characteristic variables. See Table 1 below for details of all variables, their respective measures, and references of previous studies. Reliability coefficients found for measures in the current study are reported in the next chapter. See Appendix D for a table that specifies constructs, measures, and items and Appendix E for the questionnaire completed by participants.

Role engagement.

Role engagement was measured by self-reporting on the Caregiver Competence Scale (CCS) found to have adequate ($\alpha=.74$) internal consistency (Pearlin, et al., 1990) and by two 5-item Care Receiver Efficacy Subscales Scales; Relational Coping and Self Care Performance (CRES)(Cox, Green, Seo, Inaba, & Quillen, 2006). Adequate concurrent and discriminant validity for CRES measures have been reported (Cox, et al., 2006). Cox and colleagues (2006) found internal consistency in both sub-scales ($\alpha=.91$ and $\alpha=.82$) with a care-receiving population. An example of an item from the CCS reads: “How much do you feel that all in all you are a good caregiver” with response choices of “not at all,” “just a little,” “somewhat,” and “very much.”

The CRES relational coping and care performance subscales measure a care-receiver’s degree of participation in tasks identified as those associated with receiving

care. These scales are provided with choices for likert-type response choices ranging from 1 (Strongly Agree) to 5 (Strongly Disagree). Based on the intentional dyad approach to the current study, adapted CCS and CRES parallel measures were created for the other member. For example, the caregiver questionnaire contains a parallel measure of the two 5-item Care Receiver Efficacy Subscales; for example, an original item on the scale is “I am very involved in any planning that is initiated on my behalf,” and the parallel adapted scale for the caregiver would read, “I am very involved in any planning that is made for my parent.”

Commitment.

To measure commitment, caregivers and care-receivers completed identical commitment measures. As a construct, commitment has relevancy in regard to motivations behind participation in a caregiving relationship (Agnew, Rusbult, Van Lange, & Langston, 1998; Bartsch, 2006; Levinger, 1999; Lund, 1985). The Components of Commitment Scale (Johnson, et al., 1999) items was used as a basis for scale items. All of the subscales in their original format have reported good internal consistency ($\alpha = .92$) in short-term romantic partnerships (Bartsch, 2006) and adequate internal consistency in life partner relationships, alpha ranging from .73 to .84 (Johnson, 1999).

The scale items to measure commitment were chosen from the original scale and modified based on their relevance to the caregiving/ care-receiving arrangement. Two items were added to the structural subscale that addressed aspects unique to circumstances of care dyads, i.e. institutional placement and co-habitation after living

independently. Based on the relevant caregiving literature that indicates commitment as an important influence on the care process (Pierce, et al., 2001; Piercy, 2007; Pohl, et al., 1995; Williams, 2007), commitment was measured by a 24-item scale containing personal, moral and structural commitment subscales. These are aspects of commitment hypothesized to impact caregiver and care-receiver experiences. Some item examples for moral commitment include, “If you chose to make other arrangements for care, you would feel bad because when an older parent needs care, their child has an obligation to help them,” and “If you chose to make other arrangements for care, you would be disappointed in yourself because you had made a promise,” in which a likert response ranging from 1 (Strongly Agree) to 5 (Strongly Disagree) was chosen. Some examples of structural commitment items were “If you and _____ made other arrangements for care, you would miss important income, insurance or other property,” and “Any other arrangements for care would be too expensive,” again in which the likert response ranging from 1 (Strongly Agree) to 5 (Strongly Disagree) was used.

Table 1

Study Constructs and Measures

Construct	Variable	Measures	Internal Consistency	References
Role Engagement	Caregiver	Caregiver Competence Scale	$\alpha=.74$	Pearlin, Mullan, Semple, & Skuff, 1990
	Care-receiver	Care Receiver Efficacy Scales	$\alpha=.91, \alpha=.82$	Cox, Green, Seo, Inaba, & Quillen, 2006
Commitment	Commitment	Components of Commitment Scale (adapted)	$\alpha=.92$ $\alpha=.73$ to $.84$	Bartsch, 2006 Johnson, 1999; Johnson, Caughlin, & Huston, 1999
Psychological Well-Being	Psychological Well-Being	Psychological Well-Being Scale	$\alpha=0.86$ to 0.93	Ryff and Singer, 1998; Ryff and Singer, 1995, Ryff & Keyes, 1995
	Depression	CES-D	$\alpha=.81$ to $.91$	Radolff, 1977; Beekman et al., 2000; Glass, Kasl & Burkman, 1997; Roberts, 1980
	Dyad Level Well-Being	Dyadic Relationship Scale (Positive Interaction and Dyad Strain subscales)	*c-r $\alpha=.84$ & $.86$ c-g $\alpha=.89$ & $.85$	Serbern & Whitlach, 2007
Respondent Characteristics	Age, Role (caregiver or care-receiver), Relationship, Partner Status, Gender, Education, Income, Professional Background, Religious Affiliation, Race, Formal Care Service Use, Activities of Daily Living			

Note. Measures of internal consistency reflect alpha levels reported in the identified references.

Psychological well-being.

A subset of 16 items from the 20-item Center for Epidemiologic Studies (CES-D) scale (Radolff, 1977) was used to measure depression. This instrument is well-suited for

both caregivers and care-receivers because it has been used extensively with a wide age range of adults. Reliability and validity of the CES-D is well-supported and found to accurately identify depressive symptomology in community-dwelling elders, with alpha scores ranging between .81 to .91 (Beekman et al., 2000; Glass, Kasl, & Burkman, 1997; Roberts, 1980). Clinical depression diagnoses were not determined for the purposes of the current study. Although there is mixed support in the literature for use of shorter CESD versions (Stansbury, Ried & Velozo, 2006; Zauszniewski & Bekhet, 2009), the shorter 16-item CESD version was chosen for its brevity. Both the caregiver and care-receiver questionnaires contained this measure.

Psychological well-being was also measured by Ryff's 42-item Psychological Well-Being Scale containing the subscales of Autonomy, Environmental Mastery, Personal Growth, Positive Relations with Others, Purpose in Life, and Self Acceptance (Ryff & Singer, 1998). Due to the length of the questionnaires and the limited capacity of chronically ill care-receivers, care-receivers who experienced fatigue during the questionnaire process were only asked to complete the Autonomy and Environmental Mastery subscales. Therefore the dyad level analysis only involved those subscales. This measure has strong empirical support (Clarke, Marshall, Ryff & Wheaton, 2001; Ryff & Singer, 1998; Ryff & Keyes, 1995; Abbot, Ploubis, Huppert, Kuh, Wadsworth, & Croudance, 2006), having been tested and found reliable and valid with males and females, adults and older adults, and Hispanic samples. Reliability estimates for this scale have been found to be acceptable and exceptional (from $\alpha=0.86$ to $\alpha=0.93$) in populations similar to the current study sample. One example of an item from the

environmental mastery sub-scale is “I am quite good at managing the many responsibilities of my daily life.” An example item from the autonomy sub-scale is “I often change my mind about decisions if my friends and family disagree.”

A scale designed specifically for caregiving and care-receiving dyads as the unit of analysis-- the Dyadic Relationship Scale (DRS)--was used to measure negative and positive interactions between care-receivers and caregivers. Dyad strain and positive interactions have been used determine caregivers’ and care-receivers’ perceptions of the dyadic interactions and how they relate to their own health and mental health outcomes. These subscales, Positive Interaction and Dyad Strain, are analyzed separately as opposed to creating a composite score. This measure has been assessed for reliability in negative dyadic strain (patient $\alpha = .84$, caregiver, $\alpha = .89$) and positive dyadic interaction (patient $\alpha = .86$, caregiver, $\alpha = .85$) subscales. An item example for a care-receiver dyadic strain item is, “Because of my health condition, I felt angry toward her/him,” and an example for a caregiver item is, “Because of helping my family member, I felt angry toward him/her.” An example of a relationship quality item would be, “Because of my health condition, I have felt closer to him/her,” and an example of a caregiver item for this same measurement would be, “Because of helping my family member I have felt closer to him/her.” Concurrent and discriminant validity with this concept among the caregiving dyad population has been reported (Serbern & Whitlach, 2007).

Context.

Care dyads function within an influential caregiving context. One undeniable contextual component is the physical limitations of the elder. Level of need that the elder

requires is generally a measure of the amount of care required by the care-receiver. In this study, the level of independence in activities of daily living (ADLs) performed by the care-recipient was measured with an 8-item ADL scale (Lawton & Brody, 1969); plus an additional 8-item scale was used to measure the instrumental activities of daily living (IADLs). This scale quantifies the type and level of assistance required by the care-receiver in the following areas: use of the telephone, mobility, grocery shopping, meal preparation, housework, laundry, taking medications and managing money was used (Lyons, Zarit, Sayer, & Whitlatch, 2002). In previous studies, reliability for this measure was found to be acceptable (care-receiver $\alpha=.84$, caregiver $\alpha=.81$) in populations similar to the current study population (Serbern & Whitlatch, 2007). For the purposes of this study, “ADL Index” refers to this 16-item scale of both ADL and IADL measures. Other contextual considerations included categorical variables such as relationship type (son, son-in-law, daughter, step daughter, etc.) and race.

Data Analysis Procedures

Data were entered into an excel spreadsheet and re-checked for accuracy. Random checks of entries were made on five different occasions during various points in the process. Data were then uploaded into SPSS and cleaned and analyzed for entry-related errors. Several data files were created to accommodate dyadic and individual analysis approaches. The first file contained all individual cases and scores for caregivers and care-receivers (N=108). From the first file, a second file that included only caregivers was created and used for individual level analysis. A third file identifying dyad membership was split and then merged into a dyad structure file (Kenny, Kashy &

Cook, 2006). In this file, care-receivers were entered as reference cases and caregiver scores were entered as additional data points in order to perform dyadic analysis. Thirty-five dyads participated in the study. However, due to missing data only 30 caregiver/care-receiver dyads were used in the analysis. Seventy-eight caregiver questionnaires, of the 81 original completed, were used in the analyses.

Descriptive statistics were analyzed. Measures of central tendency and dispersion were first analyzed for all demographic variables using univariate analyses. Scale items were tested for reliability and internal consistency by generating alpha coefficients for each scale for all cases (N=108), including care-receivers (n=30) and caregivers (n=78). Analyses were also performed to evaluate assumptions of normality, linearity, and homoscedasticity of residuals in relation to criteria for subsequent multivariate analyses (Tabachnick & Fidell, 2007). Based on these analyses, necessary transformations were performed after outliers were identified by a Mahalanobis test. The establishment of non-independence is a critical step in dyad analysis. Therefore, Pearson's r correlations were used to examine non-independence between care-receiver and caregiver scores (Kenny, Kashy & Cook, 2006). Each research question was addressed by a separate analysis. A dyad analysis, and an individual analysis of one - and then the other - dyad member were conducted.

Research question 1, "Is commitment to the care process, role engagement, and psychological well-being of one dyad member associated with commitment to the care process, role engagement, and psychological well-being of the second dyad member?" was addressed by computing correlation coefficients among variables. These analyses

examined correlations between caregiver independent variables and care-receiver dependent variables. In addition, correlations between care-receiver independent variables and caregiver dependent variables were examined. Care-receiver independent variables including role engagement (care performance, relational skills, and competence) and commitment variables (personal, moral, and structural commitment) were each correlated with caregiver (other dyad member) dependent variables of psychological well-being (depression and psychological well-being scales). Caregiver independent variables of role engagement (role performance, relational skills, and competence) as well as commitment variables (personal, moral, and structural commitments) were each correlated with care-receiver (other dyad member) dependent variables of psychological well-being (depression and psychological well-being scales).

An additional analysis consisted of correlating caregiver role engagement and commitment scores with care-receiver psychological well-being scores. Due to the sample size of care-receivers, only the caregivers' data were used in a standard ordinary least squares multiple regression analysis aimed at answering research question 1. After appropriate tests of assumptions and subsequent transformations, role engagement and then commitment were entered in a two-predictor model for each dependent variable (depression and Ryff's psychological well-being). Variations of role engagement and commitment as predictor variables were also entered for the dyad measures of psychological well-being as the dependent variable in a standard regression model. The models found to have significance were examined to see if such variables significantly improved the regression findings (Aiken & West, 1991; Jaccard & Turrisi, 2003).

Correlation coefficients were first examined to answer research question 2: “Are aspects between dyad members including commitment to the care process, role engagement and congruence on these variables associated with the psychological well-being of dyad members?” Score differences were calculated between the caregiver and care-receiver scores. These mean difference scores were then used to create dyad congruence groupings. The groups were examined for variation in psychological well-being scores. Due to dyad sample size, chi-square tests were performed in order to test the proportionality of particular dyad groups with higher and lower role engagement, commitment, and psychological well-being scores.

Correlation coefficients were computed among these sets of variables to answer both research question 3a and 3b: “3a.) What is the relationship among role engagement, commitment to the care process, and psychological well-being in elder **care-receivers**?” and “3b.) What is the relationship among role engagement, commitment to the care process, and psychological well-being in elder **caregivers**?” Subsequently, zero-order correlations were conducted to assess relationships among all measured variables. Significant correlations were analyzed for positive or negative relationships.

Chapter Summary

This chapter described the methodology used in the current study. Information about how the sample was recruited provided insight into the specificity of the eligibility requirements. Additionally, efforts made to embed screening for eligibility in the recruitment process were clarified. Data collection procedures were outlined and explicated. An explanation was given about how demographic variables, independent,

and dependent variable were operationalized. The instruments used to measure these variables and their prior development with regard to reliability and validity were also described. Finally, an overview of the data management and analysis procedures was presented. The following chapter presents the results of the study.

Chapter 4: Results

Analyses in this study are guided by the three major research questions derived from previous empirical evidence about care-receivers, caregivers, and dyads. The analysis strategy attended to both dyad and individual levels of analysis. Thus, in following sections I report findings related to: 1) dyad characteristics (n=30) and individual participant (n=60) characteristics grouped by care-receiver and caregivers, 2) individual participant characteristics for all caregivers (n=78), 3) reliabilities of scales used in the analyses, 4) results of dyad non-independence tests, and 5) dyad analysis results that answer research questions 1 and 2, and lastly 6) individual level results to answer research question 3.

Participant Characteristics

Dyad characteristics

Caregiver and care-receiver dyad (n=30) members' demographic characteristics are shown in Table 2. The mean age of caregivers was 49. Care-receivers average age was 76 years old. Ninety-percent (n=27) of care-receivers were women and eighty-three percent (n=25) of caregivers were women. Fifty-seven percent (n=33) of the entire dyad participant sample was white, 24 % (n=14) was Latino/a, and 12 % (n=7) was African American (n=7). Three people identified as Indian and one subject was Native American. Two caregivers and two care-receivers were multi-racial. Care-receivers

indicated they were married (13%), widowed (53%), or divorced (33%). Of the caregivers, nine were married (30%), ten were divorced or separated (36%), five caregivers had never been married (26%), and one caregiver stated they had a life partner.

Sixty-seven percent of care-receivers had a high school education or lower. Only 10% (n=3) of care-receivers completed a college undergraduate degree, and no care-receivers reported having graduate-level education or training. Eighty-three percent of caregivers indicated they had at least a high school education; 13% (n=4) of caregivers had post-undergraduate and/or graduate-level training or education. Care-receivers in general reported lower income levels with 81% (n=18) reporting an income of less than \$20,000 per year. Of those, 31% (n=7) had less than \$2,500 in annual income. Eight care-receivers chose not to report their income level. Although caregivers reported higher levels of income than care-receivers, these levels were quite low. Thirty-four percent (n=10) of caregivers reported earning less than \$15,000 income annually and 31% (n=9) made between \$15,000 and \$30,000 per year. Twenty-seven percent (n=8) of caregivers reported that their annual income was higher than \$50,000.

Thirty-eight percent (n=23) of all caregivers and care-receivers (n=60) were Catholic and eighteen percent were Baptist (n=11). Four participants reported an additional religious affiliation to the first one reported and only one person stated they did not have an affiliation. On a religiosity scale of 1 to 5 with 1 as “not religious” and 5 as “very religious,” 53% (n=16) of care-receivers ranked themselves as 4 or higher and 17% (n=5) of care-receivers stated they were not religious. Fifty-three percent of caregivers

(n=16) rated themselves as 4 or higher on level of religiosity and 13% (n=4) of caregivers stated they were not religious.

Table 2

Characteristics of Care-Receivers and Caregivers (Dyad Members)

	Care-Receivers (n=30)		Caregivers (n=30)	
Age				
M	75.5		49.0	
SD	7.0		8.2	
Gender	(%)		(%)	
Female	90	(n=27)	83.3	(n=25)
Male	10	(n=3)	16.7	(n=5)
Ethnicity	(%)		(%)	
African American	10.7	(n=3)	13.3	(n=4)
Latino/a	21.4	(n=6)	26.7	(n=8)
White	57.1	(n=16)	56.7	(n=17)
Indian	7.1	(n=2)	3.3	(n=1)
Native American	3.6	(n=1)	0	(n=0)
Percentage of Multiracial*	7.1	(n=2)	7.1	(n=2)
Education Level	(%)		(%)	
Completed 6 th grade or less	6.7	(n=2)	0	(n=0)
Junior High School (7 th -9 th grade)	20.0	(n=6)	0	(n=0)
High School (10 th -11 th grade)	20.0	(n=6)	16.7	(n=5)
Completed High School or GED	20.0	(n=6)	20.0	(n=6)
Partial College	23.3	(n=7)	33.3	(n=10)
Completed College	10.0	(n=3)	16.7	(n=5)
Graduate Level or Professional Training	-	-	13.3	(n=4)
Personal Income (%)				
1-\$2,500	31.8	(n=7)	20.7	(n=6)
\$2,501-\$9,999	18.2	(n=4)	10.3	(n=3)
\$10,000-\$19,999	31.8	(n=7)	3.4	(n=1)
\$20,000-\$29,999	13.6	(n=3)	10.3	(n=3)
\$30,000-49,999	4.5	(n=1)	27.1	(n=8)
50,000-\$100,000	-	-	27.1	(n=8)

*Indicated an additional race(s) than 1st chosen

Three dyad characteristics are listed in Table 3. Dyads were engaged in the caregiving arrangement for approximately five years (M=5.38, SD=5.47). However, the average number of years dyads had lived in the same residence was 10 years (M=10.6, SD=14.04); two caregivers had lived with their parents their entire lives. The measure of each care-receiver's activities of daily living index (ADL) was computed using the total number reported on a 16-item scale, with the lowest possible points being 0 and the highest being 32. A higher score indicates a greater level of need for assistance with activities of daily living (ADLs). The mean ADLs index for care-receivers was 15.1 (SD=5.8). The ADL score was reported by both the caregiver and the care-receiver. Caregiver and care-receiver means ADLs index scores were examined but no significant differences were found.

Table 3

Dyad Characteristics

	Dyads (n=30)	
	M	SD
Years in caregiving arrangement	5.4	5.5
Years in living arrangement	10.6	14.0
	M	SD
ADL Index	15.1	5.8

Caregiver characteristics

Seventy-eight (n=78) caregivers were examined in the caregiver analyses. As shown in Table 4, the mean age of caregivers was 52 years old. Eighty-two percent (n=64) of caregivers were women. Fifty-eight percent were white (n=45), 27 percent (n=17) were Latino/a (n=17), ten percent were African American, four percent (n=3) were Asian (n=3), and one percent (n=8) was Indian (n=1). Six percent (n=5) of

caregivers out of those reported above identified as multi-racial. Forty percent (n=31) of caregivers were married or had a life partner, five percent (n=4) were widowed, 28% (n=21) were divorced or separated, and fifteen percent (n=12) had never been married. Thirty-three percent (n=27) of caregivers reported having a high school education or less, 36% (n=28) completed some college, 17% (n=13) obtained an undergraduate degree, and 12% (n=9) had graduate level training or education. Sixty percent (n=46) of caregivers made less than \$40,000 per year. Twelve percent (n=9) of caregivers reported earning less than \$2,500 in annual income and 26% (n=20) made over \$50,000 per year.

There was considerable variation in religious affiliation among caregivers. Twenty-seven percent (n=21) were Baptist and 19% were Catholic (n=15). Five percent (n=4) of participants reported an additional religious affiliation to the first one reported and six percent (n=5) of caregivers stated they did not have an affiliation. On a scale of 1 to 5 with 1 as not religious and 5 as very religious, 53% (n=16) of caregivers ranked themselves as a 4 or 5 and 13% (n=10) reported they were not religious. The average number of years in which caregivers were caring for their parents was 6.5 years (SD=6.1). Seventy-eight caregivers, 48 of whom were not part of the dyad analysis portion of the study, reported their care-receiving parent ADL index mean as 17.8 (SD=6.6). Caregivers were offered the opportunity to complete the questionnaire as a hard-copy (n=48) or online (n=30). Independent sample t-tests were performed between subjects by test method on pertinent variables to assess potential differences in age, parental ADL index, and years providing care. There were no significant differences by test method on any of these variables. Chi-squared tests were conducted to assess income

categories between groups. Online completion caregivers had a significantly higher income than other subjects ($\chi^2 = 18.8, p = .042$).

Table 4

Characteristics of Caregivers (n=78)

Age		
M	51.8	(n=78)
SD	9.8	
ADL Index		
M	17.8	(n=78)
SD	6.6	
Gender		
	(%)	
Female	82.1	(n=64)
Male	15.4	(n=12)
Ethnicity		
	(%)	
African American	10.3	(n=8)
Latino/a	21.8	(n=17)
White	57.7	(n=45)
Asian	3.8	(n=3)
Other	1.3	(n=1)
Percentage of Multiracial*	6.4	(n=5)
Education Level		
	(%)	
High School (10th-11th grade)	11.5	(n=9)
Completed High School or GED	21.8	(n=17)
Partial College	35.9	(n=28)
Completed College	16.7	(n=13)
Graduate Level or Professional Training	11.8	(n=9)
Personal Income		
	(%)	
1-\$2,500	11.5	(n=9)
\$2,501-\$9,999	11.5	(n=9)
\$10,000-\$19,999	9	(n=7)
\$20,000-\$29,999	14.1	(n=11)
\$30,000-39,000	12.8	(n=10)
\$40,000-49,999	10.3	(n=8)
\$50,000-74,999	19.2	(n=15)
\$75,000-\$100,000+	6.4	(n=5)

*Indicated an additional race(s) than 1st chosen

Scale score reliability

Reliability coefficients for each scale used in the analyses are shown in Table 5.

It is important to estimate the amount of errors in scores when using scales (Gable & Wolf, 1993); therefore, the reliability of scales was examined. All scale scores were analyzed for reliability using Cronbach's alpha to estimate internal-consistency (Cronbach, 1951). These measures were described fully in Chapter 3.

Table 5

Scale Reliability Results

		<u>Cronbach's Alpha Scores</u>		
Construct	Scale	All Participants (N=108)	Care-Recipients (n=30)	Caregivers (n=78)
Role				
	Care Receiver Efficacy	0.83	0.85	0.82
	Competence	0.86	0.68	0.84
Commitment				
	Personal	0.78	0.85	0.75
	Moral	0.85	0.87	0.84
	Structural	0.84	0.86	0.80
Psychological Well-Being				
	Depression	0.89	0.84	0.91
	Autonomy	0.77	0.61	0.82
	Environmental Mastery	0.78	0.71	0.79
	Personal Growth	N/A	N/A	0.70
	Positive Relationships	N/A	N/A	0.80
	Purpose in Life	N/A	N/A	0.87
Dyad Psychological Well-being				
	Positive Interaction	0.87	0.85	0.86
	Strain	0.87	0.75	0.89

Reliabilities for nearly all measures were in the acceptable to high range. With the exception of two measure reliabilities, care-receiver autonomy ($\alpha=.61$) and care-receiver competence ($\alpha=.68$), all measures ranged from .75 to .91. Slight differences in reliability

coefficients were noted between caregiver and care-receivers on measures of psychological well-being, autonomy and role engagement, and competence.

Findings for Dyad Analysis

Dyad non-independence.

The purpose of dyad analysis is to examine how members of the dyad are related, whether they are similar or dissimilar from one another. The theoretical framework that guides the current study of dyadic interaction suggests that the members of a dyad are related. The assumption of the independence of data is important to most common statistical tests and to classical test theory. However, using the dyad as the unit of analysis presents a scenario in which non-independence is central to how data are analyzed. For this reason, dyad analysis has often been dubbed the study of “non-independence” (Kenny et al., 2006). Kenny et al. (2006) recommend that a test of non-independence be performed for any study in which data are collected from both dyad members. Distinguishable member dyads are those in which an independent variable constitutes a natural difference between the two members. The current analysis examined dyad members who are distinguished by their role in the relationship between care-receiving and caregiving. For distinguishable dyad members, the test of non-independence is determined by using Pearson’s r correlation with a two-tailed analysis in order to detect both positive and negative correlations. Kenny et al. (2006) recommend that the lowest sample size of dyads that should be tested is 25.

It is necessary to control for other independent variables that may influence non-independence (Kenny, et al., 2006). For example, the length of time people interact with

one another increases the opportunity for influence to occur. Additionally, higher levels of need among care-receivers may impact dyad interactions. Therefore, to test for non-independence the following control variables were used: length of time in caregiving arrangement and care-receiver deficits in activities of daily living, controls for care-receiver activities of daily living index, and years of engagement in the caregiving arrangement. Non-independence was analyzed for the independent variables of personal, moral and structural commitment; relational coping and self-care performance; and competency and for the dependent variables of autonomy, environmental mastery, depression, dyad strain, and dyad positive interactions. Significant and relevant moderate associations found between dyad member scores are reported below. Kenny et al. (2006) recommend using the liberal test value for alpha (.20) with at least 25 dyads when testing for non-independence. These results are discussed in the following paragraphs.

Results of Dyad Non-independence for Independent and Dependent Variables.

Two significant correlations were found between caregiver and care-receiver independent variables. A significant correlation was observed between care-receiver moral commitment and caregiver personal commitment ($r=.369$, $p=.05$). Moderate correlations were found between caregivers and care-receivers on personal ($r=.288$, $p=.137$) and moral ($r=.261$, $p=.18$) commitment. Tests of non-independence were also conducted between role engagement variables of competence scale items (judgment of the other's perspective) and relational coping (appraisal of one's own behaviors from one's own perspectives). Care-receiver competence was significantly related to caregiver relational coping ($r=.539$, $p=.004$). In addition, caregiver competence was significantly

related to care-receiver relational coping ($r=.429$, $p=.026$). Significant correlations found among care-receiver and caregiver dependent variables included care-receiver and caregiver autonomy ($r=.437$, $p=.029$), depression ($r=.413$, $p=.040$), and a negative correlation between caregiver dyad strain with care-receiver dyad positive interactions ($r= -.433$, $p=.031$).

In sum, five significant correlations between caregivers and care-receivers between five measures were found. However, there were no significant correlations were found for the other independent and dependent variables. These findings indicate partial evidence that non-independence between dyad members exists.

Dyad analysis.

Data were transformed into a dyad format to conduct analyses of dyad units. Specifically, caregiver scores were entered adjacent to care-receiver's scores. Caregiver variables were relabeled and then merged to create a care-receiver data set with caregiver variables added. Pearson's r coefficients were estimated to examine the relationships within dyads by testing relationships between caregiver commitment and role engagement scores and care-receiver psychological well-being scores. Subsequently, relationships within dyads between care-receiver commitment and role engagement scores and caregiver psychological well-being scores were examined. In the following sections, results are reported to answer research question 1: "Is commitment to the care process, role engagement, and psychological well-being of one dyad member associated with commitment to the care process, role engagement, and psychological well-being of

the second dyad member?” Several significant and moderate associations were found between dyad member scores and are reported below.

Correlations between Caregiver Independent Variables and Care-Receiver Dependent Variables.

The relationships among caregiver commitment, caregiver role engagement and the four measures of care-receiver psychological well-being were analyzed to answer research question 1. Significant relationships were found between personal commitment (CG) and dyad strain (CR) (-.420, $p < .05$), competence (CG) and depression (CR) (-.471, $p < .05$), competence (CG) and dyad positive interactions (CR) (.597, $p = .002$), and relational coping (CG) and dyad positive interactions (CR) (.510, $p = .009$). Although not significant, moderate negative correlations were found between structural commitment (CG) and depression (CR) (-.352, $p = .085$), and relational coping (CG) and depression (CR) (-.288, $p = .162$).

Correlations between Care-Receiver Independent Variables and Caregiver Dependent Variables.

Next, the relationship between care-receiver commitment and care-receiver role engagement with all four measures of caregiver psychological well-being were analyzed to answer research question 1. Significant relationships were found between personal commitment (CR) and autonomy (CG) (.364, $p = .05$), relational coping (CR) and dyad strain (CG) (-.368, $p = .05$), and relational coping (CR) and depression (CG) (-.377, $p = .05$). Although not significant, notable negative correlations were found between moral commitment (CR) and dyad strain (CG) (-.261), personal commitment (CR) and

depression (CG) (-.237), and care performance and dyad strain (CG) (-.287). Positive moderate correlations were found for competence (CR) and dyad positive interactions (CG) (.245) and between relational coping (CR) and autonomy (CG) (.311).

Congruence of care-receiver—Caregiver dyads

Mean scores for independent and dependent variables were analyzed for dyad congruence to answer research question 2: “Are aspects between dyad members including commitment to the care process, role engagement and congruence on these variables associated with the psychological well-being of dyad members?” This congruence was estimated using mean score differences on independent variables (commitment and role engagement) to create three types of dyads: 1) incongruent due to higher caregiver scores, 2) congruent, and 3) incongruent due to higher care-receiver scores. Once these groups were determined, chi-square tests were conducted using dependent variables of positive interaction, environmental mastery, autonomy, and depression for care-receivers and caregivers. Differences between group means were also tested using analysis of variance (ANOVA). Due to the small sample size, nonparametric tests were used to determine even distribution across scores. Results are presented in the following sections.

Personal Commitment Congruence within Care-Receiver- Caregiver Dyads.

Commitment congruence scores for care-receivers are shown below in Table 6. No significant differences were found among care-receivers in the three congruence groups for care-receiver depression, dyad strain, positive interactions, environmental mastery, or autonomy. Although not statistically significant, depression scores between care-receiver

groups appeared to be different. Care-receiver depression was lowest for those who belonged to dyads with the same or similar types of personal commitment. Finally, the highest levels of depression were found for care-receivers that belonged to incongruent dyads in which caregivers had higher personal commitment.

Table 6

Dyad Personal Commitment Congruence for Care-receiver Scores

Care-receiver Mean Scores:	Dyad Positive Interactions		Dyad Strain		Environmental Mastery		Autonomy		Depression	
	M	n	M	N	M	n	M	N	M	n
Incongruence CG High Personal Commitment	16.6	9	10.6	9	3.5	10	4.3	10	14.3	10
Congruence CG & CR Personal Commitment	16.9	12	10.3	12	4.02	12	4.1	12	7.8	12
Incongruence CR High Personal Commitment	17.9	8	11.6	8	4.1	6	4.5	6	9.3	8

Dyad personal commitment congruence scores for caregivers are shown in Table 7. No significant differences between groups were found on caregiver positive dyad interactions. However, a higher positive dyad interaction was found among caregivers who belonged to congruent dyads (M=17.2). Lowest scores were found for caregivers who belonged to dyads that were incongruent due to higher care-receiver personal commitment (M=14.5). Significant differences ($p<.05$) in dyad strain were found between caregivers who belonged to different dyad congruence group types. Dyad strain was highest among caregivers who belonged to dyads incongruent because the care-

receiver had more personal commitment. The lowest level of dyad strain was found among caregivers who belonged to dyads that were incongruent due to higher caregiver personal commitment. This implies that caregivers experience higher dyad strain when their care-receivers experience a higher amount of personal commitment towards the relationship than they do. Little difference was found among the three groups on measures of caregiver environmental mastery and autonomy. Although not significant, moderate differences ($p=.068$) in caregiver depression were found among the three groups. The highest levels of depression occurred in caregivers who belonged to dyads incongruent due to higher care-receiver personal commitment. Depression was lowest for caregivers who belonged to incongruent dyads due to higher caregiver personal commitment. These data suggest that caregivers with less personal commitment to the relationship than their care-receivers were more likely to be depressed.

Table 7

Dyad Personal Commitment Congruence for Caregiver Scores

Caregiver Mean Scores:	Dyad Positive Interactions		Dyad Strain		Environmental Mastery		Autonomy		Depression	
	M	n	M	N	M	n	M	n	M	n
Incongruence CG High Personal Commitment	16.4	10	8.9*	10	4.7	10	4.6	10	6.6	10
Congruence CG & CR Personal Commitment	17.2	12	10.3*	12	4.6	12	4.8	12	7.8	12
Incongruence CR High Personal Commitment	14.5	8	14.5*	8	4.1	8	4.3	8	16.6	8

*significant difference between groups found ($p<.05$)

Role Engagement Congruence within Care-Receiver- Caregiver Dyads.

Categories for dyad congruence based on role engagement revealed a very different grouping than those derived from personal commitment congruence. There were considerably more dyads in which the caregiver scored themselves higher on role engagement (n=17). In addition, nine dyads (n=9) had congruent scores and only four dyads (n=4) had incongruence due to the care-receiver rating themselves higher on role engagement.

Role engagement congruence groupings in dyads and care-receiver psychological well-being scores are listed in Table 8. Little to no difference was found among care-receivers in the three groups for positive dyad interactions and dyad strain. However, it is interesting to note that the highest positive dyad interactions (M=17.5) and highest dyad strain (M=12) were found among care-receivers who belonged to dyads that were incongruent due to higher caregiver role engagement. Care-receivers from dyads congruent on role engagement had similar positive interaction scores (M=17.4). Significant differences in means ($p < .05$) of care-receiver autonomy were found between care-receivers who belonged to different dyad congruence groups. The highest levels of autonomy were found among care-receivers who belonged to dyads that were congruent on role engagement and the lowest levels of autonomy were found among care-receivers who belonged to dyads incongruent due to higher caregiver role engagement. Trends in scores were similar for care-receiver environmental mastery. However, no significant differences between group means were found. Depression in care-receivers was lowest

for care-receivers belonging to dyads incongruent due to higher caregiver personal commitment and highest for those belonging to dyads incongruent due to higher care-receiver role engagement. However, no significant differences in care-receiver depression were found.

Table 8

Dyad Role Engagement Congruence for Care-receiver Scores

Care-receiver Mean Scores:	Dyad Positive Interactions		Dyad Strain		Environmental Mastery		Autonomy		Depression	
	M	n	M	N	M	N	M	n	M	n
Incongruence CG High Role Engagement	16.6	16	10.25	16	3.6	16	3.9*	16	7.7	16
Congruent CG & CR Role Engagement	17.4	9	11.1	9	4.2	9	4.7*	9	8.7	9
Incongruence CR High Role Engagement	17.5	4	12.0	4	4.0	4	4.5*	4	9.5	4

*significant difference found (p<.05)

Caregiver role engagement scores are shown in Table 9. The lowest level of dyad strain (M=9.3) was found among caregivers who belonged to dyads that were congruent on role engagement (M=10). Dyads that were incongruent due to higher caregiver role engagement did not exhibit significantly higher dyad strain (M=11.2). Moderate differences (p=.07) in caregiver autonomy were found between caregivers of the three dyad congruence type groups. The lowest level of autonomy was found in caregivers who belonged to dyads that were incongruent due to higher care-receiver role engagement. The highest levels of autonomy were found among caregivers who were

members of congruent dyads. No significant difference was found between caregivers on environmental mastery. The highest levels of caregiver depression (M=11.4) were found among caregivers who belonged to dyads incongruent due to higher caregiver role engagement and the lowest depression levels (M=6.4) were found in caregivers who belonged to dyads incongruent due to higher caregiver role engagement. However, this difference was not significantly different between groups.

Table 9

Dyad Role Engagement Congruence for Caregiver Scores

Caregiver Mean Scores:	Dyad Positive Interactions		Dyad Strain		Environmental Mastery		Autonomy		Depression	
	M	n	M	N	M	n	M	n	M	N
CG High Role Engagement Incongruence	16.8	17	11.2	17	4.6	17	4.5	17	11.4	17
Congruent CG & CR Role Engagement	15.8	9	9.3	9	4.5	9	5.1	9	8.5	9
CR High Role Engagement Incongruence	14	4	10	4	4.2	4	4.1	4	6.4	4

In sum, two significant differences were found when caregiver- care-receiver dyad congruence and incongruence groups were compared. When considering dyad congruence of role engagement, care-receivers differed on autonomy. When considering dyad congruence of personal commitment, dyad strain was the measure for which there were significant differences between caregiver groups. Implications of these findings are discussed in chapter 5.

Congruence on Personal and Moral Commitment within Care-Receiver-

Caregiver Dyads. Cross tabulations between dyads for congruence on personal, moral and structural commitment were examined to explore variation in congruence that existed for dyads on different **types** of commitment. As shown in Table 10 there was a significant difference in the number of dyads that were categorized for personal commitment and structural commitment ($\chi^2=11.23, p=.024$). Fifty-three percent (n=16) of dyads were found in one of two categories. Thirty-three percent (n=10) of dyads were congruent on personal commitment and incongruent on moral commitment due to higher care-receiver scores. Twenty-percent (n=10) of dyads were found to be incongruent due to higher care-receiver personal commitment and incongruent due to higher care-receiver moral commitment. No dyads were found to be congruent on both moral and personal commitment.

Table 10

Dyad Congruence in Structural vs. Personal Commitment

		Structural Commitment			Total
		CG High	Congruent	CR High	
Personal Commitment	CG HIGH	4	4	2	10
	Congruent	2	0	10	12
	CR HIGH	1	1	6	8
Total		7	5	18	30

No significant differences in the number of dyads that were categorized for personal commitment and moral commitment were found. However, it is interesting to note that moderate differences in distribution of these groups were found. Twenty-three percent of dyads (n=7) were incongruent due to higher caregiver personal and structural

commitment, as shown below in Table 11. The rest of the cases were fairly evenly distributed except that no dyads were found to be incongruent due to higher care-receiver structural commitment and higher caregiver personal commitment.

Table 11

Dyad Congruence in Moral vs. Personal Commitment

		Moral Commitment			Total
		CG High	Congruent	CR High	
Personal Commitment	CG HIGH	7	3	0	10
	Congruent	4	4	4	12
	CR HIGH	2	3	3	8
Total		13	10	7	30

Findings for Individual Analysis

Care-receivers

Correlations among care-receiver commitment independent variables, role engagement independent variables, and care-receiver dependent variables.

Correlation coefficients were calculated between all care-receivers' independent and dependent variables to answer research question 3(a): "What is the relationship among role engagement, commitment to the care process, and psychological well-being in elder care-receivers?" Personal commitment was significantly related to competence ($r=.689, <.001$), depression ($r=-.402, p=.045$), care performance ($r=.430, p=.032$), and relational coping ($.387, p=.056$). Moral commitment was significantly related to dyad positive interactions ($r=.399, p=.048$), competence ($r=.559, p=.004$), and care performance ($r=.494, p=.012$). A significant relationship was found between structural commitment and care performance ($r=.462, p=.020$). Autonomy was significantly

associated with dyad positive interactions ($r=.506$, $p=.010$). Dyad positive interactions were negatively associated with depression ($r=-.491$, $p=.013$). Care performance and environmental mastery ($r=.405$, $p=.045$) were significantly related. Relational coping was related to environmental mastery ($r=.535$, $p=.006$), and negatively related to depression ($r=-.542$, $p=.005$). As expected, relational coping and care performance were significantly positively related ($r=.577$, $p=.003$). Dependent variables that were significantly correlated included depression, autonomy ($r=-.617$, $p=.001$) and environmental mastery ($r=-.738$, $p<.001$).

Caregivers

Correlations among caregiver commitment independent variables, role engagement independent, and caregiver dependent variables.

Correlation coefficients were calculated between all care-receivers' independent and dependent variables to address research question 3(b): "What is the relationship among role engagement, commitment to the care process, and psychological well-being in elder caregivers?" Personal commitment was significantly associated with dyad strain ($r=-.514$, $p=.005$), dyad positive interaction ($r=.470$, $p=.012$), competence ($r=.452$, $p=.016$), and depression ($r=-.473$, $p=.011$). Structural commitment was correlated with dyad positive interactions ($r=.382$, $p=.045$). Competence was significantly related to dyad strain ($r=-.580$, $p=.006$), dyad positive interactions ($r=.541$, $p=.003$), depression ($r=-.375$, $p=.04$), and relational coping ($r=.377$, $p=.048$). Relational coping and dyad positive interactions ($r=.538$, $p=.003$) were related. Environmental mastery was significantly

associated with dyad strain ($r=-.391$, $p=.040$) and depression ($r=-.554$, $p=.002$). Finally, autonomy was significantly negatively related to depression ($r=-.720$, $p<.001$).

Caregiver Multiple Regression Analysis.

Research question 3(b) examines the relationship between commitment and role engagement and psychological well-being in caregivers. Ordinary least squares regression was performed with caregivers ($n=78$) using five independent variables (personal and moral commitment, role engagement: relational coping, self-care performance, and competence) and four dependent variables measuring depression and psychological well-being. All variables in each of the four models were entered simultaneously.

Four separate regression analyses were completed to assess measures of dependent variables that represented different aspects of psychological well-being. Two of these dependent variables measured individual well-being (Ryff Psychological-Well-Being Scale and CESD) and two dependent variables measured an individual as a member of a dyad (DRS: dyad strain and dyad positive interactions). Three combinations of personal, moral and structural commitment were also analyzed as separate predictors because they represented three very different aspects of commitment as distinguished in the literature. Structural commitment was not included in the model due to its inconsistency with the other commitment variables found in previous analyses.

Depression was regressed on personal and moral commitment variables, and on relational coping, self-care performance, and competence role engagement variables. Results are shown in Table 12. Personal commitment was significantly related to

depression scores ($B = -1.27$, $t = -3.27$, $p = .002$) as was moral commitment ($B = .273$, $t = 2.06$, $p < .05$). However, none of the three role engagement variables were significant predictors. The overall model was significant ($F = 3.13$, $p < .05$) and predicted 12% of the variation in depression scores.

Table 12

Regression of Depression on Personal and Moral Commitment, Relational Coping, Self-Care Performance, and Competence

	B	SE	t	p
Personal Commitment	-1.27	.39	-3.27	.002
Moral Commitment	.273	.13	2.06	.043
Relational Coping	3.42	3.48	.982	.330
Self-Care Performance	.80	3.18	.252	.801
Competence	-.48	.35	-1.389	.170

Note: N=77 (F= 3.13, p<.05) Adjusted $R^2 = .123$

The results of the second regression model are displayed in Table 13. In this analysis, psychological well-being regressed on personal and moral commitment, and on the role engagement variables of relational coping, self-care performance, and competence. Similar to the results of the previous model, personal commitment (B = 4.71, t = 4.00, p < .001) and moral commitment (B = -1.05, t = -2.63, p < .05) were significant predictors of psychological well-being. The other three independent variables--relational coping, self-care performance, and competence--were not significant. Twenty-one percent of the variation in psychological well-being scores (F=4.97, p=.001) is explained in this analysis.

Table 13

Regression of Psychological Well-Being on Personal and Moral Commitment, Relational Coping, Self-Care Performance, and Competence

	B	SE	t	p
Personal Commitment	4.71	1.18	4.00	.000
Moral Commitment	-1.05	.40	-2.63	.011
Relational Coping	-1.29	10.50	-.12	.903
Self-Care Performance	7.30	9.60	.76	.450
Competence	.59	1.045	.57	.574

Note: N=77 (F=4.97, p=.001) Adjusted $R^2 = .21$

Dyad strain was regressed on the two commitment variables and the three role engagement variables in the third model. Results are shown in Table 14. Personal commitment was the only variable found to significantly predict dyad strain in caregivers (B = -.58, t = -4.44, p < .001). Seventeen percent of the variation in dyad strain was accounted for in analysis.

Table 14

Regression of Dyad Strain on Personal and Moral Commitment, Relational Coping, Self-Care Performance, and Competence

	B	SE	t	p
Personal Commitment	-.58	.14	-4.44	.000
Moral Commitment	.06	.05	1.80	.076
Relational Coping	.44	1.23	1.64	.106
Self-Care Performance	.174	1.12	.86	.391
Competence	.05	.12	.39	.669

Note: N=77 (F=4.00, p=.003) Adjusted $R^2 = .17$

In a final analysis, dyad positive interactions were regressed on personal and moral commitment, and the role engagement variables of relational coping, self-care performance, and competence. As shown in Table 15, two of the five variables were significantly related to dyad positive interactions. Personal commitment ($B = .53$, $t = 4.61$, $p < .001$) and relational coping ($B = 2.19$, $t = 4.61$, $p < .05$) were significant predictors of dyad positive interactions. This model explained 41% of the variance in dyad positive interactions, a much larger percentage than the previous regression models examining the other types of psychological well-being measures.

Table 15

Regression of Dyad Positive Interactions on Personal and Moral Commitment, Relational Coping, Self-Care Performance, and Competence

	B	SE	t	p
Personal Commitment	.53	.12	4.61	.000
Moral Commitment	-.04	.04	-.96	.339
Relational Coping	2.19	1.024	2.14	.036
Self-Care Performance	-.062	.936	-.07	.948
Competence	.15	.102	1.51	.136

Note: $N=77$ ($F=11.43$, $p<.001$) Adjusted $R^2 = .41$

In sum, personal commitment was the independent variable that was a significant predictor in all four models. Moral commitment was found to be significant in the two psychological well-being variables. Implications of these findings are discussed in the next chapter.

Chapter Summary

Findings were presented for each of the three major research questions in this chapter. The final chapter discusses the relevance and implications of the results as they

relate to the interpersonal dynamics between chronically ill older adults and child caregivers during the care process. An explanation of how the current study contributes to care-receiving and caregiving literature and to gerontological social work practice, policy, and research is also provided.

Chapter 5: Discussion

This chapter discusses the relevance and implications of study results for gerontological social work practice, policy, and research. Methodological limitations and recommendations for future research are noted.

Dyad Analysis

Non-independence

Results of the current study provide evidence of a relationship between dyad members' scores. Significant correlations were found on measures of personal commitment, moral commitment, competence, relational skills, dyad strain, and dyad positive interactions. Three significant correlations were found among dyad variables. Although correlations on same and concurrent variables between dyad members were not unanimously significant, these findings do provide support to the claim that the experiences of parent-child caregiving dyad members are related. This further establishes legitimacy to the inclusion of both dyad members when attempting to examine the experiences of individual caregivers and care-receivers.

Relationships between dyad member variables

The study hypothesized that types of commitment to the care process, role engagement, and the psychological well-being of one dyad member would be related to psychological well-being outcomes of the second dyad member. This hypothesis was

supported in several cases. The results indicate that certain relationships between caregiver commitment and role engagement and care-receiver outcomes do exist. First, relationships between caregiver independent variables and care-receiver psychological well-being will be discussed. Second, psychological well-being outcomes of caregivers and how they are related to type of care-receiver commitment and role engagement are presented.

Caregiver Role Engagement and Commitment and Care-receiver Psychological Well-Being. Findings suggest that higher caregiver personal commitment to their care-receiver is related to the care-receiver's experience of dyad strain, but not necessarily to their experience of positive interactions. This relationship with dyad strain was not found among moral or structural commitment, which may indicate that these types of commitment are not associated with specific dyad strain experienced by care-receivers. Higher caregiver perception of care-receiver competence was associated with lower care-receiver depression. This implies that caregivers reporting lower care-receiver competence in assisting with their own care have more depressed care-receivers. Caregiver report of competence was also related to positive interactions. Thus, the more competent caregivers perceive care-receivers to be, the more positive are the interactions experienced by the care-receiver. Caregivers' participation in role engagement through relational coping skills was also associated with positive interactions experienced by care-receivers. The presence of several moderate associations suggest the possibility that a higher structural commitment and higher levels of relational coping skills on the part of caregivers may be related to lower levels of depression among care-receivers.

Care-receiver Role Engagement and Commitment and Caregiver Psychological

Well-Being. There were some significant associations between caregivers' psychological well-being and care-receivers' commitment and role engagement. Higher levels of personal commitment in care-receivers were related to higher levels of caregiver autonomy. Higher care-receiver relational coping was related to lower levels of caregiver dyad strain and depression. These findings imply that when care-receivers relate better with their caregivers, caregivers tend to experience less depression and less strain in the caregiving relationship. Based on relationships found between care-receivers and caregivers it may be reasonable to conclude that certain aspects of care-receiver commitment and role engagement, and caregiver autonomy, dyad strain, and depression should be examined in future research studies.

Moderate correlations suggest higher care-receiver moral commitment and higher care-receiver self-care performance may be related to lower caregiver dyad strain. Additionally, moderate correlations suggest that higher care-receiver personal commitment may be related to lower caregiver depression. Finally, although correlations were not significant, care-receivers with higher caregiver competence perceptions could be related to higher caregiver dyad positive interactions and higher levels of care-receiver relational coping may be related to higher caregiver autonomy . Based on lack of significant or moderate correlations found, structural commitment of care-receivers does not appear to be related to any type of caregiver psychological well-being.

Relationships found between caregivers and care-receivers provide some support for the hypotheses that the role engagement and commitment of one dyad member is

related to the other dyad member's psychological well-being. The establishment of these relationships has implications for assessment and intervention with older care-receivers and their children who are providing care for them. Although it is not possible to determine causal relationships in the current study, it is important to consider that variations in aspects of commitment and role engagement in one dyad member could be accompanied by particular psychological well-being issues in the other dyad member. Additionally, these results confirm the assumption that these experiences can be quite different depending upon whether or not the member is a caregiver or care-receiver. It appears that personal commitment was strongly associated with aspects of psychological well-being, suggesting this type of commitment is the most relevant when considering the psychological well-being of both dyad members. Relational coping appeared to be relevant for both caregivers and care-receivers in different ways. For caregivers, care-receiver relational coping related to increased positive interactions, while care-receivers experienced lower levels of strain and depression when their care-receivers reported higher relational coping.

Dyad congruence

There were distinct dyad groups that formed when analyzing dyad congruence for role engagement and commitment. However, no apparent important variations in scores were identified except for depression scores for both caregivers and care-receivers. For all dyads with incongruence in personal commitment and role engagement, the dyad members with the higher level of personal commitment and higher role engagement scores had higher levels of depression. Care-receivers of dyads with incongruence due to

higher caregiver personal commitment had higher levels of depression (M=14.3). Caregivers from dyads with incongruence due to higher care-receiver personal commitment had considerably higher depression scores (M=16.6). These findings suggest that in order to detect depression for both caregivers and care-receivers, it might be important to look at congruence and incongruence to determine which dyad member has higher levels of role engagement and/or personal commitment.

Another important implication of the findings regarding congruence between dyad members concerns the occurrence of incongruence when caregivers score high on role engagement (relational coping and care performance). In the case of personal commitment, there appeared to be a fairly even distribution of incongruence due to high caregiver scores, congruence, and incongruence due to high care-receiver scores. This set of findings may be important because it is rare for care-receivers to perceive that they participate in their own care at higher levels than caregivers believe they do. This may seem like an obvious finding due to the nature of care relationships. However, this measure of role engagement is not related to physical limitations; in fact, it is defined by the range of possible ways that cognitively-competent care-receivers can participate in their own care. If this were to be explored further and confirmed in other studies there may be an important trend in passivity among care-receivers that could be addressed. Further, this passivity may not be detected or the extent of if it may not be fully understood were it not compared with caregiver participation using the same measure.

In general, the variation between dyads on their level of congruence is an important finding. Findings that reveal different types of commitment and role

engagement between dyad members have several implications. For example, caregiving dyads consisting of a caregiver who has a much higher level of commitment to their care-receiver than their care-receiver has to them may exhibit a much different dynamic than dyads with congruent levels of commitment. These varying circumstances may impact how well a dyad functions. Such variations may be very useful to addressing the needs of older adults and their caregivers.

Individual Analysis

Individual level analysis examined whether or not, for both care-receivers and caregivers, there was a relationship between one's level of role engagement and commitment and individual psychological well-being. I hypothesized that there would be a significant relationship among these variables. The results of the study partially support this hypothesis.

Care-receivers

A number of significant correlation coefficients for the care-receivers (n=30) scores were found. It appears that the higher a care-receiver's personal commitments to their caregiver, the lower their depression scores were. Additionally, high personal commitment was associated with higher role engagement in care performance and relational coping skills. This may be important when determining the amount of engagement that could be anticipated. Moral commitment was also associated with positive dyad interactions. This may mean that a care-receiver's motivations for being in the care arrangement are highly driven by obligation to their caregiver may actually relate to whether they perceive their interactions as positive.

Two types of role engagement were significantly associated with environmental mastery. A care-receivers' perception of their own control over their environment was related to how well they cope with their caregiver and participate in their own care. This is an important finding because it suggests that care-receivers could achieve a sense of environmental mastery through their caregiver and role participation even in light of physical limitations. In addition to associations between independent and dependent variables, significant relationships among measures of psychological well-being--autonomy, environmental mastery, depression, positive dyad interactions, and dyad strain--support previous findings that associations have been made between these and similar measures (Cox, et al., 2006, Ryff & Singer, 1998, Serbern & Whitlach, 2007).

The findings of the individual analysis of care-receivers partially support the original hypothesis for the above mentioned associations. However, the lack of significance between moral and structural commitment with depression, environmental mastery and autonomy are cases in which the null hypotheses are retained. This could imply that these types of commitment may be more useful in the cases of dyad specific interactions since significance was found between care-receiver positive dyad interactions and both care-receiver moral and structural commitment.

Caregivers

Several significant relationships were found among caregiver commitment, role engagement, and psychological well-being. However, these findings differed somewhat from results found for care-receivers. Like care-receivers, caregivers with higher levels of personal commitment also had lower levels of depression and lower dyad strain, higher

positive interaction, and higher perception of care-receiver competence. The fact that these and other variables were significantly associated may provide guidance to working with caregivers on issues related to personal commitment. Caregiver personal commitment and perceived role competence of care-receiver were significantly associated with depression in caregivers. It is interesting to note that a caregiver's personal affinity to their care-receiver, and how good they believe their care-receiver is at their role, is related to his or her levels of depression. If this were to be replicated in future research, the importance of addressing both caregiver expectations and care-receiver participation as protective factors against depression in caregivers might be further established.

Regression analyses revealed several interesting findings. Four types of psychological well-being were regressed on five independent variables, including personal and moral commitment, relational coping, self-care performance, and competence. The measures of psychological well-being consisted of depression, Ryff's psychological well-being scale composite score, dyad strain, and dyad positive interactions. The model in which 41% was dyad positive interactions regressed on the five independent variables explained the greatest amount of variation.

Personal commitment was a significant predictor in all four models. This finding suggests that level of personal commitment is an important factor to consider when assessing needs of caregivers who are caring for their parent in close proximity. Moral commitment was significantly related to depression and Ryff's psychological well-being measures but not to dyad related psychological well-being variables, dyad strain, or

positive dyad interactions. These findings indicate that personal and moral commitment may be important predictors of psychological well-being. However, it is important to make the distinction between types of commitment versus individual context when assessing caregivers of aging parents. In all four models, the only role engagement variable that significantly predicted the dependent variable was relational coping with dyad positive interactions. Based on these findings, it appears that role engagement has a minimal effect on individual psychological well-being measures but has some potential in predicting caregiver experiences in dyad interactions.

The variation in psychological well-being explained in these models has certain implications in regard to the hypothesis of the current study. How much a caregiver personally cares about, truly enjoys interactions with, and feels benefits from their relationship, paired with how well they overtly express their support has implications for their own mental health and experience of strain in the care provision interactions. The most important implication of the caregiver regression analysis is the apparent importance of focusing on a caregiver dyad personal relationship and how dyad members relate to one another in their roles.

Contributions and Theoretical Implications

The key theoretical elements of interdependence theory include an understanding of mutual dependence, motivation, mutuality of expectations, and contextual influence. Assumptions associated with these elements imply that people have intrinsic motivations to collaborate with each other in order to achieve goals they both find important (Holmes, 2002; Rusbult & VanLange, 2003). Using the interdependence structure, it is assumed

that caregivers have social-psychological needs that are being met (or not) through their care-receiver that impact the relationship and the individuals. When considering dyad interactions, interdependence theory alleges to explain each person's needs, thoughts, and motivations behind behavior concurrently with the context in which the interactions occur. The results of the current study indicate that dyad members who are participating in caregiving arrangements are in some ways mutually related to each other's experience of role engagement and commitment, not just their own experience. This confirmation of the interrelated nature of some of these variables provides partial support for the occurrence of interdependence within this type of dyad.

This study incorporates three types of commitment that exist within an individual. Three components of commitment offer a way to examine the complexity that occurs in caregiver and care-receiver relationships on a personal, moral, and structural level. It was hypothesized that three aspects of commitment--personal, moral and structural--and their relatedness to the care process relationship would illuminate how relationship quality and commitment contribute to outcomes for care dyad members. This was partially supported by the current findings.

Personal commitment, one's personal desire and attraction to be in the relationship and incorporate it into one's identity, was found to be the most important type of commitment in caregiving dyad interactions. Although many caregiving partnerships occur between people who are not or have not been intimate life partners, there is still a level of attraction and self identification a caregiver can feel towards their care-receiver

and vice versa (Coeling, et al., 2003). This study contributes to current research by adding support to this assertion.

Moral commitment, a sense of duty one feels towards another, is another component of commitment found to be relevant in care dyads in previous research. It could be felt by either the caregiver or the care-receiver and could come from past promises made (Groger & Mayberry, 2001), family role identity (Li & Seltzer, 2005), a need to protect someone else from the burden of the role (Russell, et al., 1997), or for the sake of continuity. Although the results of the current study did not consistently find that moral commitment has significant associations with psychological well-being outcomes, some significant relationships could be identified. This further supports previous literature that moral commitment can be an important factor in caregiving dyad interactions (Piercy, 2007).

Structural commitment is external to the individual, and it creates an ultimatum or a message that there is no other alternative or a sense that there are no other possible arrangements that will meet the needs of the care-receiver than the current arrangement. This concept was applied to the caregiver/care-receiver relationship in the current study. Of the three types, structural commitment, the sense of obligation to stay in a relationship regardless of personal or moral commitment (Johnson, et al., 1999), had the weakest linkages to psychological well-being for both care-receivers and caregivers. In regard to structural commitment, no significant correlations were found in the dyad analysis, no associations with psychological well-being variables for individual care-receivers, and only a small significant correlation was found with dyad positive interactions for

caregivers. This aspect of commitment and how it might apply to a caregiver/care-receiver relationship had not yet been investigated and the current study would not support further investigation. This finding was somewhat surprising because structural commitment seemed to address the frequent circumstance that limited financial resources can present to many caregivers and care-receivers. There is a possibility that that structural commitment is only a factor for caregivers and care-receivers when other types of commitment are controlled for. It is also possible; however, that the way this phenomenon was measured in the current study was not an accurate way to portray structural commitment and that alternative ways to do so should be explored.

Engagement in a role as caregiver or care-receiver was another essential component of the current study. The importance of care-receiver and caregiver roles has been established in the literature (Cox, Green, Hobart, Jang, & Seo, 2007; Montgomery & Kosloski, 2000; Russell, et al., 1997). The current study posited that it is important to examine roles unique to caregiving for an older adult and being an elder care-receiver since they are within the caregiving dyad relationship and they are very different from other dyad relationships. Role expectations in terms of unique aspects of role performance within the caregiving dyad have been examined and associated with the well-being of the care-receiver and caregiver (Izal, et al., 2005; Lyons, et al., 2002; Synder, 2000). Results of the current study re-affirm these findings but also establish that there may be important implications of how these roles are perceived to be performed by the other dyad member for care-giver and/or care-receiver member well-being.

Measuring and examining caregivers and care-receivers as dyad units was another important aspect of the current study. In addition to examining how relationship components may impact an individual, this study examined dual perspectives to provide a more in-depth approach towards a social system that traditionally uses only the individual as the unit of analysis. Compared to dyad research of other relationship types, little is known about how giving and receiving care impacts outcomes of both dyad members (Reinardy, et al., 1999). In pursuit of the accurate comprehension of dyadic interactions, the current study examines outcomes relevant to both members of the dyad. Based on the results of the dyad analysis, some evidence exists that it is possible that more can be understood about these complex relationships if the dyad is pursued as the unit of analysis.

Implications for Practice and Policy

In gerontological social work research, the community-based setting and family caregiving have been identified as relevant areas of further investigation (Burnette, et al., 2003). This study focuses on a population pertinent to these areas. There is a limited understanding in contemporary social services about the specific elements that sustain healthy care dyad relationships between elders and their adult child caregivers. Social workers are well-positioned to create interventions that adequately support elder care-receivers and their informal caregivers to prevent unnecessary poor mental and physical health outcomes and premature institutional placement.

Social workers are charged with helping to improve the lives of vulnerable people. The current study targeted HCBS clients who by definition are low income, chronically

ill older adults. These older adults are at considerable risk to suffer in the face of health and independent living challenges when they are compared within their generational cohort. Elders who receive care from others to maintain daily life are more vulnerable than those who are independent in the community (Dent, 1999; Gallo, et al., 2003). Although findings are not comprehensively generalizable to the general population of older adults with chronic illness living in the community setting, this narrow focus on a vulnerable population does provide some insights that are potentially unique to this group. Therefore, the findings of this study could inform practice of social workers who work with this population. There is a potential need to address the unique aspects of commitment and the caregiver and care-receiver roles when they are assessing the needs and planning interventions that are targeted to improve psychological well-being outcomes for caregivers and older care-receivers.

This research also recognizes the important but rarely acknowledged contributions of older adults as care-receivers and partners in the care process (Cox, Green, Hobart, Jang, & Seo, 2007). An approach towards the care dyad in this study promotes strengths-based conceptualization of the care process. The findings of this study further the support for creating a positive shift away from the deficit and burden based caregiving paradigm (Chapin, Nelson-Becker, & MacMillan, 2006). Assessments and interventions that address the care-receiver role and potential impact of the care-receiver's contributions in their own care for both members of the dyad could have many positive effects for caregivers and care-receivers. Additionally, in consideration of the point that the caregiver's perspective of how well their older care-receiving parent

engages in their role is related to psychological well-being outcomes; addressing caregiver expectations for care-receivers would be an appropriate focus for assessments and interventions.

The current study is highly relevant at a time when resources for older adults are predicted to be limited. There are clearly very few options for older adults with limited financial resources for affordable out-of-home care or in-home support outside their family support. This has serious implications for areas of health and social services that address the needs of older adults living at home (Fortinsky, Fenster, & Judge, 2004). Trends in longer life expectancy and in-home residence place significant demands on informal caregivers. Thus, finding policy and practice strategies to bolster informal caregivers and elder care-receivers could play a role in improving the country's long-term system of care. Although the study findings could not contribute to a comprehensive policy initiative directed at caregiving dyads, it would support the idea of addressing needs of caregivers and care-receivers as a unit. It could be relayed to policy makers that the needs and interactions between dyad members are related and therefore adequate support of one member can have an impact on the other member.

Limitations

The current study entails several limitations that must be considered in the interpretation of findings. Maintaining consistent conditions for the completion of questionnaires for older adults was difficult due to the variation of eyesight and dexterity among those participants. The plan to obtain a larger sample size of dyads consisting of cognitively competent, chronically older adults living with and receiving care from their

cohabitating children proved to be an extremely challenging task. This had to do with the limited number of these older adults identified, paired with the very limited direct access I had to the targeted population to properly screen and invite. Therefore a relatively small sample size limited the sophistication of analysis possible to explore the research questions posed in the study.

The sampling strategy targeted the entire population as opposed to a random sample. Due to limited control over the screening and notification process within each agency, it is difficult to confirm if all case managers followed the protocol correctly and that all potential eligible clients were invited to participate. Therefore, it is difficult to say whether or not the sample was representative of all eligible clients. This sampling frame did not include older adults who are in very similar care arrangements but by choice are not currently clients of the SEP agencies and additional agencies included. Although participants were asked to respond openly to how finances are shared in their household, two important financial circumstances that could have influenced dyad interactions were unknown in this study. First, caregivers who were receiving Medicaid waiver payments in exchange for caring for the parent were not distinguished from those who were not receiving funding for providing direct care. Secondly, information about total household income outside of the caregiver and care-receiver income was not requested.

Although efforts were made to include people from diverse racial backgrounds and although a relatively large amount of persons from diverse races participated, all non-English speaking clients were eliminated from eligibility due to lack of resources to

alternative forms of data collection that would allow participation from these groups. This did limit the recruitment process because each agency reported that a considerable portion of their clients only spoke Russian, Spanish or other languages. Therefore the sample did not reflect the racial and ethnic characteristics of the entire SEP population of older adults living with chronic illness and cared for by their family. The commitment measures used in the current study had not been normed on the targeted population. Therefore, even though acceptable to excellent reliabilities among scales were found, the psychometric properties of these measures are complicated and their validity not fully confirmed. Particularly the structural commitment scale was very different from the initial measures simply because the circumstances that face caregiving dyads are so different than any other arrangement.

Future Research Directions

Social science research often examines dyad relationships, such as romantic partnerships, parent to child relationships, and friendships, for the purpose of identifying and measuring the potential impact these relationships have on people's health, mental health and social functioning. The application of dyad research to older care-receivers and their caregivers is less common. The aim of this research was to further our understanding of how commitment and role engagement intersects with the context of a caregiver care-receiver relationships to impact individual outcomes. Considering that commitment has been found to be a salient feature of caregiving, further investigation is needed to see how this feature applies to caregiving relationships. Additionally, it is recommended that further exploration be made into how role engagement transpires for

two very unique roles within caregiving/ care-receiving interdependent relationships. Examining these roles in the context of one phenomenon could provide a more comprehensive understanding of what healthy caregiver/care-receiver partnerships consist of.

The current study contributed to the advancement of using dyad data analysis in caregiving research, although a dyadic approach in this population of caregiving research is still in the early stages. The breadth of what a dyad approach could provide for better understanding of the complex interactions between caregivers and care-receivers, particularly those that consist of older parents and their caregiving children living in close proximity, is still undiscovered. However, the findings of the current study have illuminated a reason to believe that a dyad approach could be productive in such endeavors.

Chapter Summary

This study examined the complex interactions in the care-receiver and caregiver dyad relationship. Important, yet rarely, studied elements of commitment and role engagement were applied to the dyad relationship and insights into how these components relate to caregiving arrangements were examined. Caregiver dyad research is in a very early stage. Thus, findings from this study contribute to an important and growing area of research. Further social work research and subsequent development of relevant policy and interventions that support care-receivers and their caregivers should be a focus in order to support this vulnerable population.

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Appendix A

Recruitment Protocols

Client Letter

Date

Client,

You and your son/daughter (this includes in-laws, grandchildren, your partner's child, etc.) are invited to participate in a study. The purpose of the study is to better understand what it is like to live together and what it is like to help one another. I, Jessica Haxton from the University of Denver, am conducting the study. I am looking for **adults over 64 years old and their son/daughter** who provides the most help to them at home.

I do not yet know your name or information, Long Term Care Options keeps your information private. They put your address on the envelope and mailed this letter to you because you may be a 'good fit' for the study. I would like to explain the study more and see if you'd like to participate. **Please call me at 303-500-2846 if you'd like to learn more about volunteering.** Your LTCO case manager knows about the study so if you feel more comfortable calling them first, that's okay. Calling to ask questions will not obligate you to anything.

Being in this study means you and your son/daughter would complete a one-time only questionnaire that takes about **30-40 minutes**. I would come to your home to give you the questionnaire. You and your son or daughter will each receive a **\$15 gift certificate (\$30 total)** to a local grocery store for being in the study. **You AND your son or daughter must want** to be in the study. Participation will involve answering questions about what it is like be helped by your son or daughter.

The benefits of being involved in this study include an opportunity to contribute to efforts that may improve services for older adults and their families. You may also enjoy the ability to provide information about your own experiences.

Please be assured that participation or non-participation in the study has NO influence on services you receive through Long Term Care Options. In fact, LTCO will not be informed either way unless you tell them yourself.

Call 303-500-2846 if you'd like to learn more about volunteering. Your son or daughter is also welcome to call.

Best Regards,

Jessica Haxton

Jessica Haxton, LCSW
Doctoral Student
Graduate School of Social Work
University of Denver

Email: jhaxton@du.edu
Phone: 303-500-2846

Caregiver Letter

Date

Dear Caregiver,

If you care for your parent and live with (or practically live with) them you are invited to **complete a questionnaire** and receive a **\$15 gift card** to a local grocery store. The questionnaire is available in hard copy or online.

The purpose of the study is to better understand what it is like to live with your parent and what it is like to help one another. I, Jessica Haxton from the University of Denver, am conducting the study. I am looking for **adults over 64 years old and their son/daughter** who provides the most help to them at home.

I do not yet know your name or contact information. **Please contact me at 303-500-2846 or jhaxton@du.edu if you'd like to learn more.**

Your parent may be invited to participate for their own \$15 gift card as well if they are interested and able. The benefits of being involved in this study include an opportunity to contribute to efforts that may improve services for older adults and their families. You may also enjoy sharing information about your own experiences.

Please be assured that participation or non-participation in the study has no influence on any services received by you or your parent. No one will be told if you complete the questionnaire unless you tell them yourself. **Please contact me at 303-500-2846 or jhaxton@du.edu if you are interested in taking the questionnaire.** Thank you.

Best Regards,

Jessica Haxton

Jessica Haxton, LCSW
PhD Candidate
Graduate School of Social Work
University of Denver
Email: jhaxton@du.edu
Phone: 303-500-2846

Appendix B

Callahan Six-item Screener

ID # _____

6-Item Screener

	Maximum error	score	X #	weighted score	
1. What year is it now?	1	_____	_____ x4	=	_____
2. What month is it now?	1	_____	_____ x3	=	_____

MEMORY PHASE

Repeat After Me: John/ Brown/ 42/ West Street/ Bedford

3. About what time is it (within 1 hr)?	1	_____	_____ x3	=	_____
4. Count backwards 20 to 1.	2	_____	_____ x2	=	_____
5. Say the months in reverse order.	2	_____	_____ x2	=	_____
6. Repeat the memory phrase.	5	_____	_____ x4	=	_____

(Score 1 for each incorrect response)

Total = _____

*Maximum error means the maximum number of incorrect responses you would count and record.

Appendix C

Consent Forms

Care-Receiver Consent

An Examination of Caregiving with
Community-Dwelling Older Adults

Informed Consent – Parent/Care-Receiver

You are invited to participate in a study to examine the nature of interpersonal relationships between adult child caregivers and chronically ill older adults during the care process. The study is being conducted at the University of Denver by Jessica Haxton, LCSW Telephone: 303-871-6619, E-mail: jhaxton@du.edu. The results of the study will be used to learn more about your experiences living with your son or daughter in a helping relationship. We hope to use our findings to help people who are experiencing similar circumstances. The project is being supervised by Dr. Jeffrey Jensen, University of Denver, Denver, CO 80208, Telephone: 303-871-2526, E-mail: jjensen@du.edu.

The study will take about 45-60 minutes to complete. Participation will involve responding to a number of questions about what it is like to be helped by the adult child you live with. Your involvement is completely voluntary. Your answers will not be shared with anyone, including your family with whom you reside. LTCO will not be informed of your choice to participate in the study. You may choose not to answer any question during the survey and are free to withdraw from the study at any time. Refusal to answer a question or withdrawal from participation involves no penalty.

The benefits of being involved in this study include an opportunity to contribute to efforts to improve services for older adults and their families. You may also enjoy the ability to provide information about your own experiences. You will receive a \$15 gift certificate to a local grocery food store for compensation for participating in the study. If you would like a copy of the results of the study, the researcher will be happy to provide one for you. Potential risks of being involved include the possibility that thinking about your personal experiences may be upsetting. If this occurs, the researcher will arrange for supportive care from staff or for a referral to a supportive counselor.

Your responses will be identified by code number only and will be kept separate from information that could identify you. This is done to protect the confidentiality of your responses. Only the researcher will have access to your individual data and any reports generated as a result of this study will use only group averages and paraphrased wording. However, should any information contained in this study be the subject of a court order or lawful subpoena, the University of Denver might not be able to avoid compliance with the order or subpoena. Although no questions in this interview address it, we are required by law to tell you that if information is revealed concerning suicide, homicide, or child abuse and neglect, it is required by law that this be reported to the proper authorities.

If you have any concerns or complaints about how you were treated during the interview, please contact Susan Sadler, Chair, Institutional Review Board for the Protection of Human Subjects, at 303-871-3454, or Sylk Sotto-Santiago, Office of Research and Sponsored Programs at 303-871-4052 or write to either at the University of Denver, Office of Research and Sponsored Programs, 2199 S. University Blvd., Denver, CO 80208-2121.

You have been given a copy of this page for your records.

Please sign below if you understand and agree to participate in this study.

I have read and understood the foregoing descriptions of the study called An Examination of Caregiving with Community-Dwelling, Chronically Ill Older Adults: Commitment, Role Engagement, and Psychological Well-Being. I have asked for and received a satisfactory explanation of any language that I did not fully understand. I agree to participate in this study, and I understand that I may withdraw my consent at any time without penalty. I have received a copy of the consent form.

Signature

Date

Caregiver Consent

An Examination of Caregiving with Community-Dwelling Older Adults Informed Consent –Caregiver

You are invited to participate in a study to examine the nature of interpersonal relationships between adult child caregivers and chronically ill older adults during the care process. The study is being conducted at the University of Denver by Jessica Haxton, LCSW Telephone: 303-871-6619, E-mail: jhaxton@du.edu. The results of the study will be used to learn more about your experiences living with your parent in a helping relationship. We hope to use our findings to help people who are experiencing similar circumstances. The project is being supervised by Dr. Jeffrey Jensen, University of Denver, Denver, CO 80208, Telephone: 303-871-2526, E-mail: jjenson@du.edu.

The study will take about 45-60 minutes to complete. Participation will involve responding to a number of questions about what it is like to help your parent. Your involvement is completely voluntary. Your answers will not be shared with anyone including your parent who is also participating in the study. LTCO will not be informed of your choice to participate in the study. You may choose not to answer any question during the survey and are free to withdraw from the study at any time. Refusal to answer a question or withdrawal from participation involves no penalty.

The benefits of being involved in this study include an opportunity to contribute to efforts to improve services for older adults and their families. You may also enjoy the ability to provide information about your own experiences. You will receive a \$15 gift certificate to a local grocery food store for compensation for participating in the study. If you would like a copy of the results of the study, the researcher will be happy to provide one for you. Potential risks of being involved include the possibility that thinking about your personal experiences may be upsetting. If this occurs, the researcher will arrange for supportive care from staff or for a referral to a supportive counselor.

Your responses will be identified by code number only and will be kept separate from information that could identify you. This is done to protect the confidentiality of your responses. Only the researcher will have access to your individual data and any reports generated as a result of this study will use only group averages and paraphrased wording. However, should any information contained in this study be the subject of a court order or lawful subpoena, the University of Denver might not be able to avoid compliance with the order or subpoena. Although no questions in this interview address it, we are required by law to tell you that if information is revealed concerning suicide, homicide, or child abuse and neglect, it is required by law that this be reported to the proper authorities.

If you have any concerns or complaints about how you were treated during the interview, please contact Susan Sadler, Chair, Institutional Review Board for the Protection of Human Subjects, at 303-871-3454, or Sylk Sotto-Santiago, Office of Research and Sponsored Programs at 303-871-4052 or write to either at the University of Denver, Office of Research and Sponsored Programs, 2199 S. University Blvd., Denver, CO 80208-2121. You have been given a copy of this page for your records.

Please sign below if you understand and agree to participate in this study.

I have read and understood the foregoing descriptions of the study called An Examination of Caregiving with Community-Dwelling, Chronically Ill Older Adults: Commitment, Role Engagement, and Psychological Well-Being. I have asked for and received a satisfactory explanation of any language that I did not fully understand. I agree to participate in this study, and I understand that I may withdraw my consent at any time without penalty. I have received a copy of the consent form.

Signature

Date

Appendix D

Instrument Construct, Scale, and Item Table

Construct, Scale, and Item Table

Construct	Scale (item numbers)	Item
Role Engagement	CRES 5-point likert scale: Strongly Agree-Strongly Disagree (1-5, relational coping; 6-10, self-care performance)	I make every effort to know about my caregiver's (parent's) needs and problems.
		I often provide emotional support for my caregiver (parent).
		I often tell my caregiver (parent) that I love or care about him or her.
		My caregiver (parent) and I are good friends.
		I try to fit my needs into my caregiver's (parent's) schedule
		I am very involved in any planning that is made for myself (my parent).
		I frequently make care decisions that my (parent's) professional caregivers agree to follow.
		I have learned about the knowledge and skills that various health professionals have and can offer to my (parent's) situation.
		I find out as much as possible about the medical conditions that my caregiver (parent) has.
		I often give my doctor information about my situation that helps her or him make decisions about my (parent's) care.
Role Engagement	Competence 4-point scale: Not at all, Just a little, Somewhat, Very much (11-14)	Below are some thoughts and feelings that people sometimes have about themselves as a person facing illness and disability. How much does each statement below describe your (parent)? How much does your caregiver (parent):
		Believe that they've learned how to deal with a very difficult situation.
		Feel that all in all, they're a good caregiver (care-receiver).
		Think now of all these things: the daily ups and downs that your parent (caregiver) faces as the one who needs care; assisting you in their care; and the ways she/he deals with the difficulties. Putting all these things together:
		How competent do you think _____ is at giving (receiving) help? How self-confident is she/he in assisting with care?

Commitment	Personal 5-point likert scale: Strongly Agree-Strongly Disagree (15-17, 19)	<i>“Please indicate your level of agreement with the following statements.”</i>
		Being someone who can accept (give) help makes you feel good about yourself.
		You really like being someone who can accept (give) care.
		Being a good care receiver for _____ is one of my highest priorities in life. <i>(If you chose to get out of this caregiving arrangement) You would miss the sense of being a team.</i>
Commitment	Moral 5-point likert scale: Strongly Agree-Strongly Disagree (18, 20-27)	<i>“If you chose to get out of this caregiving arrangement”</i>
		When an older parent needs care, one is morally bound to accept (provide) that care from their children (parent).
		You would be disappointed in yourself because you had broken a promise.
		Whenever you promise to do something, you should see it through.
		You feel that you should always finish what you start.
		Even when things get hard, you should do the things you have promised to do.
		My religious beliefs would tell me it was wrong.
		You would feel bad about making other arrangements for the caregiving because you promised that you would let them stay with you.
		You could never leave this living arrangement because he/she needs you too much.
You could never leave this living arrangement because you would feel guilty about making her/him feel badly.		
Commitment	Structural 5-point likert scale: Strongly Agree-Strongly Disagree (28-38)	You would miss important income, insurance, or other property.
		You would miss just having somebody around.
		You would miss living in this house/home/apartment.
		You would miss seeing the other people you encounter regularly because of this arrangement.
		You would miss the help you get around the house.
		You would be upset because your other family members would be uncomfortable with your decision to end the caregiving arrangements.
		You would be upset because you would lose some respect from friends.
		It would be difficult to face your friends and family after you decided to end the caregiving arrangements.
		It would be hard for you to find a new place to live.
Having to move your things would be a burden.		
Dealing with the move to a long term care home would be difficult.		
Psychological Well-Being (CESD)	Depression (39-54) 4-point likert scale: Rarely or none of the time, Some of a little of the time, Occasionally	<i>“Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.”</i>
		I was bothered by things that usually don't bother me.

	or a moderate amount of the time, Most or all of the time	I did not feel like eating; my appetite was poor.
		I felt that I could not shake off the blues even with help from my family or friends.
		I felt I was just as good as other people.
		I had trouble keeping my mind on what I was doing.
		I felt depressed.
		I felt that everything I did was an effort.
		I felt hopeful about the future.
		I thought my life had been a failure.
		I felt fearful.
Psychological Well-Being (Ryff Scale)	Autonomy (59-61)	I am not afraid to voice my opinions even when they are in opposition to the opinions of most people
		My decisions are not usually influenced by what everyone else is doing
		I have confidence in my opinions even if they are contrary to the general consensus
		Being happy with myself is more important than having others approve of me
		I tend to worry what other people think of me
		I often change my mind about decisions if my friends and family disagree
		It is difficult for me to voice my own opinions on controversial matters
	Environmental Mastery (62-68)	I am quite good at managing the many responsibilities of my daily life
		I generally do a good job of taking care of my personal finances and affairs
		I am good at juggling my time so that I can fit everything in that needs to be done
		I have been able to build a home and a lifestyle for myself that is much to my liking
		I do not fit very well with the people and the community around me
		I often feel overwhelmed by my responsibilities
		I have difficulty arranging my life in a way that is satisfying to me
	Personal Growth (69-75) (Caregivers only)	I think it is important to have new experiences that challenge how you think about the world
		I have the sense that I have developed a lot as a person over time
		I am not interested in activities that will expand my horizons
		I don't want to try new ways of doing things - my life is fine the way it is
		When I think about it, I haven't really improved much as a person over the years
		I do not enjoy being in new situations that require me to change my old familiar ways of doing things
		There is a truth in the saying that you can't teach an old dog new tricks

	Positive Relationships (76-82) (Caregivers only)	Most people see me as loving and affectionate
		I enjoy personal and mutual conversations with family members or friends
		People would describe me as a giving person, willing to share my time with others
		I know that I can trust my friends and they know that they can trust me
		I often feel lonely because I have few close friends with whom to share my concerns
		I don't have many people who want to listen when I need to talk
		It seems to me that most other people have more friends than I do
	Purpose in Life (82-89) (Caregivers only)	It seems to me that most other people have more friends than I do
		I am an active person in carrying out the plans I set for myself
		I enjoy making plans for the future and working to make them a reality
		I tend to focus on the present, because the future nearly always brings me problems
		My daily activities often seem trivial and unimportant to me
		I don't have a good sense of what it is I am trying to accomplish in life
		I used to set goals for myself, but that now seems a waste of time
Dyad Related Psychological Well-being (DRS)	Dyad Positive Interactions (A-E)	I sometimes feel I have done all there is to do in life
		I felt closer to ____ than I have in a while.
		I learned good things about myself.
		I have more patience than I had in the past.
		I learned good things about ____.
	Dyad Strain (F-G)	I learned nice things about other people.
		Communication between us has improved.
		I felt angry toward ____.
		I felt depressed when I had problems with my relationship with ____.
		I felt resentful.
		I felt strained.
		_____ made too many requests.

Activities of Daily Living Index

Activities I (or my parent) require assistance with:
1. Using the Telephone
2. Walking?
3. Getting in and out of bed or chairs?
4. Getting around outside?
5. Getting to Places Beyond Walking Distance
6. Eating?
7. Doing Housework or Handyman Work
8. Doing Laundry
9. Taking Medications
10. Managing Money(such as keeping track of expenses or paying bills)?
11. Bathing or showering?
12. Dressing?
13. Using the toilet, including getting to the toilet?
14. Grocery Shopping
15. Shopping for personal items (such as toilet items toilet items or medicines)?
16. Doing light housework (like doing dishes)

Please circle the best answer that represents you or fill in the blanks.

1. How old are you? Age: _____ years Year of birth: _____
2. Female or male? Female _____ Male _____
3. What is the highest grade in school that you completed?
4. What kind of work have you done in your life?
5. What is your current partner status (circle one)?
6. What race or ethnicity do you most identify yourself with?
7. How much does this background affect your everyday life?
8. What is your religious affiliation? Please circle all that apply below.
9. On a scale from 1 to 5, to what extent do you consider yourself to be religious?
Not religious__1__ 2__ 3__ 4__ 5__Very religious
10. How long have you been receiving considerable help for _____?
Years_____ and months_____
11. How long have you lived with _____?
12. How many hours each month do you receive care?
13. Please describe all of the ways you exchange financial support to one another.
14. Which category describes your annual income? Please circle one number below.
15. Medical Diagnoses

Please check below how you are related to your caregiver (parent). He/ She is my:

Daughter_____

Son_____

Step-Daughter ___
Step-Son ___
Daughter-in-law ___
Son-in-law ___
Other: _____

Appendix E

Participant Questionnaires

Parent Questionnaire

ID # _____

Part I. Please indicate your level of agreement by putting one check mark for each statement.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. I make every effort to know about my caregiver's needs and problems.					
2. I often provide emotional support for my caregiver.					
3. I often tell my caregiver that I love or care about him or her.					
4. My caregiver and I are good friends.					
5. I try to fit my needs into my caregiver's schedule					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
6. I am very involved in any planning that is made for myself.					
7. I frequently make care decisions that my professional caregivers agree to follow.					
8. I have learned about the knowledge and skills that various health professionals have and can offer to my situation.					
9. I find out as much as possible about the medical conditions that my caregiver has.					
10. I often give my doctor information about my situation that helps her or him make decisions about my care.					

Below are some thoughts and feelings that people sometimes have about themselves as people who care for someone else. How much does each statement below describe your caregiver?

How much does your caregiver:

	Not at all	Just a little	Somewhat	Very Much
11. Believe that they've learned how to deal with a very difficult situation.				
12. Feel that all in all, they're a good caregiver.				

Think now of all these things: the daily ups and downs that your caregiver faces; assisting you in their care; and the ways she/he deals with the difficulties.

Putting all these things together:

	Not at all	Just a little	Fairly	Very
13. How competent do you think _____ is at giving help?				
14. How self-confident is she/he in assisting with you with care?				

<i>Please indicate your level of agreement with the following statements.</i>					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
15. Being someone who can accept help makes you feel good about yourself.					
16. You really like being someone who can accept care.					
17. Being a good care receiver for _____ is one of my highest priorities in life.					
18. When an older parent needs care, one is morally bound to accept that care from their children.					
<i>If you chose to get out of this caregiving arrangement....</i>					
19. You would miss the sense of being a team.					
20. You would be disappointed in yourself because you had broken a promise.					
21. Whenever you promise to do something, you should see it through.					
22. You feel that you should always finish what you start.					
23. Even when things get hard, you should do the things you have promised to do.					
24. My religious beliefs would tell me it was wrong.					
<i>If you chose to get out of this caregiving arrangement....</i>					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
25. You would feel bad about making other arrangements for the caregiving because you promised that you would let them stay with you.					
26. You could never leave this living arrangement because he/she needs you too much.					
27. You could never leave this living arrangement because you would feel guilty about making her/him feel badly.					
<i>If you and your caregiver were to change this living arrangement....</i>					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
28. You would miss important income, insurance, or other property.					
29. You would miss just having somebody around.					
30. You would miss living in this house/home/apartment.					
31. You would miss seeing the other people you encounter regularly because of this arrangement.					
32. You would miss the help you get around the house.					
<i>If you chose to get out of this caregiving arrangement....</i>					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
33. You would be upset because your other family members would be uncomfortable with your decision to end the caregiving arrangements.					
34. You would be upset because you would lose some respect from friends.					
35. It would be difficult to face your friends and family after you decided to end the caregiving arrangements.					
36. It would be hard for you to find a new place to live.					
37. Having to move your things would be a burden.					
38. Dealing with the move to a long term care home would be difficult.					

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during **the past week**.

	Rarely or none of the time	Some or a little of the time	Occasionally or a moderate amount of time	Most or all of the time		
39. I was bothered by things that usually don't bother me.						
40. I did not feel like eating; my appetite was poor.						
41. I felt that I could not shake off the blues even with help from my family or friends.						
42. I felt I was just as good as other people.						
43. I had trouble keeping my mind on what I was doing.						
44. I felt depressed.						
45. I felt that everything I did was an effort.						
46. I felt hopeful about the future.						
47. I thought my life had been a failure.						
48. I felt fearful.						
49. My sleep was restless.						
50. I was happy.						
51. I talked less than usual.						
52. I felt lonely.						
53. People were unfriendly.						
54. I enjoyed life.						
Please circle one number per row:	Strongly Disagree					Strongly Agree
55. I am not afraid to voice my opinions even when they are in opposition to the opinions of most people	1	2	3	4	5	6
56. My decisions are not usually influenced by what everyone else is doing	1	2	3	4	5	6
57. I have confidence in my opinions even if they are contrary to the general consensus	1	2	3	4	5	6
58. Being happy with myself is more important than having others approve of me	1	2	3	4	5	6
59. I tend to worry what other people think of me	1	2	3	4	5	6
	Strongly Disagree					Strongly Agree
60. I often change my mind about decisions if my friends and family disagree	1	2	3	4	5	6
61. It is difficult for me to voice my own opinions on controversial matters	1	2	3	4	5	6
62. I am quite good at managing the many responsibilities of my daily life	1	2	3	4	5	6
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65. I have been able to build a home and a lifestyle for myself that is much to my liking	1	2	3	4	5	6
66. I do not fit very well with the people and the community around me	1	2	3	4	5	6
	Strongly					Strongly

	Disagree					Agree
67. I often feel overwhelmed by my responsibilities	1	2	3	4	5	6
68. I have difficulty arranging my life in a way that is satisfying to me	1	2	3	4	5	6
69. I think it is important to have new experiences that challenge how you think about the world	1	2	3	4	5	6
70. I have the sense that I have developed a lot as a person over time	1	2	3	4	5	6
71. I am not interested in activities that will expand my horizons	1	2	3	4	5	6
72. I don't want to try new ways of doing things - my life is fine the way it is	1	2	3	4	5	6
73. When I think about it, I haven't really improved much as a person over the years	1	2	3	4	5	6
	Strongly Disagree					Strongly Agree
74. I do not enjoy being in new situations that require me to change my old familiar ways of doing things	1	2	3	4	5	6
75. There is a truth in the saying that you can't teach an old dog new tricks	1	2	3	4	5	6
76. Most people see me as loving and affectionate	1	2	3	4	5	6
77. I enjoy personal and mutual conversations with family members or friends	1	2	3	4	5	6
	Strongly Disagree					Strongly Agree
78. People would describe me as a giving person, willing to share my time with others	1	2	3	4	5	6
79. I know that I can trust my friends and they know that they can trust me	1	2	3	4	5	6
80. I often feel lonely because I have few close friends with whom to share my concerns	1	2	3	4	5	6
81. I don't have many people who want to listen when I need to talk	1	2	3	4	5	6
82. It seems to me that most other people have more friends than I do	1	2	3	4	5	6
83. I am an active person in carrying out the plans I set for myself	1	2	3	4	5	6
84. I enjoy making plans for the future and working to make them a reality	1	2	3	4	5	6
85. I tend to focus on the present, because the future nearly always brings me problems	1	2	3	4	5	6

	Strongly Disagree					Strongly Agree
86. My daily activities often seem trivial and unimportant to me	1	2	3	4	5	6
87. I don't have a good sense of what it is I am trying to accomplish in life	1	2	3	4	5	6
88. I used to set goals for myself, but that now seems a waste of time	1	2	3	4	5	6
89. I sometimes feel I have done all there is to do in life	1	2	3	4	5	6
90. I have made some mistakes in the past, but feel that all in all everything has worked out for the best	1	2	3	4	5	6
91. The past had its ups and downs, but in general I wouldn't want to change it	1	2	3	4	5	6
	Strongly Disagree					Strongly Agree
92. When I compare myself with friends and acquaintances, it makes me feel good about who I am	1	2	3	4	5	6
93. In general, I feel confident and positive about myself	1	2	3	4	5	6
94. I feel that many of the people I know have got more out of life than I have	1	2	3	4	5	6
95. In many ways, I feel disappointed about my achievements in life	1	2	3	4	5	6
96. My attitude about myself is probably not as positive as most people feel about themselves	1	2	3	4	5	6

Please indicate your level of agreement with the following statements about your caregiver.

Because of my health condition....

	Strongly Disagree			Strongly Agree
A. I felt closer to ____ than I have in a while.	1	2	3	4
B. I learned good things about myself.	1	2	3	4
C. I have more patience than I had in the past.	1	2	3	4
D. I learned good things about ____.	1	2	3	4
E. I learned nice things about other people.	1	2	3	4
F. Communication between us has improved.	1	2	3	4
G. I felt angry toward ____.	1	2	3	4
H. I felt depressed when I had problems with my relationship with ____.	1	2	3	4
I. I felt resentful.	1	2	3	4
J. I felt strained.	1	2	3	4
K. ____ made too many requests.	1	2	3	4

Part II. Important Information

Please put a check in the box that most applies to your situation for each activity:

Activities I require assistance with:	Need No Help	Need Some Help	Unable to Do At All
1. Using the Telephone			
2. Walking?			
3. Getting in and out of bed or chairs?			
4. Getting around outside?			
5. Getting to Places Beyond Walking Distance			
6. Eating?			
7. Doing Housework or Handyman Work			
8. Doing Laundry			
9. Taking Medications			
10. Managing Money(such as keeping track of expenses or paying bills)?			
11. Bathing or showering?			
12. Dressing?			
13. Using the toilet, including getting to the toilet?			
14. Grocery Shopping			
15. Shopping for personal items (such as toilet items toilet items or medicines)?			
16. Doing light housework (like doing dishes)			

Please circle the best answer that represents you or fill in the blanks.

1. How old are you? Age: _____ years Year of birth: _____
2. Female or male? Female _____ Male _____
3. What is the highest grade in school that you completed?

- Completed 6th grade or less 1
- Junior high school(7th-9th grade)2
- Partial high school (10th-11th grade) 3
- High school graduate or GED 4
- Partial college training 5
- Completed college..... 6
- Graduate professional training 7
- Other_____ 8

4. What kind of work have you done in your life?
5. What is your current partner status (circle one)?

- Married 1
- Widowed..... 2
- Divorced 3
- Separated 4
- Never married..... 5
- Partnered..... 6

6. What race or ethnicity do you most identify yourself with?

__African American, __Latino/a, __White (non-Hispanic),__Indian, __Native American, __other:_____

7. How much does this background affect your everyday life?

- Not at all 0
- A little 1
- Some 2
- Quite a bit 3
- A great deal 4

8. What is your religious affiliation? Please circle all that apply below.

- Baptist 1
- Buddhist 2
- Catholic 3
- Episcopalian 4
- Holiness..... 5
- Jewish 6
- Lutheran 7
- Methodist 8
- Mormon 9
- Muslim 10
- Non-Denominational 11
- Pentecostal..... 12
- Presbyterian 13
- Protestant 14
- Unitarian Universalist 15
- Do not have any affiliation 16
- Other 17
- If other, write in _____

9. On a scale from 1 to 5, to what extent do you consider yourself to be religious?

Not religious__1 2 3 4 5__Very religious

10. How long have you been receiving considerable help for _____?
Years_____ and months_____

11. How long have you lived with _____?

12. How many hours each month do you receive care?
13. Please describe all of the ways you exchange financial support to one another.
14. Which category describes your annual income? Please circle one number below.
- | | |
|--------------------------|----|
| \$1-\$2,499 | 1 |
| \$2,500-\$4,999 | 2 |
| \$5,000-\$9,999 | 3 |
| \$10,000-\$14,999 | 4 |
| \$15,000-\$19,999 | 5 |
| \$20,000-\$24,999 | 6 |
| \$25,000-\$29,999 | 7 |
| \$30,000-\$34,999 | 8 |
| \$35,000-\$39,999 | 9 |
| \$40,000-\$44,999 | 10 |
| \$45,000-\$49,999 | 11 |
| \$50,000-\$74,999 | 12 |
| \$75,000-\$99,999 | 13 |
| \$100,000 and more | 14 |

Please check below how you are related to your caregiver.

He/ She is my:

Daughter

Son

Step-Daughter

Step-Son

Daughter-in-law

Son-in-law

Other: _____

Caregiver Questionnaire

Caregiver Questionnaire

ID # _____C

Part I. Please indicate your level of agreement by putting one check mark for each statement.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. I make every effort to know about my parent's needs and problems.					
2. I often provide emotional support for my parent.					
3. I often tell my parent that I love or care about him or her.					
4. My parent and I are good friends.					
5. I try to fit my needs into my parent's schedule					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
6. I am very involved in any planning that is made for my parent.					
7. I frequently make care decisions that my parent's professional caregivers agree to follow.					
8. I have learned about the knowledge and skills that various health professionals have and can offer to my situation.					
9. I find out as much as possible about the medical conditions that my parent has.					
10. I often give my parent's doctor information about their situation that helps her or him make decisions about my parent's care.					

Below are some thoughts and feelings that people sometimes have about themselves as a person facing illness and disability. How much does each statement below describe your parent?

How much does your parent:

	Not at all	Just a little	Somewhat	Very Much
11. Believe that they've learned how to deal with a very difficult situation.				
12. Feel that all in all, they're a good care receiver.				

Think now of all these things: the daily ups and downs that your parent faces as the one who needs care; assisting you in their care; and the ways she/he deals with the difficulties.

Putting all these things together:

	Not at all	Just a little	Fairly	Very
13. How competent do you think _____ is in helping with their own care?				
14. How self-confident is she/he in assisting with their own care?				

<i>Please indicate your level of agreement with the following statements.</i>					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
15. Being _____'s caregiver helps you feel good about yourself.					
16. You really like being a caregiver.					
17. Being a good caregiver to _____ is one of my highest priorities in life.					
18. When an older parent needs care, one is morally bound to provide that care.					
<i>If you chose to get out of this caregiving arrangement....</i>					
19. You would miss the sense of being a team.					
20. You would be disappointed in yourself because you had broken a promise.					
21. Whenever you promise to do something, you should see it through.					
22. You feel that you should always finish what you start.					
23. Even when things get hard, you should do the things you have promised to do.					
24. My religious beliefs would tell me it was wrong.					
<i>If you chose to get out of this caregiving arrangement....</i>					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
25. You would feel bad about making other arrangements for the caregiving because you promised that you would let them stay with you.					
26. You could never leave this living arrangement because he/she needs you too much.					
27. You could never leave this living arrangement because you would feel guilty about making her/him feel badly.					
<i>If you and your parent were to change this living arrangement....</i>					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
28. You would miss important income, insurance, or other property.					
29. You would miss just having somebody around.					
30. You would miss living in this house/home/apartment.					
31. You would miss seeing the other people you encounter regularly because of this arrangement.					
32. You would miss the help you get around the house.					
<i>If you chose to get out of this caregiving arrangement....</i>					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
33. You would be upset because your other family members would be uncomfortable with your decision to end the caregiving arrangements.					
34. You would be upset because you would lose some respect from friends.					
35. It would be difficult to face your friends and family after you decided to end the caregiving arrangements.					
36. It would be hard for you to find a new place to live.					
37. Having to move your things would be a burden.					
38. Dealing with the move to a long term care home would be difficult.					

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during **the past week**.

	Rarely or none of the time	Some or a little of the time	Occasionally or a moderate amount of time	Most or all of the time
39. I was bothered by things that usually don't bother me.				
40. I did not feel like eating; my appetite was poor.				
41. I felt that I could not shake off the blues even with help from my family or friends.				
42. I felt I was just as good as other people.				
43. I had trouble keeping my mind on what I was doing.				
44. I felt depressed.				
45. I felt that everything I did was an effort.				
46. I felt hopeful about the future.				
47. I thought my life had been a failure.				
48. I felt fearful.				
49. My sleep was restless.				
50. I was happy.				
51. I talked less than usual.				
52. I felt lonely.				
53. People were unfriendly.				
54. I enjoyed life.				

Please circle one number per row:	Strongly Disagree					Strongly Agree
55. I am not afraid to voice my opinions even when they are in opposition to the opinions of most people	1	2	3	4	5	6
56. My decisions are not usually influenced by what everyone else is doing	1	2	3	4	5	6
57. I have confidence in my opinions even if they are contrary to the general consensus	1	2	3	4	5	6
58. Being happy with myself is more important than having others approve of me	1	2	3	4	5	6
59. I tend to worry what other people think of me	1	2	3	4	5	6
	Strongly Disagree					Strongly Agree
60. I often change my mind about decisions if my friends and family disagree	1	2	3	4	5	6
61. It is difficult for me to voice my own opinions on controversial matters	1	2	3	4	5	6
62. I am quite good at managing the many responsibilities of my daily life	1	2	3	4	5	6
63. I generally do a good job of taking care of my personal finances and affairs	1	2	3	4	5	6
64. I am good at juggling my time so that I	1	2	3	4	5	6

can fit everything in that needs to be done						
65. I have been able to build a home and a lifestyle for myself that is much to my liking	1	2	3	4	5	6
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Please indicate your level of agreement with the following statements about your parent. Because of my parent's health condition....

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N. I have more patience than I had in the past.	1	2	3	4
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R. I felt angry toward ____.	1	2	3	4
S. I felt depressed when I had problems with my relationship with ____.	1	2	3	4
T. I felt resentful.	1	2	3	4
U. I felt strained.	1	2	3	4
V. ____ made too many requests.	1	2	3	4

Part II. Important Information

Please put a check in the box that most applies to your parent's situation for each activity:

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A little 1
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8. What is your religious affiliation? Please circle all that apply below.

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Buddhist 2
Catholic 3
Episcopalian 4
Holiness..... 5
Jewish 6
Lutheran 7
Methodist 8
Mormon 9
Muslim 10
Non-Denominational 11
Pentecostal..... 12
Presbyterian 13
Protestant 14
Unitarian Universalist 15
Do not have any affiliation 16
Other 17
If other, write in _____

9. On a scale from 1 to 5, to what extent do you consider yourself to be religious?

Not religious__1 2 3 4 5__Very religious

10. How long have you been providing considerable help for _____?

Years_____ and months_____

11. How long have you lived with _____?

12. How many hours each month do you receive or provide care?

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14. Which category describes your annual income? Please circle one number below.

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- \$20,000-\$24,999 6
- \$25,000-\$29,999 7
- \$30,000-\$34,999 8
- \$35,000-\$39,999 9
- \$40,000-\$44,999 10
- \$45,000-\$49,999 11
- \$50,000-\$74,999 12
- \$75,000-\$99,999 13
- \$100,000 and more 14

Please check below how you are related to your parent.

I am his/her:

Daughter ___

Son ___

Step-Daughter ___

Step-Son ___

Daughter-in-law ___

Son-in-law ___

Other: _____