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# How Adult Children Experience Parent Dependency in a Caregiving/Care-Receiving Dyad

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2013

Abstract

How Adult Children Experience Parent Dependency

in a Caregiving/Care-Receiving Dyad

by

Anna C. Johnson

MA, Saint Martin's University, 2003

BA, The Evergreen State College, 1999

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Clinical Psychology

Walden University

June 2013

## Abstract

Despite plentiful research on the physical, psychological, and emotional demands on adult child caregivers, there are few studies that highlight developmental issues in the adult child/dependent parent dyad. This study was designed to highlight the dependency factor in this dyad, thus addressing the gap in the literature. With family systems theory, attachment theory, and role conceptualizations constituting the bases for the study, research questions addressed how adult child caregivers experience parental dependency and how dependency affects the caregiving/care-receiving dynamic. Ten volunteer participants were interviewed, and the results were analyzed using a variation of the van Kaam method of data analysis in which themes emerged from qualitative phenomenological data. Results of this study revealed 6 main themes; in descending order of the number of participants endorsing each, the themes were as follows: caregivers did not receive enough help from family/friends ( $n = 10$ ), caregiving evolved on its own ( $n = 8$ ), expectations changed ( $n = 8$ ), roles changed ( $n = 8$ ), dementia caused changes ( $n = 7$ ), and new relationship provided benefits ( $n = 5$ ). The first 2 themes indicated the ways in which adult child caregivers experience parental dependency. The remaining 4 themes illuminated participant-reported changes following the addition of dependency to the adult child/parent dynamic. Findings from this study can influence social change by promoting appropriate support interventions that support the physical and mental health of the caregiver population.



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## Dedication

This study is dedicated to my family and friends who have provided love and support to this endeavor, and to my volunteer participants, whose frankness and generosity of time, energy, and goodwill made this research a reality.

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Many people contributed to the process of this research; without their generous gifts of time, energy, and patience, this study would not have been possible. First, I would like to thank my Dissertation Chairperson, Dr. Lee Stadtlander, for her commitment, guidance, patience, and understanding throughout this process. My other committee member, Dr. Benita Stiles-Smith, provided a deep and sustaining knowledge of the subject matter, as well as her support and kindness. Each of the 10 study participants provided valuable material, and gifts of time, energy, and goodwill. Thank you all so much.

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## Chapter 1: Introduction to the Study

### **Introduction**

The current study provides focused observations, by informal care providers, of the effects of parental dependency on the adult child/parent caregiving/care-receiving dynamic. This phenomenological study also elucidates these experiences through reflective analysis, followed by a comprehensive interpretation of the results. This study will give a voice to adult children experiencing that phenomenon.

The current chapter begins with a brief overview of recent research on the topic at hand and an introduction to the underlying theoretical conceptualizations. A description of the problem statement is followed by an explanation of the nature and purpose of the current study. The research and interview questions are listed, followed by a justification of the theoretical premises necessary for an examination of the phenomenon under study. Statements of the study's overall significance, definitions of key terms, and limitations of the current study are given, followed by a brief summary of issues covered that completes Chapter 1.

### **Background**

There has been an explosion of recent quantitative research (e.g., American Association of Retired Persons [AARP], 2009; Aggarwal, Liao, Christian, & Mosca, 2009; Bailey, Perez, Aft, Liu, Schootman, & Jeffe, 2010; Carek & Barton, 2010; Doubova, Perez-Cuevas, Espinosa-Alarcon, & Flores-Hernandez, 2010; Elliott, Burgio, & DeCoster, 2010; Family Caregiver Alliance [FCA] & National Center on Caregiving [NCC], 2009; Gaugler, 2010; Haley et al., 2010; Nelson, Smith, Martinson, Kind, &

Luepker, 2009; Ostwald, Bernal, Cron, & Godwin, 2009; Peacock et al., 2010; Pressler et al., 2009; Stajduhar et al., 2010; Wilson-Genderson, Pruchno, & Cartwright, 2009) on elements of the caregiving experience. By contrast, qualitative research (e.g., McConigley, Halkett, Lobb, & Nowak, 2010; Montgomery & Kosloski, 2009; Nguyen, 2009; Peacock et al., 2010) that serves to elucidate interpersonal phenomena as they occur during the lives of caregiving/care-receiving dyads is scant.

Qualitative research that specifically examines the effects of care-recipient dependency briefly emerged (Ziemba & Lynch-Sauer, 2005) following a controversy over terminology used to describe a change in the adult child/dependent parent dynamic. Crouch (1987), Brody (1990), and Selzer (1990) came in conflict over use of the term *role reversal* to describe a dramatic change that, according to Crouch, can lead to a complete reversal of the parent/child role. Ziemba and Lynch-Sauer used the term “role reversal” to describe the loss of parental support, combined with expectations of providing support to that parent. Since Ziemba and Lynch-Sauer’s dramatic account of adult children’s experiences with parental dependency, there have been no further studies that qualitatively examine that phenomenon. The current study provides further adult child/participant validation of the existence of role reversal in a caregiving relationship, closing the gap in literature following the study by Ziemba and Lynch-Sauer. A comprehensive review of current literature that has illuminated the effects of dependency on the caregiving/care-receiving relationship follows in Chapter 2.

The current study relied on a basic understanding of the dyadic dynamic that usually begins at the birth of a child and lasts throughout the lifetime of the child/parent

relationship. The child/parent dynamic is viewed in this study as continually evolving in response to changes within and outside itself, eventually becoming a caregiving/care-receiving relationship. A theoretical premise espoused by the current study is the tendency of family dynamics to change naturally over time and through the effects of changes within and outside of the family. That premise was established by an examination of attachment and Bowen's (Bowen, 1978; Bowlby, 1947; Kerr & Bowen, 1988; van Ecke, Chope, & Emmelkamp, 2006) theories, as presented in Chapter 2. The effects of dependency on the adult child/parent dynamic constitute one aspect of inherent changes presumed by both of the aforementioned theories. Van Ecke et al. (2006) used attachment and Bowenian theories to describe changes in the family system following emigration and subsequent relocation of some family members. The current study complements the work by van Ecke et al. by using attachment theory's paradigm of the existence and crucial aspects of the original parent/child attachment bond, as well as Bowenian theory's focus on interpersonal dynamics and their propensity for change. The current study on the adult child/dependent parent dynamic will augment existing literature on the addition of dependency to an established caregiving relationship and literature using both attachment and Bowenian theories to explicate the adult child/parent dynamic.

### **Problem Statement**

Adult children providing caregiving to one or both parents in the United States face physical, mental, emotional, and financial burdens that develop over time and extend beyond their personal resources. Around 30 million "baby boomers" are informal carers

of dependent parents (Tobin, 2009); only a scant amount of recent research has exposed the lived experiences of these vulnerable providers of essential care.

Many recent quantitative (Aggarwal et al., 2009; Bailey et al., 2010; Carek, Norman, & Barton, 2010; Doubova et al., 2010; Elliott et al., 2010; Gaugler, 2010; Godfrey & Warshaw, 2009; Martini & Busseri, 2010; Nelson et al., 2009; Ostwald et al., 2009; Pressler et al., 2009; Stajduhar et al., 2010; Wilson-Genderson et al., 2009) and some recent qualitative studies (Clukey, 2008; Gonyea et al., 2008; Nguyen, 2009; Peacock et al., 2010; Pierce, Steiner, Govoni, Thompson, & Friedemann, 2007) were found that addressed the impact of variables on informal caregivers and the utility of instruments designed to measure them (Nguyen, 2009). For example, a recent study (Andrieu et al., 2007) examined the usefulness of an assessment instrument that measures the effects of varying levels of dependency on informal caregivers. While Andrieu et al.'s study quantitatively illuminated the impact of dependency on a sample of informal carers, the actual experiences that took place within the caregiving dyads remain invisible. Many recent studies provide statistics that show the effects of numerous variables on the caregiving experience, yet research highlighting lived experiences of the affected individuals is scant.

Care-recipient dependency creates the need for caregiving and fosters a deterioration of the physical, emotional, and psychological health of informal caregivers (Carretero, Garces, & Rodenas, 2007). Some recent research addresses the effects of dependency on informal caregivers. For example, Andrieu et al. (2007) acknowledged that the greater the dependency experienced by caregivers, the higher their rates of

reported depression. Similarly, Bailey et al. (2010) demonstrated that having both breast cancer and multiple caregiving roles dramatically increased the risk for depressed mood. Qualitative, phenomenological research on caregivers' day-to-day lived experiences with dependency has enhanced the important findings by Andrieu et al., Bailey et al., and Carretero et al. Empirical, phenomenological research affords a clear, focused view of phenomena underlying lived experiences that is typically absent from quantitative and many qualitative analyses (Moustakas, 1994). Although caregiving research is plentiful, a focus on day-to-day realities of informal caregiving is conspicuously absent from recent literature.

Family caregivers are most often middle-aged women, who could be caring for one or more children or grandchildren while simultaneously performing caregiving duties for a parent (National Alliance for Caregiving [NAC] & AARP, 2009). Individuals caught between caregiving demands from both parents and children may, additionally, be employed outside the home (Keene & Prokos, 2007). Informal caregivers are often burdened with responsibilities that include providing income to their households (Stephens, Franks, Norton, & Atienza, 2009). As informal caregiving is typically an unpaid position, the caregiver herself must depend on employment income and public resources to meet the added expense of providing for a care recipient. At times, the financial stressors of informal caregiving lead to bankruptcy or divert funds set aside for a child's college education (Davenport & Eidelman, 2007). Many women may be unprepared for the magnitude of the responsibility associated with providing full-time care to a dependent individual; furthermore, problems associated with informal care

provision are draining government funds and straining public policies designed to support family caregivers.

Financial stressors of informal care providers are multiplied once a caregiver/care-recipient relationship is established. Once financial, physical, mental, and/or emotional resources of dependent care recipients are depleted due to disability and/or illness, caregivers may provide financial support that could total several thousand dollars per year (Davenport & Eidelman, 2007). Although some public policies allow employed, informal caregivers yearly paid leave, unexpected problems that require absences from work, or voluntary termination of employment, continue to cost U.S. businesses while affecting the employability of working carers. Competition for government resources amid the current U.S. economic crisis creates a conundrum for struggling businesses; similarly, the lack of affordable health care dampens the likelihood that new policies will lift some burden from overworked carers. Whether or not they are otherwise employed, informal caregivers do not appear to be getting the support they need to provide optimal care to loved ones. Research focused on the caregiver/care-recipient relationship provides a basic understanding of specific problems inherent in that relationship, and subsequent solutions. The current study elucidated the effects of dependency as factors in the caregiver/care-recipient relationship by drawing on the lived experiences of those most affected by it—adult child caregivers—and by providing authentic accounts of their experiences. Discussion of the research methodology used in the current study is provided, in detail, in Chapter 3.

A paucity of current research has examined the interpersonal dynamic between a caregiver and a care recipient. Without a clear understanding of the emotional and psychological needs of caregivers, government resources cannot be made available to meet those needs. While informal care providers are saving the U.S. government both money and human resources (Schultz & Sherwood, 2008), carers themselves are becoming physically, emotionally, psychologically, and financially depleted. Most current caregiving research has quantitatively examined the effects of variables such as caregiver burden, leisure time, outside employment, and specific care-recipient illnesses such as heart disease, stroke, cancer, and Alzheimer's dementia (AD) on informal carers. Qualitative studies that highlight the interdyadic experiences of caregivers, that is, how they are affected by the interpersonal dynamics that have evolved during the caregiving relationship, are so few as to compel an examination that comprised the focus of the current study. The dearth of studies on actual caregiver experiences, which may reveal dynamics that are common to other individual carers, renders these lived experiences invisible to potential research interests.

A few studies in current caregiving literature were found that focused on discrete dyadic dynamics. Some research that qualitatively highlighted caregiver/care-recipient experiences was contributed by Maysless, Bartholomew, Henderson, and Trinke (2004); Ziembra and Lynch-Sauer (2005); Brown (2007); Clukey (2008); Montgomery and Kosloski (2009); and McConigley et al. (2010). Older, expository research (Brody, 1990; Crouch, 1987; Hasseltine, 2001; Selzer, 1990; Watson & Mears, 1996) followed a controversy among Crouch (1987), Brody (1990), and Selzer (1990) over the validity of

the term role reversal within the caregiver/care recipient relationship. According to Crouch, emotional themes repeat themselves over generations, manifesting in various ways according to current family dynamics. Crouch's insistence that adult child/parent role reversal can reflect changes from earlier generational dynamics was not qualitatively reexamined and subsequently validated until Ziembra and Lynch-Sauer's research in 2005.

Some research has highlighted different aspects of the adult child/dependent parent dynamic. Interdyadic experiences were examined from the perspective of caregivers by Cicirelli (2006), Clukey (2008), Maysseless et al. (2004), McConigley et al.(2010), Montgomery and Kosloski (2009), and Ziembra and Lynch-Sauer (2005), and from the viewpoint of care recipients in Brown (2007). No recent research was found that focused exclusively on the effects of care-recipient dependency over time. A more thorough examination of caregiving research that addresses aspects of both dependency and dyadic dynamics follows in Chapter 2.

Through the current study that examined the effects of dependency on the adult child/parent caregiving dynamic, individuals most responsible for making policy changes and allocating resources will be exposed to this aspect of the informal caregiving experience. Social change depends on awareness of critical issues, especially those that may negatively affect the most vulnerable individuals among us. Qualitative research provides a platform for those individuals to expose their most pressing needs; changes in policies affecting caregivers, in medical and psychotherapeutic treatment planning, and in future research directions can converge to make positive social changes.

The current study closes the gap in caregiving literature following the qualitative examination by Ziembra and Lynch-Sauer (2005) that addressed caregiver/care-recipient relationships consisting of adult children and their dependent parents. That study examined changes in the adult child/dependent parent dyad as care-recipient dependency increased over time. In the current study, child/parent role reversal emerged as one of six themes reported by more than half of the 10 participants, similar to Ziembra and Lynch-Sauer's results indicating reports of role reversal by half the study's participants.

### **Purpose of the Study**

The purpose of this qualitative, phenomenological study was to describe the phenomenon that results from the addition of dependency to the adult child/dependent parent dynamic within a caregiving/care-receiving relationship. Reflections of experiences with dependency, over time, were gathered from volunteer adult child carers. Highlighting interpersonal dynamics of these vulnerable adult children and their dependent parents could lead to a deeper understanding of an aspect of lived experiences by those in the medical and/or psychological professions. Moreover, adult child caregivers were given a voice in an area that concerns them; the existence of scant opportunities afforded by current studies of caregiver/care-recipient dynamics compelled the current study.

As data for this research were gathered from participants within a small, purposive sample, the results are not generalizable to a larger population. However, as care-recipient dependency is a universal quality of caregiving/care-receiving dyads (Carretero et al., 2007) and dependency is considered quantitatively measurable (Andrieu

et al., 2007), this study provides opportunities for future quantitative research. This study also extended Ziemba and Lynch-Sauer's (2005) examination of the impact of dependency on the adult child/parent caregiving dyad.

### **Research Questions**

The experiences of adult child caregivers with parental dependency were examined through participant responses to the following research questions:

1. How do adult child caregivers experience parental dependency?
2. How does dependency affect the aforementioned caregiver/care-recipient dynamic?

### **Theoretical Foundation**

The focus of the current study was on the interpersonal dynamics of dyads composed of an adult child and a dependent parent over 80 years of age. Dependency is an inherent factor in aging and the concomitant emergence of chronic illnesses that are common to individuals over 80; in fact, the existence of dependency establishes the need for a caregiver (Carretero et al., 2007). Therefore, an examination of the effects of dependency on caregivers was presumed to be a worthwhile topic, the illumination of which could lead to positive social change. Interpersonal dynamics, however, are only discrete entities within theories that proclaim them as such; in order to elucidate the experience of dependency that increases over time in a caregiving relationship, for example, that relationship was examined through lenses previously established by attachment and Bowenian theorists.

The adult child/dependent parent dynamic usually evolves from the attachment bond formed during the infancy of the adult child. In such cases as adoption and step parenting, this evolution may not originate at birth and thus may not apply. According to attachment literature, the original bond is either health promoting or anxiety provoking for the infant and may endure throughout the lifetime of the adult child (Bowlby, 1947). Attachment theory provided a focus on the dyadic relationship; according to van Ecke et al. (2006), the child/parent attachment bond remains throughout the life of an individual and becomes the foundation for future relationships. As the intent of this study was to explore a discrete dynamic rather than relationship functionality, attachment theory must be accompanied by a nonjudgmental paradigm that overshadows the idea that some relationship dynamics are healthy while others are not. Family systems, or Bowen's theory, were used to further the egalitarian assumption that all dyadic relationships are equally significant, thus furthering the goal of contributing to positive social change.

Bowen's theory has been used to examine relationships among individuals through a systemic lens. Bowenian theory parallels the attachment idea that systemic functionality originates at birth; however, no "fault" is assigned to individuals. In this view, family dynamics evolve indefinitely through generations, producing family members at all stages of the health-giving/health-depleting spectrum (Bowen, 1978). According to Bowen's theory, when anxiety between two individuals within a family system becomes overwhelming, triangulation occurs, thus relieving the initial two by adding a third member to the dynamic. A Bowenian emphasis on triangulation was not focused upon in the current study; rather, the dyadic dynamic itself was explored through

attachment theory's focus on the dyad within the multigenerational family system. While the idea of the dyadic dynamic is affirmed by attachment logic, a systemic paradigm supplants the judgmental bias emerging from an attachment lens.

Attachment theory, originating in the mid-1940s, and Bowen's theory, which emerged in 1966, share views on the origin of interpersonal dynamics and beliefs in the endurance of functional aspects of the original dynamics. Attachment theory posits that infants are motivated by survival needs to remain "attached" to a parent; earlier attachment behavior continues through adulthood as a way to maintain safety and security within relationships (van Ecke et al., 2006). According to Bengtsson and Psouni (2008), caregiving represents a reciprocal relationship between a caregiver and a care-recipient; each individual is influenced by mental representations that depict her/his role in the dyad. For example, maternal ideas of caregiving guide role performance within a caregiving dyad (Bengtsson & Psouni). Bowen's theory assumes that interpersonal conflicts motivate dyadic members towards autonomy/separateness, while attachment theory focuses on a universal need for security.

The concept of *role* is used repeatedly in caregiving literature to elucidate the dynamic that applies to caregiving of a dependent parent. As the current study relied on such research to provide a platform for an examination of discrete relationship dynamics, an explanation of the origin of the concept was included in a review of the literature. The idea of *role taking* was introduced by Mead (1934) as a way to explain how one individual is able to take the perspective of another. When one individual manifests signs of helplessness, that condition elicits *caretaking* responses in another individual (Mead,

1934). In a given society, individuals have a common understanding of how specific role taking ought to take place (Biddle, 1986). The concept of role taking, introduced by Mead in 1934, is used liberally in older, and more recent, caregiving literature to describe aspects of the caregiver/care-recipient interpersonal relationship.

### **Theoretical Considerations**

While Bowenian and attachment theories, and role conceptualizations, were utilized in the current study as bases for reviewing pertinent literature and bridging a knowledge gap between studies of the adult child/dependent parent caregiver/care-recipient dynamic, I intended to preserve the research data in its authentic form, free from theory-generated bias. For example, van Ecke et al.'s (2006) research used a combination of attachment and Bowenian theories to analyze specific experiences. The current study aligned with the grounded theory paradigm found in McConigley et al. (2010) in which theory about the phenomenon under study evolved from the data. The literature review includes examinations of the phenomenon of changing dyadic dynamics, suggested by attachment and Bowenian theories that provided background for participant observations that reflected changes to the original child/parent bond. Although the current study did not focus on purely retrospective phenomena, the participants, due to the nature of the research questions, provided some historical insight into their current dyadic dynamic. Any changes in the dyadic dynamics reported by adult child caregivers in the current study were supported by literature presented in Chapter 2 (Benefield & Beck, 2007; Butler, 2008; Campbell, 2009; Clukey, 2008; Cohen & Lee, 2006; Keeling, Dolbin-McNab, Hudgins, & Ford, 2008; Mitrani et al., 2006; Ostwald et al., 2009; van Ecke et

al., 2006). A more thorough discussion of Bowenian and attachment theories' premises and how they pertain to the adult child/dependent parent dynamic is provided in Chapter 2.

### **Nature of the Study**

A qualitative, phenomenological design was chosen to best address the research topic of dependency added to the adult child/parent dyadic dynamic. Following the qualitative tradition, interview questions that reveal participant experiences with a given topic can serve a dual purpose. This research can both give a voice to a vulnerable population of caregivers and reach a target group of medical and psychological professionals. Instrumental social change can, in turn, be brought about by widening needed financial and/or human resource availability for this population.

This study examined the phenomenon of an adult child's experiences with dependency in a caregiving/care-receiving dynamic over 6 months or longer with a parent over 80 years of age. This dynamic, which originates at the birth of the adult child, changes with the addition of the dependency of the care-receiving parent. To determine what changes, if any, took place in the dynamic over time, a series of interview questions were posed to 10 participants and the results were analyzed using Moustakas's (1994) 7-step variation of the van Kaam method of data analysis.

### **Definition of Key Terms**

*Baby boomers*: This term is used to describe "the large cohort of babies born in the 2 decades following World War II . . .who are now in their parent-care years" (Stephens et al., 2009, p. 148).

*Caregiver burden:* A common term in caregiving literature; it refers to factors that deplete caregiver functioning, including time constraints, social constrictions, physical symptoms, family repercussions of taking on the role of caregiver, and emotional disturbances (Razani et al., 2008).

*Dependency:* For the purpose of this study, dependency creates the need for assistance with daily living tasks (Carretero et al., 2007).

*Dyadic dynamics:* Interpersonal reactions to one another within a dyad; dynamics reveal activity in the relationship. For example, informal caregivers of patients with aggressive brain cancer reported changes in the dyadic relationship associated with the care-recipient diagnosis (McConigley et al., 2010).

*Informal caregiver:* An unpaid provider of in-home assistance with daily living tasks (Schulz & Sherwood, 2008; Zhu et al., 2008).

*Role reversal:* Byng-Hall (2008) addressed this concept as it pertains to the abrogation of a parent's role and its subsequent assumption by a thus "parentified" child. Ziemba and Lynch-Sauer (2005) suggested that role reversal can occur between an adult child and his or her dependent parent. According to Maysel et al. (2004), role reversal is associated with unmet attachment needs.

*Sandwiched generation:* The subset of adult children who provide caregiving to both parents and dependent children (Keene & Prokos, 2007).

### **Assumptions**

Bowen's theory assumes that changes occur constantly in dyadic relationships; therefore, that assumption was applied to this study. Attachment theory, on the other

hand, provides descriptions of dyadic dynamics that originate at the birth of the adult child and remain static throughout the life of the relationship. Role conceptualizations provided further basis for the assumptions of changes in dyadic relationships; this assumption is suggested in this study's results showing endorsement of role reversal in the adult child/parent dynamic.

The 10 participants' accounts of experiences with parental dependency over time described changes in the dyadic dynamics. While these qualitative accounts cannot completely validate the presumption that dependency causes changes in existing relationships, this study nonetheless suggests a basis for future quantitative research that may determine a causal relationship between dependency and changes in dyadic dynamics.

Study participants were presumed to provide authentic accounts of their experiences with parental dependency. As telephone interviews were employed for data collection, thus preventing the collection of visual data, it was necessary to adopt the assumption that participants provided accurate data.

### **Scope and Delimitations**

This study's specific focus on dependency in the adult child/parent relationship was chosen in part because of the researcher's background in providing services to families of dependent older adults. The overall problem that inspired the current study was that adult child caregivers were assuming responsibilities that exceeded their capacity to manage them. The current study focused on one aspect of the problem facing adult child caregivers.

While dependency in the adult child/parent dynamic is only one component of this problem of adult child overburden in that dyad, previous studies have pointed out the adverse effects of dependency in a caregiving/care-receiving relationship (Aggarwal et al., 2009; Andrieu et al., 2007; Carretero et al., 2007; Doubova et al., 2010; Gardner & Helmes, 2006; Ziembra & Lynch-Sauer, 2005). The addition of care-recipient dependency to a caregiving dyad, as suggested by previous research, increases the extent to which adult children are assuming responsibilities beyond their capacities to manage them, thus suggesting a need for this study.

As this study's data were preserved in their original form, and the research design and methodology were clearly outlined in Chapter 3, this research could be replicated and used as a model for future studies. In fact, the spirit of phenomenological research lends itself to future explorations by exposing personal accounts of a vulnerable population to public scrutiny. This study's replicability is demonstrated by its methodology, outlined in Chapter 3.

### **Limitations**

As with any qualitative, phenomenological research, sample size in the current study was necessarily small enough to allow for sufficient examination of the data; benefits of a large sample size were sacrificed in favor of closer scrutiny. Therefore, generalizing of results was not possible. As suggested by McConigley et al. (2010), quantitative studies can follow qualitative research to expand topics for further clarification of specific components and to achieve far-reaching results. According to Stajduhar et al. (2010), quantitative research not only affords causal inferences between

variables, but also can expand results over a broad population segment. Once a topic has been identified and highlighted by qualitative research, future studies can explore components of the subject matter quantitatively, generating results that can be generalized to a larger population.

Another limitation to the current study was subjective bias. Each of the participants was chosen by meeting the criteria of having provided caregiving to a dependent parent over 80 years of age for at least 6 months. The interpersonal dynamics of any dyad shift according to an exchange of energy at a given moment, creating a unique balance (Kerr & Bowen, 1988). Therefore, each dyadic member's experience is not only based on the moment-to-moment actions comprising the caregiving/care-receiving roles, but on internal perceptions, or biases, that color the unique experiences.

If objective observation had been used to examine dyadic dynamics in the current study, any subjective bias would have been on the part of the researcher. In that case, however, objective reporting would have entailed either a live-in arrangement with each participant or the unethical invasion and expense of cameras throughout each participant's home, neither of which was possible or desirable. Cicirelli (2006) compared the advantages of using authentic experiences to the limitations inherent in simulated tasks when highlighting dyadic dynamics. In that study, simulated "decision-making" tasks were assigned to dyadic pairs, and the results were qualitatively explored. The current study, in examining subjective data, exchanged the clinical advantage of researcher observations for secondhand reporting of participant-generated responses. Participant responses in the current study were authentic accounts of real-time

experiences; these responses were subsequently examined through qualitative analysis, as an objective examination of the dynamic under study was not possible.

A third limitation to the current study was the geographic confinement of the sample of participants. The purposive study sample was drawn from the population of caregivers participating in support groups within a narrow selection of geographic locations. As I desired to draw participants from as wide a range of geographic locations as possible, requests for permission to post flyers were sent to support group facilitators in several different states. As Since only 10 participant volunteers were desired, the researcher selected states for recruitment that would comprise a horizontal “band” across the country, thus providing richer data than if all participants had resided in the same state. Data from only 10 participants, however, could not be entirely applicable to informal caregiver/care-recipient dyads living elsewhere. Dependency, on the other hand, is a universal characteristic of aging; increased life expectancy and chronic disease prevalence leading to dependency, for example, were noted in Mexican elders by Doubova et al. (2010), and as pertaining to U.S. elders in Talley and Crews (2007). Although participants of the current study were found to be residing in a narrow sample of geographic locations, the results are likely to be universally applicable.

A fourth limitation to the current study concerns purposive sampling. In the interest of obtaining participants who had experienced parental dependency, support groups were utilized as likely sources of volunteer data reflecting that particular type of caregiver vulnerability. As volunteer participants were recruited from online support groups, however, I recognized that this population might bear characteristics not present

in adult child caregivers not attending support groups; therefore, generalizability to the whole population of adult child caregivers was not possible.

### **Significance of the Study**

The current study supplemented existing research on the adult child/dependent parent relationship (e.g., Andrieu et al., 2007; Bengtsson & Psouni, 2008; Carretero et al., 2007; Cicirelli, 2006; Gonyea et al., 2008; Kim, Wellisch, & Spillers, 2008; Marks et al., 2008; Monin & Schulz, 2009; Montgomery & Kosloski, 2009; Nguyen, 2009; Sanders, Ott, Kelber, & Noonan, 2008; Wong & Chau, 2006; Yi & Lin, 2009) and on some effects and manifestations of care-recipient dependency (e.g., Aggarwal et al., 2009; Andrieu et al., 2007; Carretero et al., 2007; Doubova et al., 2010; Gardner & Helmes, 2006; Ziembra & Lynch-Sauer, 2005). Research on the adult child/dependent parent caregiving relationship proved to be much more plentiful than was research on dependency in the adult child/parent dynamic. While the current study augmented caregiving research that focused on the adult child/dependent parent dynamic, the discrete focus of this study on subjective experiences of dependency was its most significant contribution, due to the paucity of research on that topic.

The goal of this research was to expose participant experiences with care-recipient dependency to scrutiny by medical and psychological professionals, and to close a significant gap in literature on the effects of dependency on the adult child/parent caregiving dyad. It is only through direct exposure that public policy changes can occur; this research, then, will increase the likelihood that financial and/or human resources will be allocated to this vulnerable population of adult child caregivers

## Summary

In summary, Chapter 1 began with a brief introduction to the current study, then provided background to the exploration of the topic and stated the problem to be addressed, as well as the purpose of the study. Then research questions were introduced, followed by a description of the theoretical framework grounding the study. Further theoretical considerations were put forth, and the nature of the study was discussed. Key terms were defined and assumptions were discussed, followed by the scope and delimitations of the current study. Then limitations of this study were discussed, followed by the study's significance and ending with a concise summary of this chapter. Chapter 2 presents and discusses literature that provided background material and that best described the phenomenon of care-recipient dependency. Chapter 2 also discusses the origins of attachment and Bowen theories, and of role conceptualizations. Chapter 3 outlines research methodology and describes research participants and method of recruitment, ethical considerations, research design, and data analysis. Chapter 4 presents the results of the current study, and Chapter 5 discusses the results and the application of this research to social change factors and implications for future research.

## Chapter 2: Literature Review

### **Introduction**

While numerous recent studies have explored the effects of variables on one or both members of the adult child/dependent parent dyad, no recent research was found that addressed the question of whether the interdyadic dynamic itself changes over time, with or without the addition of dependency to the dyad. This study examined an aspect of the adult child/dependent parent dyad through a focus on the possibility of a dynamic change associated with increasing dependency of the parent. Adult child caregivers are usually unpaid for this work and thus represent a vulnerable population that needs representative voices to reveal specific aspects of difficulties inherent in the caregiving experience.

The purpose of the current study is to close a significant gap in caregiving literature. Since 2005, when Ziembra and Lynch-Sauer qualitatively explored the effects of care-recipient dependency on adult child caregivers, there have been no intervening studies that served to reveal experiences of adult children with that dynamic. This study may also result in policy changes that would allow these individuals to receive needed money and/or other resources that have been depleted during their time spent caregiving. This study served a dual purpose—to close a gap in caregiving literature and to allow vulnerable adult child caregivers a voice in literature that concerns them.

This chapter will provide, first, a brief review of literature that serves to establish the relevance of this particular study. Then, a review of the search engines and keywords used to search specific databases for current and seminal literature is provided. Next, the theoretical foundation is given that grounds this study, along with a historical review of

research that has explicated both attachment and Bowen's theory and that has utilized the theories, together or separately, as bases for other pertinent research. Next, a history of the phenomenon of the adult child/ parent dynamic is provided, followed by a brief review of other pertinent research on this topic.

### **Caregiving Demographics**

Recent statistics for informal caregiving in the United States are plentiful and reflect a substantial demographic. Around 30 million individuals of the "baby boomer" generation provide caregiving to a dependent parent (Tobin, 2009, p. 69). Twenty-nine percent of individuals living in the United States are informal care providers, or 31% of U.S. households (AARP, 2009). Most caregivers are employed, middle-aged women providing unpaid care to dependent mothers (FCA, 2009). Around one-third of family caregivers are 65 years of age and older (Godfrey & Warshaw, 2009). According to these statistics, most informal caregiving in the United States is provided by women between approximately 45-65 years of age who combine outside employment with caregiving responsibilities.

The length of time informal caregivers can expect to provide service to care recipients is steadily expanding. Individuals in the United States are living longer; prior to the emergence of antibiotics, average life expectancy was around 45 years (Talley & Crews, 2007). With advancements in medicine and medical technology, life expectancy has increased dramatically, and most individuals now die from complications of chronic illnesses (Talley & Crews). Average life expectancy for individuals in the United States increased more than 30 years from 1900-2005, more than 5 years from 1980-2005, and

over 2 years from 1990-2005 (U.S. Department of Health and Human Services, 2010). In July 2009, the U.S. Census Bureau estimated that close to 40,000,000 individuals were over 65, with over 5,500,000 being 85 or over. More individuals are reaching *oldest-old* in the United States than any other age group (Benefield & Beck, 2007). Concomitant with the growing number of older adults in the United States is the need for informal care.

Informal caregivers are becoming an increasingly important commodity in the United States. With average life expectancy nearing 80 years of age and a current shortage of health care employees, informal caregiving is gaining momentum as a significant community resource (Talley & Crews, 2007). Most individuals with chronic illnesses such as dementia are cared for by informal caregivers (Montgomery & Kosloski, 2009). For example, over 5 million individuals living in the United States have AD (Montgomery & Kosloski, p. 424); approximately 80% of those individuals have caregivers who are family members (Etters, Goodall, & Harrison, 2008). Over 1 million individuals per year receive a new cancer diagnosis; an increasing number are being cared for at home by informal carers (Given et al., 2005, p. 2). Every 45 seconds, an individual in the United States suffers a stroke; most are provided care at home by informal caregivers (Pierce et al., 2007, p. 1). Out of the nearly 800,000 individuals per year who have a stroke, around 660,000 survive (Carek et al., 2010, p. 91). The aforementioned statistics reveal that over 1.5 million newly diagnosed survivors of cancer and strokes each year will be living at home, provided with informal care.

Expansion of the number of individuals who receive caregiving at home has led to an increase in the number of informal caregivers. Out of the over 51 million individuals with disabilities in the United States, most live at home, assisted by informal caregivers (Davenport & Eidelman, 2007, p. 36; Potter, 2010). The number of informal caregivers in the United StatesU.S. has likewise increased; approximately 43.5 million adult caregivers now provide caregiving for individuals 50 years of age and older (AARP, 2009).

According to the U.S. Census Bureau (2009), the number of noninstitutionalized adults between 35 and 64 years of age who have at least one disability is close to 9,000,000. Of those individuals, around a third are employed. This raises the possibility that adult child caregivers themselves have at least one disability.

Demographics related to women and caregiving availability are changing. More women are employed and thus may be less inclined to undertake a caregiving role for a family member (Potter, 2010). Likewise, adult children who do provide caregiving to dependent parents may have other significant obligations (Stephens, Franks, Norton, & Atienza, 2009). Many women at the midpoint of their lifespans juggle existing role responsibilities, connected to employment and parenting, with new roles as caregivers to parents (Stephens et al., 2009). Significantly more grandparents today are providing parenting to their grandchildren than two decades ago (Gerard, Landry-Meyer, & Roe, 2006). An adult child providing care to both grandchild(ren) and parent is not unlikely, given the aforementioned statistics. There are a number of combinations of caregiving responsibilities occupied by adults today--for children, grandchildren, or parents--all of which may be simultaneous with outside employment. Given the weight of individual

responsibility borne by the growing number of informal care providers, financial, physical, and educative support for this demographic could be driven by research that highlights their experiences.

### **Caregiving Research**

Problems associated with aspects of the caregiving/care-recipient dyad have driven plentiful research on a wide range of related topics. Caregiving research has ballooned in recent years; studies range from broad views of the effects of care providing on the public health sector (Talley & Crews, 2007) to qualitative examinations of intradyadic phenomena reported by individual care providers (e.g., Cicirelli, 2006; McConigley et al., 2010; Montgomery & Kosloski, 2009; Ziemba & Lynch-Sauer, 2005). The availability of plentiful research on correlational changes, for example in caregiver health alongside care recipient physical/mental functionality (Etters et al., 2008; Kim et al., 2008; Nelson et al., 2009; Pressler, 2009), can lead to timely provision of targeted interventions for informal caregivers. Similarly, the dearth of qualitative analyses examining interpersonal relationships between caregivers and care recipients ignores the lived experiences of millions of burdened caregivers, thus depriving them of social, psychological, financial, and emotional benefits that can emerge from appropriate research. Numerous and wide-ranging problems have been reported by informal care providers; the vast majority of recent studies on caregiving have quantitatively examined these issues, while the difficulties compelling this research remain.

A plethora of research was found that objectively explored caregiver conflicts, including time management, cultural demands, stress, and identity. Foci of recent

caregiving studies have included such personal choices as whether to comply with cultural demands of filial responsibility (Lee, 2007), how to balance caregiving with outside employment (Bernard & Phillips, 2007), and the effects of variables such as stress on both members of a caregiving dyad (Campbell, 2008). Montgomery and Kosloski (2009) described how changes in caregiver duties and caregiver identity, respectively over time, parallel changes in care recipient health. While those authors acknowledged a dynamic change between adult child caregivers and dependent parents resulting from increasing dependency, their focus was on caregivers' shifting role identities. Stajduhar et al. (2010) noted how, among palliative (end-of-life) caregiving research, most studies within the past decade have highlighted effects on carers such as caregiver burden/rewards of caregiving, and quality of life. Palliative research that examined the experiences of caregivers overshadowed explorations of dyadic dynamics (Stajduhar et al., 2010). While many recent studies have covered the effects of numerous variables on caregivers, fewer have focused on dynamics between caregivers and care recipients.

Few studies have explored discrete interpersonal dynamics between caregivers and care recipients. Campbell (2009) asserted that management of the dyadic interpersonal relationship was among the responsibilities of informal caregivers to dementia patients. Gaugler (2010) examined and synthesized secondary data from studies of stroke patient/caregiver dyads, in part to determine whether there was a change over time, for example in caregiver stress levels. McConigley et al. (2010) investigated changing interrelationship dynamics in couple dyads in which one member had been

diagnosed with an aggressive brain tumor. That study acknowledged both the rapidity of physical and cognitive changes experienced by the cancer patient, as well as the role changes and emotional reactions of the spouse (McConigley et al., 2010). Interpersonal dynamics between spouses were not explored beyond acknowledging the difficulty of such a relationship for the caregiving spouse (McConigley et al 2010.). Of the research that mentioned interpersonal changes in the adult child/dependent dyad, Campbell, Gangler, and McConigley et al. viewed care-recipient dyadic members as presentations of their particular illnesses—dementia, stroke, and high-grade glioma, respectively. No recent studies were found that singularly explored the effects of dependency added to an adult child/parent caregiver/care recipient dyad.

An exploration of role reversal in a child/parent relationship mainly highlighted the effects of such a dynamic on children. Byng-Hall (2008) addressed the concept of parentification as it applies to the abdication of parental responsibilities by adults and its influence on involved children. Children in such situations must acclimate to the unfamiliar role of *parent*, which includes assimilating an oversized “caretaker” burden (Byng-Hall, 2008). A parentified identity, over time, can lead to unrealistic self-expectations. When such an individual undertakes a “caregiver” role in another setting, for example, she/he may assume too much responsibility for the success of the role performance (Byng-Hall, 2008). Some research also examined aftereffects of childhood parentification on adults.

The dynamic of role reversal as it applies to parents and children is one facet of dyadic change that is modestly represented in literature. Katz, Petracca, and Rabinowitz

(2009) explored the phenomenon of “emotional role reversal” (p. 185), involving adults and their parentified daughters, and the endurance of negative effects of this dynamic later in life. According to Katz et al. (2009), children drafted into becoming caretakers to adults are thus developmentally arrested, manifesting such symptoms as attachment anxiety and excessive reassurance-seeking (ERS; p. 186) that can remain throughout the lifespan. Mayseless et al. (2004) found that daughters are more likely to undergo childhood role reversal with mothers than are sons with either parent, and that the phenomenon of role reversal can take many forms. For example, a child caretaker of a parent can become over-responsible for adults’ emotional needs, or can become a “pleaser” (p. 83). Mayseless et al. pointed out how, through a family system lens, role reversal occurs automatically to achieve a system-wide balance. Ziembra and Lynch-Sauer (2005) qualitatively examined the concept of adult child/dependent parent interpersonal dynamics in a small sample of caregiving dyads; half of those adult child participants reported role reversal with their dependent parents.

If role reversal can occur in a parent-child dyad in response to the void when the parent cannot or does not provide parenting, could this dynamic manifest in response to an aging parent’s dependency later in life? If, as Mayseless et al. (2004) pointed out, role reversal can result in different manifestations of the resulting dyadic dynamic, could that implication of dyadic dynamic versatility suggest that dependency needs later in life may trigger adult child/parent role reversal? The present examination of the adult child/dependent parent dynamic extended Mayseless et al.’s and Byng-Hall’s (2008)

exploration of the adult-to-child dependency factor to the exertion of parental dependency onto adult children as examined in Lynch-Sauer (2005).

### **Contributions of This Study to Existing Research**

The current study provided an introduction to the adult child's experience of parental, care-recipient dyadic dependency. Qualitative, phenomenological research was appropriate for this examination, as interpersonal dynamics can only be sufficiently described by the individuals for which they are most pertinent—adult children. Adult children of dependent parents are sometimes unprepared for the magnitude of the informal caregiving task financially, physically, and emotionally; this role can add stress to the lives of adult children that can lead to actual illness. For example, Andrieu et al. (2007) pointed out the relationship between dependency in care receivers and depression in informal caregivers. Examinations of dynamics within the relationship between adult children and their dependent parent[s] have occurred, yet so seldom as to seem obscured by the dominance of quantitative research. The magnitude of quantitative studies on the topic of caregiving itself, while necessary, has failed to improve the day-to-day experiences of informal caregivers.

This study has augmented existing qualitative research on interdyadic dynamics by examining the adult child/dependent parent dynamic from a multigenerational family systems perspective. Clark, Brown, Bailey, and Hutchinson (2009) pointed out the usefulness of qualitative studies to introduce, for example, the examination of family caregiving for individuals with traumatic brain injury. Ziembra and Lynch-Sauer's (2005) qualitative examination of an emotional dynamic experienced by adult daughter

caregivers to dependent parents served to highlight the uniqueness of responses characteristic of qualitative analyses.

Just as each individual experiences caregiving in a unique way, each dyad represents a discrete unit that, nonetheless, affects and is affected by the family system. Montgomery and Kosloski (2009) stressed the contribution of each dyadic experience, arising from unique family systems, to caregiving research designed to improve caregivers' satisfaction with their respective caregiving roles. Similarly, Clukey (2008) examined the experiences of caregivers who retrospectively reported symptoms of "anticipatory grief/anticipatory mourning" (pp. 316-317) associated with their care recipients' expected death. This qualitative study highlighted interdyadic dynamics from the perspective of informal caregivers (Clukey, 2008). Some responses to the research questions described emotional and cognitive changes in the interpersonal relationships between carers and care recipients as the latter approached death (Clukey, 2008). Qualitative research both in Montgomery and Kosloski and in Clukey served to reveal changes relative to caregiving experiences in dementia care and palliative care, respectively. Clukey discussed the concept of "transitioning" (p. 319) between care-recipient healthfulness and active dying, viewed from the perspective of the caregiver. The current study extended all the aforementioned qualitative examinations to include specific experiences of the effects of interdyadic dependency over time.

### **Search Strategy**

Databases used in the current study included: PsycINFO, Academic Search Complete, PsycARTICLES, SocINDEX, and PubMed Central. Keywords used in

research for the current study included: *Caregiving, adult child, informal caregiving, care provider, care recipient, attachment theory, family systems theory, Bowen's theory, and role theory.*

### **Theoretical Bases**

Two established theories were used to ground this research: Family systems, or Bowen's theory, and attachment theory. Bowen's theory explains the systemic functionality of the dynamic between two adults; according to this view, there are no "motives" assigned to the behaviors of either, nor is one member of a dyad seen as "causing" the behavior of the other. The larger context of the intergenerational family system is viewed in relationship to the evolutionary premise that is inclusive of all living things.

Bowen's theory has been used for several decades to explore and explain family dynamics; it is modestly represented in current literature. Murray Bowen introduced family systems theory in 1966; research leading up to this mode of viewing family functionality replaced, for many, both the predominate focus on individuals, and on cause-and-effect thinking (Kerr & Bowen, 1988). Bowen's theory was chosen as a basis for this study for three principal reasons; first, the nonjudgmental character of the theory (Bowen, 1978) provided necessary flexibility for the depth of exploration needed to interpret data from open-ended research questions. Bowenian theory also supported an examination of the adult child/dependent parent dynamic through a focus on interpersonal dynamics between members of a family system (Bowen, 1978; Kerr &

Bowen, 1988). Last, the systemic nature of the theory invited a perspective of the family as equally affecting and being affected by its members (Shaffer & Stroufe, 2005).

A family systems viewpoint evolved from the psychoanalytic presumption that mental/emotional dysfunction originates with parental impact on early development (van Ecke et al., 2006). Bowen's theory has been used as both a central and a peripheral framework for analyses of relationship dynamics. Bertrando (2006) examined early and current use of Bowenian theory as a treatment model for families in which a member was diagnosed with schizophrenia. Role conceptualizations pertaining to aspects of caregiving were included in this review as lenses for viewing the dyadic dynamic of caregiving/care-receiving.

Bowen's theory and attachment theory each offered a perspective that is both unique and similar to the other. Bowenian theory not only provided an avenue for meta-analyses of communication patterns within families that contain members with mental illness, but has also provided an explanation for functionality that is considered normative within its culture (Bertrando, 2006). Van Ecke et al. (2006) used both Bowen's and attachment theories to explore the effects of separation from family on recent immigrants to the U.S. According to these authors, the compatibility of Bowen's and attachment theories provided a basis for exploration of intergenerational conflicts between family members when separation created excessive anxiety (van Ecke et al., 2006). While recent studies that used attachment theory are more plentiful than those that employed Bowen's theory, both were useful to the current study. Attachment theory

focuses on dyadic dynamics, in contrast to Bowenian theory, which views a family as the principal unit of exploration.

Attachment theory emerged around 20 years prior to Bowen's theory. Introduced by Bowlby in the mid-1940s, attachment theory consists of four distinct categories of attachment—one that is "healthy," and three that breed anxiety and ensure future difficulty in relating to others (Bowlby, 1947). Van Eecke et al. (2006) described childhood attachment styles as secure, insecure avoidant, insecure anxious, and disorganized, becoming secure, dismissive, preoccupied, and unresolved, respectively, in adulthood (p. 91). Attachment theory provided a view of the adult child-dependent parent dyad that examines the functionality of the original dyadic dynamic, and its potential for change. Attachment theory was also used to align the original parent-to-child caretaking dynamic with the more recent adult child-to-parent caregiving relationship, both from the perspective of the adult child. To make optimal use of Bowen's and attachment theories in the current study, the idea of role taking was introduced through a brief exploration of how this concept came into use.

The concept of "role" was used as a vehicle in the current study through which Bowenian and attachment theories can be more succinctly explained. Mead (1934) first discussed how the ability to take the perspective of another individual is uniquely human, and how role taking predisposes one to act sympathetically toward others. When feeling helpless, one becomes childlike; this condition elicits parenting responses from others towards the individual who needs help (Mead, 1934). Without the ability to put oneself in another's place, an automatic response to the helplessness of another would not occur

(Mead, 1934). The human ability to understand another's experience, thus, leads to caretaking responses.

Aside from the dyadic experience highlighted in Mead's (1934) clarification of role taking, the concept of roles was extended to explain the relationship between an individual and society. Mead emphasized the crucial role that society plays in the minds of individuals; communication between any two persons is always more than it appears, necessarily including mental references to the assumption of societal roles by participants. Individuals in a given society have common understandings of what constitutes a specific role fulfillment (Biddle, 1986). Moustakas (1994) discussed how the observer and the observed are inseparably entwined in meaning making; experiences lead to unique perceptions that include feelings about the events experienced. The roles of caregiver and care-recipient can be seen as emerging from the lived experiences of each individual; the two interact in various ways as the relationship continues.

As a caregiving relationship evolves, behaviors of each dyadic member become apparent to the other; also apparent is the effect of these behaviors on each other. Functionalist role theory emphasizes expectations of particular behaviors assigned to specific role conceptualizations (Lynch, 2007). Ideas of what an individual ought to be doing while occupying a particular role drives other individuals to expect certain behavior, while the role occupier performs the role to fulfill her/his perception of that expectation (Lynch, 2007). The functionalist concept of roles, however, ignores any discrepancy that may occur between role performance that is expected by one individual and role enactment by another (Lynch, 2007). In a caregiving dyad, each member's

behavior does not follow a preset pattern; behaviors of each depend in part on the reaction of the other.

Instead of simply reacting to another's behavior, an individual has unique ideas and beliefs that govern, in part, responses to the other. The development of an interactionist role theory filled the need for a model that views as meaningful the communication between role takers and observers of role performances; if one's role enactment fails to measure up to another's expectations, modification can be made by either that includes the other's perspective (Lynch, 2007). Through interactionist role theory, an examination of dynamics within the caregiving/care-receiving dyad can indicate how expectations of each dyadic member can change with actual behavior(s) of the other, comprising a change in dynamics. Role conceptualizations are complex, involving a "role-taker," an observer of the role performance, and the dynamic between the two. Assertions by Mead (1934), Biddle (1986), and Lynch (2007) have identified role-based societal conceptualizations, the constitution of individual role fulfillment, and implications of interactionist role theory, respectively.

Attachment theory, Bowen's theory, and role conceptualizations were all utilized in the current study to clarify components of the dependency dynamic for optimal scrutiny. Attachment theory provided a focus on the child/parent dyad and its evolution into an adult child/dependent dynamic, while Bowenian theory added a framework for the establishment of the caregiving/care-receiving dynamic within a multigenerational family system. Role theory and conceptualizations supplied a close scrutiny of adult children's perceptions of the dynamic they share with a care-receiving parent. Altogether,

each conceptualization of the adult child/dependent parent dynamic converged to highlight the phenomenon under study.

### **Informal Caregiving**

Informal care providers were identified in the literature by using several different terms; in this study, these were used interchangeably. They are referred to as, “informal caregivers” (Carretero et al., 2007, p. 739; Montgomery and Kosloski, 2009, p. 47), “informal carers” (Arksey & Glendinning, 2007, p. 165), “carers” (Bernard & Phillips, 2007, p. 140), and “filial caregivers” (Marks et al., 2008, p. 1). These individuals comprise the bulk of overall care provision to individuals in the U.S. requiring long-term assistance with daily living tasks (Montgomery & Kosloski, 2009). In the U.S., 29% of all adults provide informal care to elders or children with disabilities; 66% of those individuals are women (AARP, 2009). Twice as many adult daughters become care providers to dependent parents as do adult sons (Gonyea et al., 2008). Typically, then, of the nearly 90,000,000 informal caregivers in the U.S., around 59,400,000 are women, and women are twice as likely to provide caregiving to dependent parents as are men. Women in midlife are more likely than younger or older women to take on an informal caregiving role.

Along with the aging of the current population of informal caregivers comes increased susceptibility to physical illness and disability. Family carers, especially women in their 40s, are the most likely segment of the U.S. population to provide caregiving to older adults with long-term care needs (Godfrey & Warshaw, 2009). The time spent providing care to dependent parents has been increasing for decades, resulting

in many care providers themselves being over 60, with health problems of their own (FCA, 2009). Older caregivers not only have to adapt to their own aging processes, but also to those of the care recipients (Ziemba & Lynch-Sauer, 2005). This is another example of the particular difficulties faced by informal caregivers; aging is inevitable, and its effects add to the total burden borne by adult child carers. Moreover, the aging process of care recipients may come with unforeseen changes that must be factored into caregiving responsibilities of caregivers, including changes in interpersonal dyadic dynamics.

Examinations of caregiving/care-receiving dyadic dynamics in current literature are few, which underscores the importance of studies that highlight this facet of this population's overall experience. Montgomery and Kosloski (2009) discussed how each caregiver/care recipient dyad is a distinct unit; each individual brings her/his unique contribution to the role dynamic that has evolved over time. For example, ideas based on culture-specific norms, or more specifically, multigenerational family-specific norms for caregiving responsibilities may guide decision-making by adult children (Montgomery & Kosloski, 2009). This qualitative, phenomenological examination of several adult child/dependent parent dyads served to extend Montgomery and Kosloski's focus on shifting role identities in caregivers to include effects of other variables on the specific dynamics of each dyad. Caregiving/care-receiving roles evolve from unique dyadic dynamics that transform caregiver self-perceptions to match, for example, intensified responsibilities (Montgomery & Kosloski, 2009). In the current study, the interdyadic

dynamics themselves were reported by participants to have undergone similar transformations as dependency in the parent(s) increased over time.

The day-to-day reality of providing informal care has been found to increase susceptibility to many kinds of physical and/or psychological problems; some can even add to the existing health problems of care recipients. Informal caregivers of stroke survivors, for example, are vulnerable to posttraumatic stress reactions that increase with time, following the event of a stroke in the care recipient (Carek et al., 2010). The more informal caretaking tasks a woman with breast cancer undertakes, the greater her chance of having depressed mood (Bailey et al., 2010). According to Bailey et al. (2010), participants who had received a diagnosis of breast cancer and who were not caregivers were less likely than participants who had undertaken caretaking obligations to several dependents to have depressed mood at a 6-month follow-up. Informal caregiving can lead to or exacerbate physical and/or psychological problems. In addition to the direct influence of caregiving stress on carers, the effectiveness of informal caring is indirectly compromised by carer difficulties.

A given caregiver/care-recipient relationship can manifest problems in either or both members of the dyad. Pressler et al. (2009) asserted that the existence of depression in informal carers of heart failure patients can mean decreased effectiveness of care provision. A recent study of care providers to cardiac patients (Aggarwal et al., 2009) found that carers themselves could be at increased risk of contracting cardiovascular disease, due to common lifestyle/psychosocial factors such as unemployment, reduced physical activity, and low social support. In addition to increased likelihood of

developing medical or psychiatric difficulties, many informal caregivers also devote time and energy to child care and outside employment.

### **Caregiver Burden**

A good deal of recent research has emerged from the caregiving context to denote specific causes and effects of caregiver burden. Caregiver burden is associated with a number of factors that are present in a given caregiver/care-recipient dyad. According to Razani et al. (2008), caregiver burden is related to actual emotional and physical constraints imposed by caregiving responsibilities that interfere with caregiver health and diminish social functionality. Razani et al. discussed the impact of care-recipient cognitive impairment on care-provider reports of burden in a quantitative analysis. Adult child caregivers, representing most care providers for dependent parents, experience emotional stress in the caregiving relationship (Kang, 2006). Difficult behaviors of dependent parents, demands on time, social constraints, in-family arguments, and personal health problems can deplete caregiver emotional functionality (Kang, 2006). Caregiver burden can mean feeling “stuck” in the relationship, due to the extent and intensity of care-recipient physical and emotional problems, as well as family conflicts, in addition to the caregiver’s own health/emotional issues. Caregiver burden can also be related to discrete health problems of care recipients.

The amount and intensity of caregiver burden depends on factors in both caregivers and care-recipients. Caregiver burden is related to specific care-recipient illnesses such as cancer (Dumont et al., 2006; McConigley et al., 2010; Schumacher et al., 2008), AD (Campbell, 2009; Etters et al., 2008; Montgomery & Kosloski, 2009),

stroke (Carek et al., 2006; Gangler, 2010; Nelson et al., 2009), and heart disease (Gure et al., 2008; Pressler et al., 2009). As care recipient health-related functionality worsens, caregiver burden increases (Nguyen, 2009). Caregiver burden affects both members of a caregiving/care-receiving dyad (Wilson-Genderson et al., 2009). According to Wilson-Genderson et al. (2009), spousal caretakers of end-stage renal failure patients and the patients themselves are affected by caregiver burden. That study highlighted the importance of research that examines the effects of variables on both members of a dyad. Caregiver burden has also been suspected as a cause of some health problems in caregivers.

Caregiver burden is associated with physical and psychological illness in care providers (Hebert & Schulz, 2006; Schulz & Sherwood, 2008). The older the caregiver, the more health problems were reported that deplete physical and financial resources (Schulz & Sherwood, 2008). According to Hebert and Schulz (2006), depression is more common in caregivers than in peers who are not informal carers and can persist despite potentially mitigating circumstances such as nursing home placement of care recipients. Caregivers to individuals with dementia reported higher levels of depression than did other care providers (Nguyen, 2009). The high level of care required by individuals with dementia can lead to erosion of physical and mental health functioning in informal carers (Nguyen, 2009; Razani et al., 2008). For older caregivers, caregiver burden can be damaging, especially if accompanied by existing health or financial issues, or if the care recipient has a form of dementia. Caregiver burden can affect caregivers both directly and indirectly.

Believing oneself to be burdened with caregiving responsibilities is a risk factor for experiencing caregiver burden. A recent British study that used a demand-control model (D-C; Molloy et al., 2008, p. 403) to measure caregiver burden in informal carers of heart disease patients found that perceptions of lower control over caregiving demands was associated with higher subjective burden. Perception of control in this study was measured by asking caregivers to what extent they are relied upon to perform tasks related to daily living (Molloy et al., 2008). Amount of caregiver burden was determined by how little, or how great, the sense of control over performance of duties (Molloy et al., 2008). Caregiver burden is linked not only to day-to-day physical, mental, and emotional effects of informal caregiving, but to the idea that one is responsible for the care of a dependent individual. Caregiving can also affect the financial stability of informal carers.

### **Financial Burden of Informal Care**

Informal caregiving creates a financial dilemma for many care providers. Loss of income, loss of employment-related medical and retirement benefits, and depletion of savings used for care recipient necessities create financial hardship for many U.S. carers (FCA, 2009). Many informal carers are unprepared for the actual costs of total care provision for a family member with a disability, which is estimated at around \$6300-\$16000 per year (Davenport & Eidelman, 2007). Nearly 21 million Americans have at least one family member with a disability; financial consequences can range from foregoing plans to buy a house or finance college education, to bankruptcy (Davenport & Eidelman, 2007). Half of all U.S. bankruptcies are related to medical care expenses (Davenport & Eidelman, 2007, p. 36). About five to seven million Americans provide

informal caregiving at a considerable distance from the care-recipient's home (Benefield & Beck, 2007). Around half of those individuals arrange for and supervise others who provide in-home care. *Distance caregivers* (Benefield & Beck, 2007, p. 268) experience financial stressors connected to travel, care costs, and loss of wages. Providing caregiving to a family member can take many forms, all of which mean less available financial resources for the caregiver. Informal caregiving can be accomplished in many ways, all of which can deplete carer resources; some must give up hope for continuing a middle class lifestyle. Financial problems tied to informal caregiving are not confined to in-home care providers; distance caregivers encounter expenses associated with travel that must be factored into expected costs of informal care.

Informal caregiving affects caregivers, care recipients, formal health care providers, public policy, and governmental resources. Caregiving in the United States is formally recognized as a public health concern (Schulz & Sherwood, 2008; Talley & Crews, 2007). Impairments associated with care recipient illnesses affect not only caregivers, but also burden health care providers and strain resources earmarked by public policies (Talley & Crews, 2007). Knowledge of health needs of family caregivers has caused some public policy changes, resulting in yearly time off, with pay, in many cases (FCA, 2009). Care providers who must quit work, or have frequent absences due to emergent caregiving needs, however, continue to cost U.S. businesses millions of dollars per year (FCA, 2009). Moreover, average family size in the United States is shrinking, due to lower birth rates and rising divorce rates, while at the same time the number of older adults requiring care is growing, resulting in less availability of informal care

human resources (Potter, 2010). While changes in government policies have improved the financial aspect of informal care provision somewhat, caregivers and the U.S. economy continue to suffer as families are decreasing in size while government resources for this population are being drained by caregivers who must slow down or stop working to maintain their health.

Solutions to the problem of waning resources for dependent older adults and their caregivers will not emerge without an understanding of where this problem originates and how far it has spread. Healy (2008) emphasized the importance of understanding the overall social and economic impact of informal care. Informal care provision helps minimize elder care-related depletion of national health care costs (Schulz & Sherwood, 2008). According to Zhu et al. (2008), over 70% (p. 2) of individuals diagnosed with AD are cared for at home by informal care providers; as dependency needs increase, the amount of time spent caregiving increases proportionately. As dependency on adult child carers increases, those individuals turn to outside help to manage growing demands on time and other personal resources; this, in turn, depletes family and governmental reserves set aside for this population (Zhu et al., 2008). Family carers of advanced cancer patients, for example, experience increasing levels of psychological distress parallel to the decrease in mobility status of the care recipient (Dumont et al., 2006). Research that targets dependency of care-recipients that, in turn, causes caregivers to lengthen their time spent caregiving, as mentioned by Zhu et al., highlights the increased care-recipient needs brought about by dependency. Care-recipient dependency increases over time, for example, in AD; this and other chronic illnesses that require caregiver assistance drives

personal and government spending. Research that targets the caregiver/care-recipient dynamic provides answers to the economic problems faced daily by caregivers, including how to manage multiple roles.

Attempts to understand and facilitate solutions for the amount of personal energy required to perform multiple roles has driven some research on energy as a resource. Stephens et al. (2009) addressed a decades-old question of whether there is more, or less, intrinsic energy available for individuals who undertake several roles at once. According to Stephens et al., two competing models predict either erosion or expansion of available energy for adult child caregivers with other role responsibilities; one highlights losses that lead to interdyadic conflict, and the other focuses on gains in areas such as self-esteem and role identity. When the adult child/dependent parent interdyadic dynamic changes with increasing dependency of the parent, then, could a focus on positive aspects of the caregiving role result in increased available energy for the caregiver which would, in turn, lead to decreased demand for governmental and social resources?

This qualitative examination of the adult child/dependent parent caregiving/care receiving dynamic has highlighted reported changes in the dynamic as dependency increases over time. Identification of changes in caregiving dyads will, hopefully, lead to timely provision of psychological resources that could, in turn, diminish caregiver burden and supplemental home health care costs. Other recent caregiving research has neglected to examine interpersonal dynamics within the dyad itself that form the basis for the current study.

### **Dependency and Older Adults**

Older individuals are more likely than younger ones to need help from others. Individuals become dependent when they require the assistance of others to perform basic tasks that are vital to daily living (Carretero et al., 2007). Adults grow progressively more dependent on others as they age (Scharlach, Damron-Rodriguez, Robinson, & Feldman, 2000). The chance of individuals suffering from a debilitating physical or mental impairment increases exponentially between the ages of 65 and 85 (Scharlach et al., 2000). For example, around 15% of adult Americans over 65 have some form of dementia; although only 1% of individuals have dementia at 65, the risk doubles every five years, so by the age of 85 one in every five individuals suffers from the disease (Scileppi, 2002, p. xi). In Taiwan, an expanding elder population balanced against declining fertility rates has caused alarm, as Taiwanese culture depends on the availability of adult children to provide elder care when it becomes necessary (Yi & Lin, 2009). Similarly, elder dependence on adult children remains primarily unquestioned in Chinese households, where this transition fosters reliance on multigenerational households (Yi & Lin, 2009). Elder dependency in the Asian culture is factored into a lifestyle that expects older adults to rely on their children for help at some point; in contrast, U.S. adult children choose whether or not to provide caregiving when parents need it. Although Taiwanese and U.S. cultures have different ideas about aging and dependency, both share concern over the scarcity of informal care providers.

Some older adults never require assistance with day-to-day tasks, while others may manifest physical or mental/emotional problems earlier in life that render them more

incapacitated as their aging process continues. Still others are suddenly stricken with a disability that causes some relinquishing of independence. Individuals at 85 are over four times more likely to require assistance from others than at 65 (Scharlach et al., 2000, p. 523). Dependency in older adults has personal, interfamilial, and societal implications; financial, psychological, or functional dependence prompts familial and/or societal support (Doubova et al., 2010). According to Gardner and Helms (2006), dependency in an interpersonal caregiving relationship is associated with depression and reduced physical mobility in a care-recipient. Fiori, Consedine, and Magai (2008) discussed how dependency is an integral part of both childhood and old age; dependency, in this view, is not a choice but rather an eventuality of growing older. Different views and reactions to dependency in older adults by both caregivers and care-recipients lead to innumerable manifestations of caregiving relationships.

### **The Adult Child/Dependent Parent Relationship**

Most relationships between an adult child and a parent evolve over the lifetime of the adult child. The child/parent dynamic is governed by forces that compel both members of the dyad to maintain a close bond while remaining autonomous, thus maintaining the child/parent dynamic (van Eecke et al., 2006). According to van Eecke et al. (2006), adults continue attachment patterns learned in infancy, when the motivation to connect with the mother was linked to survival and provided security. Future relationships are similarly based on attachment behaviors learned in childhood, where one learns to elicit responses from others based on security needs (Stevenson-Hinde, 2007). The evolution and maintenance of the adult child/parent dyadic relationship

depends on factors within each dyadic member and on the strength of their interpersonal relationship, as well as on involvement in other relationships.

Family dynamics are based on relationships both within, and outside of a family system. The motivation to be with others and to be autonomous occurs simultaneously, creating a dynamic unique to family members involved in a given interaction in that moment in time (van Ecke et al., 2006). Individual behaviors, however, are not simply byproducts of family systems; individual dynamics influence the systems they are part of just as family systems exert influence on the individuals therein (Aslan, 2009). When the forces of togetherness and separation are off-balance, the resulting anxiety compels a shift in interpersonal dynamics (van Ecke et al., 2006). Byng-Hall (2008) discussed how some children become, “parentified,” (p. 148) or drafted into an adult role early in life due to the need for caregiving within a family. Such a drastic shift in roles from child to adult can, nevertheless, foster the development of caregiving skills (Byng-Hall, 2008). Preparation for a caregiving role can also evolve, for example, from the experience of raising one’s own children (Cicirelli, 2000). Adult children can become caregivers to dependent parents by following a sense of compulsion, or obligation to the parent; some fall into the role naturally due to years of experience as care provider to children.

### **Evolution of Caregiving/Care-Receiving Roles**

Just as relationships between adult children and parents develop and grow over decades, some continue as the parent becomes dependent and the adult child assumes the role of caregiver. Montgomery and Kosloski (2009) emphasized the uniqueness of caregiving/care-receiving dyadic dynamics. Feeney, Cassidy, and Ramos-Marcuse (2008)

invoked the assertion by Bowlby that the endurance of original attachment proclivities was likely given the unconscious nature of the bond. Whether the dependency bond that emerges from within the aforementioned dynamic endures throughout the life of the relationship, however, is a controversial assumption only partially supported by attachment-based literature (Bengtsson & Psouni, 2008). Recent research did not supply a definite answer as to whether the caregiving/care-receiving dyadic dynamic evolved from a prior attachment-based experience.

Adoption of the role of informal caregiver to a dependent parent, nonetheless, involves extending a relationship that has evolved over some time. Lingler, Sherwood, Crighton, Song, and Happ (2010) asserted how three distinct caregiver/care-recipient relationships evolve from informal care arrangements; reciprocal carers, caregiver constellations, and “intergenerational family care chains” (p. 4). According to Lingler et al., reciprocity of caregiving refers to couples with episodic care needs, caregiver constellations involve various family members who share caregiving duties, and care chains describe what Keene and Prokos (2007) referred to as being “sandwiched” between caring for dependent children and dependent parents (p. 366). While Montgomery and Kosloski’s (2009) view of the nature of caregiving/care-receiving dyads included every possible caregiver/care-recipient arrangement, Lingler et al.’s description excluded, for example, adults without dependent children who care for dependent parents without assistance from other family members. Different perceptions of caregiving roles can lead to various foci of study.

Recent research reflected perceptual differences in how, and why, the caregiving role is assumed. Caregiving can evolve, for example, from observations by an adult child of the parent becoming more fragile and in need of assistance. Progressive vulnerability in a dependent parent can trigger security needs based on a sense of impending loss of an attachment figure, thus compelling caregiving behavior (Lee, 2007). According to Eaves (2006), a decision to assume informal caregiving responsibilities can result from filial obligation, desiring to return to the parent the caregiving she/he received as a child, or wishing to prolong the satisfaction derived from the existing emotional bond with the care recipient. Numerous situations compel adult children to assume caregiving responsibilities for parents, and they do so in different ways.

The relationship between an adult child and a dependent parent determines to some extent the foundation of the newly adopted caregiving role. An adult child who becomes the principal caregiver for a dependent parent can assume that role in a variety of ways, based on the dynamic within their existing relationship (Kanervisto, Paavilainen, & Heikkila, 2007; Montgomery & Kosloski, 2009). If the relationship is open, supporting mutual growth and individuation, adopting a caregiving role by the adult child is likely to be a smooth transition (Kanervisto et al., 2007). Mitigating factors, such as filial piety (Yi & Lin, 2009; Lee, 2007; Wong & Chau, 2006), can result in cultural expectations overriding personal needs and responsibilities to one's nuclear family. Adult children vary widely in both degrees of pressure to provide caregiving, and in preconceived ideas of the reality of the caregiving experience (Montgomery & Kosloski, 2009). Some informal caregivers unrealistically estimate their own abilities to provide care in specific

circumstances (Benefield & Beck, 2007). Just as there are many types of caregiving relationships, each adult child caregiver has chosen that role for a reason unique to her/him. Once the caregiving role is assumed, the adult child must incorporate this new role into a sense of self, alongside other roles that she/he performs.

Each family system has preconceived ideas of how roles, both inside and outside of the family, are performed. Informal caregivers adopt role identities that conform to societal, cultural, and interfamilial expectations (Montgomery & Kosloski, 2009). Expectations within a family system include who should provide care, which caregiving duties are part of the role, and when to turn to outside assistance. As the caregiver/care-recipient relationship evolves, an increase in care-recipient needs parallels a shift in caregiver role identity. Identity role changes do not follow a preconceived pattern; they depend on many variables, including the magnitude and types of changes in dependency needs, and whether care-recipient needs collide with the care-provider's initial expectations (Mongtomery & Kosloski, 2009). Eaves (2006) discussed how some informal care providers discovered how expectations of assistance from other family members result in frustration when help is not forthcoming. Just as each family system has expectations for how a caregiving role is performed, the actuality of family involvement or disengagement is part of family dynamics—that may or may not have been apparent to the carer prior to assuming the caregiver role.

The role of caregiver comes with a new self-perception, unless one has previously performed caregiving duties. Byng-Hall (2008) discussed how individual identities are formed from a family attachment perspective. If an individual frequently provides care to

another family member, that behavior becomes expected; if the individual begins to shy away from the aforementioned caretaking role, other members may attempt to coax her/him back into it. If the individual succumbs to pressure and resumes the role of caretaker, she/he may, in time, see her/himself as “a caretaker of others” (Byng-Hall, 2008). Women at midlife may be faced with the prospect of taking on the new role of caretaker to a dependent parent at the same time they are letting go of the responsibility of raising children (Stephens et al., 2009). Caregiving duties, prior obligations, and/or family dynamics, may present unforeseen difficulties once caregiving is underway; attempts to relinquish the caregiving role can result in reactions from family members the adult child had not prepared for. For example, dependency in AD can increase at any time in the life of the caregiving/care-receiving dyad (Peacock et al., 2010). Adopting and performing the caregiving role provides a self-identity that may be difficult to abandon, despite emergent problems.

Since there is a change in the identity structure of an adult child that parallels increasing dependency of the care-recipient parent (Montgomery & Kosloski, 2009; Stephens et al., 2009), other noteworthy changes may take place within the interdyadic dynamic associated with growing dependency. Some studies view the role of caregiving to an aging parent as part of the transition from childhood to adulthood; elder dependence and concomitant frailty is, thus, part of the lifespan trajectory (Marks et al., 2008). According to Marks et al., satisfaction with dyadic dynamics prior to undertaking an adult child/dependent parent caregiving role leads to similar interpersonal satisfaction once the role is established. Recent research has determined that an adult child’s

perceptions of the quality of her/his relationship with a parent/care recipient affects interpersonal dynamics more than the quantity of work she/he must do once a caregiving relationship is established (Ward, 2008). Neglecting an examination of interpersonal dynamics while conducting research on caregiving/care recipient dyads would be to compromise the success of research and educational endeavors designed to augment informal caregiving resources (Sink, Covinsky, Barnes, Newcomer, & Yaffe, 2006).

### **Role Adaptations**

Once a caregiving role is accepted, it is up to an individual to incorporate that role into other self-perceptions. Lynch (2007) pointed out how an individual must identify his/her role before performing it. A given role performance can range from a highly structured, mechanical approach to an acutely sensitized, maximally integrative adaptation (Lynch, 2007). An individual's attempt to fit into a given role can even result in exaggerated role accommodation, due to that individual's tendency to ingratiate her/himself to the recipient of the role performance (Katz et al., 2009). Bengtsson and Psouni (2008) stressed the role of mental representations associated with role performances; each member of a mother/daughter caregiving dyad assumes a position in relation to the other based on ideas of how their respective roles should be performed. How an adult child adapts to the role as caregiver to a parent is based on conscious and unconscious ideas of role performance.

Assuming an informal caregiving role to a parent presumes that changes in thinking about oneself accompany instrumental behavior changes. Transition into the role of caretaker of one's parent is a twofold task; one must implement the role of caretaker

while adopting a new view of oneself in relation to one's parent (Montgomery & Kosloski, 2009; Rabin, Bressler, & Prager, 1993). Cicirelli (2000) pointed out how adopting the caregiver role for one's dependent parent occurs in response to a perception of the parent's physical and/or mental instability. In Lynch's (2007) view, undertaking the role of caregiver is more than the fulfillment of preset expectations of the function of "caregiver;" it is an ongoing process that could include any number of adaptive events. Adoption of the role of caregiver is accomplished in a variety of ways and for a number of reasons.

### **Cultural Differences in Perceptions of Informal Care**

A global view of caregiving reveals a wide range of cultural norms, emphasizing the versatility of dyadic dynamics within the overall human experience. According to Aslan (2009), cultural demands of Turkish society shape family systems to regard the importance of group, as opposed to individual, goals; harmonious group interactions and conformity to group needs are cultural imperatives. Wong and Chau (2006) described the Asian family system as faced with the same struggles as in other developing and developed countries in regard to population aging and concomitant filial resource expectations. For example, Lee (2007) discussed the conflict experienced by adult children of dependent parents in Taiwan who face the societal responsibility of providing caregiving within their families of origin while also providing resources for nuclear families. Other conflicts can include lack of formal preparation for tasks involved in actual caregiving provision (Wong & Chau, 2006). Since dyadic dynamics adapt to a

wide range of cultural norms, dynamic changes over time may, in turn, represent an adaptation based on the propensity for change within each dyadic pair.

### **Shifts in Dyadic Dynamics**

Anxiety causes changes throughout a family system. Anxiety within a dyad is triggered by a sense of imbalance between forces of togetherness and of separation (van Ecke et al., 2006). Anxiety, in turn, prompts a shift within the family system that affects all family members and their interrelationships with one another (van Ecke et al., 2006). Clukey (2008) discussed the automatic shift in roles precipitated by anticipated grief associated with illness and eventual death of a family member. According to Clukey, changes in relationship status to a dying family member interfere with attachment dynamics, realization of loss, and shifts in other interfamilial relationships. Cicirelli (2006) discussed how decision-making processes in adult child/parent dyads were dominated by adult children, concluding that the power differential (i.e. the care recipient has less power due to a greater need to maintain the caregiving relationship) was responsible for the position of deference by care-recipients. Anxiety in one aspect of the caregiving/care-receiving dyad causes a change in the other, comprising an overall dynamic change.

Family dynamics shift and change to accommodate input from sources in the environment of the family system. A family system constantly balances energy from outside the system with energy generated within the system (Aslan, 2009). Systemic maintenance in a caregiving/care recipient context involves behavior on the part of the caregiver designed to balance actual caregiving tasks with other care-related obligations,

including self-care (Pierce et al., 2007). Relationships between family members and each other, as well as exchanges between those members and all others with whom they come in contact cause shifts in dyadic dynamics (Butler, 2008). When an adult child provides caregiving to a dependent parent with dementia, for example, the parent's mental condition worsens alongside the adult child's reactivity to stressors inside and outside the dyad (Campbell, 2009). Cognitive decline in dependent parents may also lead to shifts in relative decision-making power (Cicirelli, 2006). Aggressive medical treatment for cancer patients near the end of life is associated with increased depression in informal care providers (Wright et al., 2008). Dynamic shifts occur automatically, as needed to accommodate the reactions of behaviors that trigger them. Over time, a family system and, concordantly, a dyadic relationship within a given family, may shift innumerable times and to varying degrees as the relationship progresses. The caregiving/care-receiving dyad can, itself, affect family-wide changes.

Interpersonal dynamics between informal caregivers and care-recipients are affected by changes within the larger family system. Dynamics between caregiver and care-recipient can be affected by relationships with other, non-care-providing family members; longstanding sibling rivalries, for example, can weaken the sense of interrelatedness in an adult child/dependent parent dyad (Keeling et al., 2008). Similarly, positive family dynamics contribute to functionality of the dyad (Cohen & Lee, 2006; Mitrani et al., 2006). Change, then, is an expected component of dyadic dynamics. From the level of family system, affected by forces both within and outside of it, as seen in Aslan (2009), to intradyadic anxiety (van Eecke et al., 2006), change is a factor that can

affect dyadic functionality (Clukey, 2008; Cohen & Lee, 2006; Keeling et al., 2008; Mitrani et al., 2006).

### **Factors Associated With Dyadic Dynamic Changes**

Interpersonal dynamics within adult child/dependent parent dyads change relative to factors inherent in the caregiving relationships; these changes can be associated with specific illnesses. A recent study of informal care providers of diabetic care recipients revealed intrapersonal dynamic shifts in response to increasing intensity of diabetic symptoms (Awadalla, Ohaeri, Al-Awadi, & Tawfiq, 2006). Family awareness of the intensity of needs of diabetic patients is associated with greater caregiver efficacy (Awadalla et al., 2006). When informal caregivers of stroke patients receive physical assistance from others in the performance of caregiving duties, they concomitantly experience emotional support (Steiner et al., 2008). Ostwald et al., (2009) noted a shift in caregiver/care recipient dyadic dynamics that accompanied stroke rehabilitation. According to Ostwald et al., family support was paramount to effective stress-reduction strategies in those dyads. Dyadic dynamics are flexible; they change, for example, in accordance with symptom intensity and some dimensions of family support.

As care recipients age their symptoms increase, which can affect the caregiving/care-receiving relationship. Aging, necessarily associated with time, systematically causes a change in the dependency status of care recipients (Benefield & Beck, 2007). Similarly, intrapersonal caregiver changes occur that are concomitant with changes in symptomatic intensity of care-recipients (Awadalla et al., 2006). Changes in the level of support provided to care providers promote changes in intradyadic stress

levels (Ostwald et al., 2009). If all the aforementioned changes occur simultaneous with changes over time in dependency of care-recipients, those changes must be factored into an examination of family and intradyadic stress.

Family dynamics can affect the interpersonal dyadic dynamic. Mitrani et al. (2008) found family functionality to have a moderating effect on caregiver/care recipient interdyadic stress. Stability of interdyadic dynamics is, thus, associated with systemic family functionality. Research on the effects of dependency within the adult child/dependent parent dynamic will augment existing research on the effects of change in both family functioning and the effects of stress on interdyadic dynamics. Clark et al. (2009) suggested that an emphasis on the effects of family systems on the caregiver/care-recipient dyad would assist in planning effective care provision for those affected by traumatic brain injury (TBI). The caregiver/care-recipient dyad may benefit from support from the larger family system.

Both caregiving adult children and care-recipient parents may experience health-related changes that, subsequently, affect the other. An adult child performing a caregiving role to a dependent parent can experience stress that, over time, may lead to illness (Carretero et al., 2007). Bereavement associated with the multiplicity of losses connected with prolonged caretaking of a dependent parent can have both mental and physical health consequences for the adult child (Sanders et al., 2008). For example, symptom intensity in patients with advanced cancer was found to positively correlate with psychological distress in family caregivers; the lower the capability to do self-care in care-recipients, the higher the experience of distress in care providers (Dumont et al.,

2006). Similarly, the anticipation of care-recipient death includes systemic changes that affect not only interdyadic dynamics, but also affect all members of the family system (Clukey, 2008). Not only do actual changes in recipient physical health affect informal care providers, but the anticipation of death and symptom changes in recipients can similarly contribute to caregiver health decline. Dependency needs in care-recipients can also be related to specific health problems.

Dementia and other chronic, progressive illnesses can add cumulative stress to the informal carer's experience. For an adult child providing direct care to a parent with progressive cognitive decline such as in AD, the consequences are protracted due to the sometimes lengthy survival time once the disease is diagnosed (Peacock et al., 2010; Sanders et al., 2008). An adult child caring for a parent with AD is exposed to situations that promote intense grief over an extended period of time. Informal carers of AD-diagnosed individuals not only face a sense of continual loss, but must conform to changing roles within the family as the illness progresses. The common incidences of both grief and depression among AD caregivers can deplete caregivers' coping resources (Sanders et al., 2008). With the increased chance of health-related problems, care providers to individuals with chronic, progressive diseases see caregiving responsibilities multiplied over time.

Depletion of personal health resources in informal caregivers for individuals with AD may intensify with time. Caregivers of parents with degenerative illnesses such as AD see the time spent caregiving over time as the illness worsens (FCA, 2009). Healthfulness in caregivers of dementia patients was associated with lower reported

caregiver burden (Elliot et al., 2010). According to Elliot et al, interventions aimed at improving emotional and physical health in caregivers of dementia patients resulted in lower perceptions of caregiver burden and higher subjective ratings of physical health. While deterioration of health is problematic in providers of informal care to AD sufferers, some interventions aimed at cognitive self-perceptions have proven useful.

Providing informal care to stroke victims has elements common to informal carers of individuals with chronic diseases. Similar to providing caregiving to an individual with a progressive illness such as AD, stroke care provision has a longitudinal component that must be factored with other elements of the caregiver role (Gaugler, 2010). Caregivers for stroke survivors can face an array of emotional and physical care-recipient needs that correspond to significant changes in stroke-affected adults' functionality (Pierce et al., 2007). Symptoms of stroke survivors can include paralysis, aphasia, balance/coordination difficulty, swallowing problems, and mood swings (Carek et al., 2010, p. 91). Not only do caregivers of stroke patients face long-range care commitments, but they must be alert to functional and emotional changes in care-recipients.

The stroke event itself not only affects care-recipients, but informal carer mental/emotional stability. Caregivers to stroke-affected individuals can experience reactions to witnessing the stroke event of a family member so severe as to cause lasting mental/emotional problems (Carek et al., 2010). Some other caregiver-reported problems associated with stroke-recipient dependency are management of memory problems, anxiety, and depression (Haley et al., 2010). According to Haley et al., caregivers of stroke survivors must manage both their own and the survivor's anxiety when events are

forgotten, for example, thus are repeated over and over. Moreover, the aftereffects of a stroke event can cause susceptibility to falls, which may lead to hospitalization and a greater workload for an informal caregiver upon the return home (Gaugler, 2010). Care providers for stroke-affected individuals must cope with not only the sudden onset of the stroke itself, but with other changes experienced by stroke victims. Heart disease can also cause specific stress for an informal caregiver.

Individuals providing care for care-recipients with heart disease face certain difficulties specific to that illness. Informal carers for individuals with heart disease found that behavior problems in care recipients presented the most difficulty in performing the caregiving role (Pressler et al., 2009). Other stressors specific to patients with heart failure include the need to monitor the patient and, at times, devices that regulate heart activity, for symptoms that may require medical intervention (Pressler et al., 2009). Patients with congestive heart failure (CHF) require caregiving over a longer period of time than patients with, for example, coronary artery disease (CAD; Gure et al., 2008). Caregivers of geriatric patients with CHF are likely to encounter other medical conditions such as incontinence, fall-related injuries, and dementia (Gure et al., 2008). McConigley et al. (2010) similarly revealed striking interpersonal changes in dyadic dynamics and subsequent caregiving roles associated with rapid worsening of patients' conditions. Specific factors in the caregiving role of heart disease patients are linked to caregiver/care-recipient stressors.

### **Dependency and Dynamic Change**

The factor of dependency in older adults added to an informal caregiving relationship can be indirectly, yet incompletely, explored by research highlighting similar changes in family dynamics. Van Ecke et al. (2006) discussed dependency from the perspective of attachment and Bowen theories, in which dynamics between individuals shift in response to changes within or outside the family system. Van Ecke et al. found that individuals who immigrated to the United States suffered from a lack of family support enjoyed by other individuals who did not immigrate to the United States, remaining close to their families of origin. Those immigrants, thus affected, had lost the support of families they had formerly depended on; due to the emigration from their country of origin, they were found to have insecurity in attachment to others and experienced emotional isolation from their families (van Ecke et al., 2006). That study, however, only illuminated the experiences of individuals who were affected by a geographical change resulting in loss of support, without examining interpersonal changes between participants and their family members who had formerly provided them with support.

Several studies have explored changing dynamics between adult children and their care-recipient parents; research that revealed drastic interpersonal changes in this population appeared rarely, sometimes after 10 years of silence on the topic. The possibility of change in the dynamic between older dependent individuals and their adult child caregivers has been sporadically explored; a facet of the change was reported to

constitute a complete reversal of the parent/child role (Brown, 2007; Crouch, 1987; Watson & Mears, 1996).

Some research has explored the effects of dynamic changes on both members of a caregiving dyad. While current research has stressed how dynamic changes such as caregiver stress affecting dementia care-recipients (Campbell, 2009), and power shifts in collaborative decision-making (Cicirelli, 2006; McConigley et al., 2010), interpersonal changes within caregiving dyads, with time and dependency as intervening factors, have barely been acknowledged by caregiving literature. Montgomery and Kosloski (2009) recognized that change occurs over time in the interpersonal relationships between dependent parents and caregiving adult children; however, the focus was on how caregiving participants' sense of identity was affected by that change. Of recent literature that studied interpersonal changes over time in caregiving dyads, emphasis was on predetermined variables such as decision-making (Cicirelli, 2006; McConigley et al., 2010), identity (Montgomery & Kosloski, 2009), and caregiver stress (Campbell, 2009).

In the current study, participants reported how dependency is associated with changes in dyadic dynamics; all participants reported some changes that occurred, over time, in the relationship with their parent(s). Role reversal was reported by eight out of 10 participants in the current study; participants revealed how this dramatic shift in roles affected the dynamic between themselves and their dependent parents. Prior to this study, the existence of adult child/dependent parent role reversal was acknowledged in gerontological literature (Crouch, 1987), criticized as inaccurate (Brody, 1990; Selzer, 1990), and again presumed valid in a study of family caregiving (Watson & Mears,

1996). Haseltine (2001) discussed the phenomenon in a medical journal. Mayseless et al. (2004) qualitatively analyzed interviews with adults who reported early parent/child role reversal, noting how role reversal can occur specific to, say, a physical disability of the parent, without entirely disrupting original roles of “parent” and “child.” Role reversal was re-examined by Ziemba and Lynch-Sauer (2005) in an article on women and aging. Brown (2007) examined care recipient experiences in caregiving dyads; in this study, care recipients reported role reversal and loss of control. Interpersonal effects of dependency, including role reversal, have been explored consistently, yet sporadically, in prior caregiving literature.

Prior to the current study, no recent studies were found that specifically explored the concept of role reversal in the adult child/dependent parent dyad, reported by half the participants in Ziemba and Lynch-Sauer (2005). That study focused on the single aspect of adult daughters’ preparedness for becoming caregiver to their parents. According to that study, adult daughters who become caregivers experience both the loss of a parent and the loss of their own youthfulness. Role reversal, in the aforementioned study, was viewed from the perspective of adult daughters who had to abandon the idea that the now-dependent parent will continue to provide them with parenting (p. 103). The “dual-loss” theme was repeated in the article by a description of how adult daughters must face not only their own aging process but also that of their parent(s) (Ziemba & Lynch-Sauer, 2005). Brown (2007) explored the dyadic dynamic from the perspective of care-recipients, specifically noting a sense of losing control. That study stressed the importance of shifting research focus in this population to interpersonal relationship

experiences. The purpose of the current study was not to highlight emotional aspects of the adult child/dependent parent dyad, rather it examined the interpersonal dynamic, reported by adult children, as to the effects of dependency on the evolving dyadic dynamic.

### **Summary**

Research has revealed links between dependency and specific care-recipient illnesses such as AD, stroke, heart disease, diabetes, and cancer; as symptoms of each disease increase, dependency on caregivers likewise increases. Other factors such as family dynamics, interpersonal role conflicts, caregiver health, financial stressors, and cultural factors affect caregiver stress levels. In a caregiving/care-receiving dyad, stress affects both dyadic members; the resultant dynamic changes, in turn, affect the larger family system, which can respond by affecting changes back to the dyad, and so on. The qualitative research as shown in the current study has provided introductory material for future research on specific challenges faced by a sample of the growing number of adult children in the United States who provide caregiving to dependent parents.

## Chapter 3: Research Method

### **Introduction**

The current study explored a neglected area in caregiving research using a qualitative, phenomenological design. This design was chosen for reasons explained in this chapter. Inherent in this design paradigm are the dual assumptions that, first, the caregiving/care-receiving dynamic is a living entity that continually evolves, and, second, that this relationship originated when the dyad was first established, usually at the birth of the now-adult child. These assumptions combined to form the basis for examining the adult child/dependent parent dyadic dynamic.

Both Bowenian theory and attachment theory presume that changes occur automatically—for example, when anxiety becomes overwhelming for at least one dyadic member (van Ecke et al., 2006). Participants in the current study, adult child caregivers, were recruited for their perceived immersion in, and, thus, presumed experience with, the emergent dynamic of dependency over time. Open-ended questions that addressed these unique caregiving experiences matched the level of scrutiny sought by the researcher. Both the research questions and interview questions are presented in this chapter.

Socio-cultural problems addressed by the current study include lack of qualitative research attention to the complex plight of informal caregivers, who, by definition, deliver unpaid caregiving to family members or close friends in their homes. Responses to interview questions by adult child caregivers provided descriptions of experiences that highlighted the dynamic of dependency and how it affects the caregiver/care-recipient dyad. Researcher analysis of collected data elucidated descriptions of emerging

phenomena related to dependency, without the intrusion of objective assessments that would have obscured the essence of the interpersonal dynamics reported by participants.

### **Study Design**

A qualitative research method provides reflections and subsequent analyses of lived experiences, as opposed to presentations and analyses of assessment scores and other types of objective inquiry that can distance researchers from study data. The current study examined personal experiences of the phenomenon that developed through the addition of dependency to the adult child/parent caregiving dynamic. Inasmuch as phenomena are products of individual perceptions (Moustakas, 1994), an examination of specific circumstances surrounding care-recipient dependency provided by informal caregivers illuminated unique participant experiences. Ziembra and Lynch-Sauer (2005) examined the effects of multiple losses on informal caregivers to care-recipient parents. Ziembra and Lynch-Sauer used data from a mixed-methods study to highlight specific experiences related to preparedness for providing caregiving within the adult child/dependent parent dynamic. Clukey (2008) extended research on the phenomenon of grief through highlighting the experience of anticipating loss. Clukey examined aspects of that phenomenon through personal interviews with informal caregivers who were asked to report retrospectively on their experiences. Highlighting personal experiences with dependency in caregiving/care-receiving dyads will, hopefully, lead to a deeper understanding of this component of the caregiving experience.

The idea for the current study design emerged from a desire to, first, highlight the dynamic being explored (the phenomenon of care-recipient dependency added to the

informal caregiving/care-receiving dyad), and then to examine participant responses related to the resulting phenomena under study. It was not possible, due to methodology constraints, to objectively observe the dynamic under exploration; therefore, subjective reporting by participants was utilized. I chose an empirical phenomenological design to examine the unique phenomenon of care-recipient dependency. This research approach involved a focus on the phenomena within the revealed experiences of selected participants (Moustakas, 1994). An advantage to this design was found in the preservation of the dynamic in its natural environment, as recalled by the study's participants. Empirical phenomenological research involves gathering descriptions of participant experiences with the phenomenon under study, then reflectively analyzing the underlying structural components that have come to light (Moustakas, 1994). The phenomenological research design served to both highlight and preserve the dynamic under study.

### **Role of the Researcher**

In the interest of ease and simplicity of data gathering, I recruited participants, conducted tape-recorded interviews with each participant, and collected, transcribed, and analyzed data from the interviews. Singlehanded data management proved to be efficient in maximizing opportunities to develop a growing understanding that would accompany immersion in the phenomenon under study. According to Moustakas (1994), qualitative research can provide contextual understandings of phenomena through adopting a focus on “the whole picture” and meaning making, as opposed to presentations of facts. Having as complete an understanding as possible of the phenomenon of care-recipient

dependency as described by caregivers led to the desired experience of substantive theory development.

### **Selection of Participants**

I recruited all volunteer participants from online caregiver support groups. I distributed flyers to support group facilitators who expressed interest through responding to email requests; volunteers were gathered by collecting email responses to flyers posted by willing group facilitators. Criteria used to screen prospective participants were as follows: (a) having provided caregiving for 6 months or longer and (b) providing care to a parent who is at least 80 years of age. I chose both these criteria to maximize the likelihood that care-recipient dependency would be recognizable to adult child caregivers within their dyadic dynamics.

The primary goal of conducting this research was to elucidate caregiver experiences of specific interrelational dynamics; therefore all interview questions reflected this focus. I have been working with families of dependent older adults for several years in a clinical capacity, so every attempt was made to avoid researcher bias in the structuring of the interview questions.

The focus of the current study was on unique caregiver experiences, so I chose subjective reporting by informal caregivers to best capture the desired data. Katz et al. (2009) used retrospective reporting to examine the experience of a daughter's emotional role reversal with parents. Undergraduate student participants in that study were asked to report childhood experiences that implied mother/daughter role reversal; possible "memory bias" (p. 193) was among the study limitations. The current study may also be

subject to this type of participant bias; however, the support groups from which participants were chosen consisted of informal caregivers who were currently providing services to care recipients, thus narrowing the gap between events and memory retrieval. Furthermore, caregiver/care-recipient dynamics remain essentially stable due to the inherent interplay of reciprocal emotional processes (Kerr & Bowen, 1988). The impact of care-recipient dependency, comprising the focus of the current study, was made accessible through participant self-reports; these data will, in turn, inform current and future research on interpersonal dynamics of informal caregiving/care-receiving dyads.

### **Procedure**

All qualitative, phenomenological studies rely on human observation and data collection. In the current study, subjective accounts of experiences, described by study participants in audiotaped interviews and reflectively analyzed are presented in their original form. Telephone interviews with participants continued until saturation was reached. I desired to recruit 10 participants at most; this number of participants proved adequate to the task of reaching saturation. Participant data, collected through posing a prepared set of interview questions to each participant, are presumed to provide authentic accounts of individual experiences with care recipient dependency. Human observation and data collection, used to both generate and analyze the data, provided authentic accounts of the phenomenon under study. Some qualitative studies, while not as plentiful as quantitative or mixed-methods studies of caregiving experiences used similar methodology.

An emergent qualitative design allows a new theory about phenomena to emerge from the data during the data collection and analysis process (McConigley et al., 2010). McConigley et al. used an emergent study design to gather and present data supplied by carers of patients with aggressive brain cancer. The aforementioned study utilized “expert knowledge and clinical experience” (p. 474) to approach human subjects, collect data, and perform data analysis. The theory that emerged from the research of McConigley et al. was informed by the central theme concerning the speed at which informal caregivers of high-grade glioma patients must perform in order to effectively provide care. While the patients were undergoing rapid physical and cognitive changes, the caregivers, in turn, were compelled to act more quickly than they would have if the patients’ cancers had not been so aggressive. Therefore, McConigley et al. surmised that informal caregivers to patients with aggressive brain cancer may face higher stress levels than informal caregivers to patients with types of cancer with longer disease trajectories. The current study aligned with grounded theory methodology as described by Moustakas (1994) by allowing a theory to emerge that is based on the collected data, the process of collection and analysis, and my own experience of collecting these particular data from study participants.

Research questions addressed in the current study were as follows: (a) how do adult child caregivers experience parental dependency? (b) how does dependency affect the aforementioned caregiver/care-recipient dynamic? Interview questions representing both of the aforementioned research questions highlighted individual experiences with

dependency, then applied perceptions of how dependency had affected child/parent dynamics over time.

Interview questions for current study participants were as follows:

1. Tell me about your caregiving relationship with your parent(s). When did it begin? Where does the caregiving take place?
2. Please describe how this caregiving relationship got started. How did you and your parent(s) decide that you would provide caregiving?
3. What were your expectations for this caregiving arrangement? Have your expectations changed over time? Has the real caregiving experience been the same or different from your expectations? How?
4. Would it be accurate to say that your parent(s) depends on you for care? Could you give me some examples of that dependency?
5. How do you think dependency has changed your relationship with your parent(s) since you began caregiving?
6. Is there anything I have not asked you about your caregiving relationship with your parent(s) that you would like to share?

As researcher-participant interviews evolved, clarifying questions were needed to ensure accuracy of responses. Appendix F provides a sample of each interview transcript.

### **Data Analysis**

Analysis of collected data followed a procedure described in Moustakas (1994); I developed themes and created codes singlehandedly in response to the emerging themes. Moustakas's seven-step modification of the van Kaam method of data analysis provided

an outline for an in-depth examination of qualitative data, including criteria for elimination of textual descriptions that do not aid in understanding and/or explicating the phenomenon under study. According to Moustakas, this examination includes, first, obtaining a complete transcription of an interview. Next, a list is constructed that includes all expressions relevant to the participant's experience with the phenomenon. Then, each expression on the list is tested, in the interest of eliminating redundancy, against the dual criteria of (a) whether it is necessary for the purpose of understanding the experience, and (b) whether it can be presented in abstract form and labeled. Data that meet these criteria are called "invariant constituents" (Moustakas, 1994, p. 121).

From the data chosen for further examination, themes are formed into clusters, then labeled, that best represent points of convergence of participant responses, and that will best aid in concisely and comprehensively presenting the data. Next, all the aforementioned steps must undergo "final identification" (p. 121) by checking each invariant constituent and each developed theme against each participant's transcribed interview for relevance based on explicitness and compatibility. Next, the researcher develops an "individual textural description," including verbatim examples, then an "individual structural description" for each participant from her/his own data. Finally, a "textural-structural description" is compiled for each participant that conveys "the meanings and essences of the experience," followed by a "composite description of the meanings and essences of the experience, representing the group as a whole" (Moustakas, 1994, p. 121).

I had originally planned to use software to streamline the process of theme development and data analysis; this idea was abandoned upon realizing the ease at which this process could be accomplished by hand. Singlehanded processing of interpretation and theory-generation proved to be efficient and provided optimal control over the theme development process. Nonverbal communication was recorded and presented as auditory data, following the example of Ziemba and Lynch-Sauer (2005), and included, in italics and parentheses, as part of the transcription. Next, I developed a manual coding system that extracted only pertinent data for theme development, which I then color-coded to signify individual participant responses and categorized into six themes that emerged logically from the available data.

### **Ethical Treatment of Participants**

Participants in the current study were advised of the nature of the research and the possible risks and benefits of their involvement in this study (see Appendix C). I anticipated that participants who showed interest and enthusiasm for an examination of care-recipient dependency would not be adversely affected by the interview process. The interview questions were expected to bring participants face to face with unexpected emotions; therefore, I included a warning statement to this effect in the informed consent and was prepared to manage emotional upsets should they occur, with empathy to match circumstances. I was also prepared, if necessary, to remind participants of their freedom to withdraw from the study at any time, or to provide telephone numbers and locations of local therapists who could provide help specific to their needs. During the data collection

process, no instances arose that required the aforementioned precautions to come into play.

Participants were advised that their participation was voluntary, that there would be no monetary or other compensation provided, and that they could withdraw from the study at any time. Participant confidentiality and the legal limits to confidentiality were addressed as participants were presented with informed consent documents to sign, date, and return. Interview dates and times were agreed upon by myself and the participants to afford privacy and to allow participants to maintain proximity to their parent/care-recipients, if needed. Interviews involved open-ended questions therefore I was prepared to arrange several meeting times for completion.

According to Walden University's Institutional Review Board (IRB), permission must be obtained by a student from the IRB prior to data collection to ensure that ethical procedures will be utilized and maintained. I then, accordingly, submitted the required application to the IRB before beginning the data collection process. The IRB issued approval number 10-27-11-0041697 for data collection in the current study, which expired on October 27, 2012.

### **Summary**

To conclude, this chapter presented the current research methodology by first presenting a review of the nature and purpose of the study underlying the selection of the study design. Then, basic theoretical assumptions compelling the use of a qualitative, phenomenological approach to data collection, analysis, and reporting of findings were presented, along with a brief review of the study's purpose and significance.

A description and rationale for the selection of the study design included comparisons to other designs that were determined not to be suitable for this research. The methods for participant selection and data collection were presented, and the instrumentation was discussed. Research questions and interview questions were presented, and an explanation for the selection of the data analysis methodology included a description, with examples, of this type of analysis. An explanation of how I ensured ethical treatment of the current study's participants completed this chapter. Chapter 4 will present the results with examples from participant data.

## Chapter 4: Results

### **Introduction**

This chapter presents the results of the current study, continuing the qualitative exploration of the adult child/dependent parent caregiving experience conducted by Ziemba and Lynch-Sauer (2005). In order to further explore the dependency phenomenon, two research questions—“How do adult children experience parental dependency?” and “How does dependency affect the adult child/parent relationship?”—were addressed through posing six open-ended questions to 10 participants (see Appendix D). Each of the interviews was conducted over the telephone while being tape-recorded and was later transcribed by hand. A pilot study was conducted to ensure applicability of interview questions and to test the voice recording equipment. The next section will describe the pilot study process, followed by a presentation of participant demographics. Then, the data collection process is described, followed by a description of the data analysis and evidence of trustworthiness. A summary of the contents of this chapter follows a presentation of the results, organized by research questions.

### **Pilot Study**

A pilot study was conducted prior to data collection. A workplace acquaintance, who was a caregiver to a dependent parent, agreed to participate in the pilot study and returned a signed informed consent document to the researcher’s email address prior to beginning the interview process. The pilot interview was completed over the telephone and was audio-recorded without difficulties. Since data collection proceeded without difficulty throughout the pilot study, the interview questions and the voice recording

equipment were considered trustworthy and data collection began without making strategic or instrumental changes.

### **Participant Demographics**

Participants were not asked to provide demographic information beyond a general geographic location where the caregiving took place, the parent or parents (i.e., mother or father or both) for which the participant provided caregiving, and participant gender. The paucity of collected demographic data was in the interest of eliciting frank responses to interview questions while providing the reader with a vague visual description of each participant. All of the individuals who responded to participant recruitment flyers were female; this fact and any speculation as to reasons for it could be a topic for future research. General geographic location was elicited and provided to add depth to visual descriptions for the reader. Table 1 provides the demographic information collected from each participant. Participants were identified by the letter “P” for “participant” and a subject number from 1-10: “P1, P2, P3,” and so on. Some participants were presented twice to indicate they provided caregiving to both parents (P1, P2).

Table 1

*Participant Demographics*

	Where Does Participant Live?	Where Does Caregiving Take Place?	Which Parent(s) is Care Recipient?	Participant Gender
P1	TX	Care Recipient's Home	Father	Female
P1	TX	Caregiver's Home	Mother	Female
P2	PA	Independent Living Facility	Mother	Female
P2	PA	Caregiver's Home	Father	Female
P3	WA	Caregiver's Home	Mother	Female
P4	IL	Independent Living Facility	Mother/Father	Female
P5	CA	Caregiver's Home	Mother	Female
P6	WA	Assisted Living Facility	Mother	Female
P7	WA	Assisted Living Facility	Mother	Female
P8	MA	Care Recipients' Home	Mother/Father	Female
P9	IA	Assisted Living Facility	Mother	Female
P10	WA	Care Recipient's Home	Mother	Female

### **Data Collection**

Eight participants were recruited for this study through screened responses to printed requests posted by facilitators of caregiver support groups (see Appendix A), listed by the website <http://www.caregiver.com>, throughout the United States. Caregiver.com provides names and email addresses/telephone numbers of caregiver support group facilitators, organized state by state and county by county. I sent requests to support group facilitators in Washington, Florida, Vermont, Massachusetts, Georgia, Nebraska, Pennsylvania, Iowa, Texas, and California, selected at random in an attempt to cover as wide an area of the United States as possible until saturation of data was reached. Potential participants responded to flyers posted by their caregiving support group facilitators (see Appendix B); once an emailed assent to participate in the current study was received, I emailed the interested party an informed consent document (see Appendix C) with instructions to electronically sign and return, with a telephone number, to my university email address. Once I received an email that included both a signed informed consent document and a telephone number, I called the participant on the telephone and scheduled a date and time for the interview that was convenient for us both. Two participants were workplace acquaintances who volunteered for the study; the procedure of collecting informed consents and scheduling telephone interviews followed an identical path to that used for participants who were recruited from the caregiver.com website.

Criteria for participation in the current study were as follows: (a) having English proficiency and (b) having provided caregiving for at least six months to a care-recipient

parent or parents 80 years of age or older (see Appendix A). All participants who responded affirmatively to the printed recruitment requests met all criteria and were accepted for participation in the current study. All participants submitted signed informed consents (see Appendix C) through email correspondence. Each interview was scheduled at a convenient time for myself and each participant; all interviews were conducted over the telephone to ensure uniformity of data collection, and all were tape-recorded. Once eligibility was determined for each of the 10 participants, informed consents were collected, and interviews were scheduled and completed over the telephone.

Participants were asked to respond to six open-ended questions designed to correspond to the research questions (see Appendix D). No additional questions were posed to participants beyond what was necessary for clarification of existing data. All 10 participants completed the entire interview process; none of the interviews lasted over 2 hours. I remained alert to the possibility that participants could experience overwhelming emotions at any time during the interview process. However, all interviews proceeded smoothly; emotions that appeared to surface during some interviews did not appear to cause participants unmanageable distress. The interview processes for all 10 participants were completed without intervening circumstances that caused participants to withdraw from the current study.

## Data Analysis

### Theme Development

As interviews were transcribed, responses were coded and categorized into evolving themes. I designed a manual coding scheme, which proved to be more compatible with the desired presentation of data than coding software. The “invariant constituents” (Moustakas, 1994, p. 121), or data that met the dual criteria of relevance to the research questions and capability of conversion to abstract form and labeling, were grouped under six theme headings. During the transcription process, invariant constituents were identified according to applicability to the research questions. When a participant included data in response to a question, for example, that reflected a repetition of what she said earlier in the interview, those words/sentences were not included in the transcription and were represented by an ellipsis. Only statements that directly addressed the research questions and were capable of inclusion into the coding scheme were included.

Viewed together, Research Questions 1 and 2 were designed to first introduce and then to explore the topic of dependency in the adult child/dependent parent relationship. The first research question (“How do adult children experience parental dependency?”) prompted Interview Questions 1 and 2. Interview Question 1 included two subquestions: “Tell me about your caregiving relationship with your parent(s). When did it begin and where did the caregiving take place?” These questions encouraged participants to think back to the beginning of their caregiving experiences. Five out of 10 participants provided large amounts of data in response to Interview Question 1. Two of the

transcribed responses to Question 1 covered more than one typed, single-spaced page (P1, P6), while three other responses to Question 1 covered more than one-half page (P2, P4, P9). Once participants had completed responses to the introductory question/subquestions, Interview Question 2, with one subquestion, called for more specificity: “Please describe how this caregiving relationship got started. How did you and your parent(s) decide that you would provide caregiving?”

Participant responses to Interview Question 2/subquestion were varied, yet all converged around the idea that the participants were somehow personally designated to manage the role of care provider for their parent(s). Three participants described an automatic transition into caregiving following a change in parent/care-recipient health (P1, P9, P10). Those participants discussed evolving reciprocity stemming from declining care-recipient health, in which participants felt more and more compelled to provide what they perceived was needed. Three participants reported living in closer proximity to their care-recipient parent than other family members and indicated that they were therefore “chosen” by default to provide caregiving (P4, P7, P8). Four participants described being “expected” by their care-recipient parent to provide caregiving (P2, P3, P5, P6). All 10 participants provided responses indicating awareness of how they became caregivers to their parent(s). Themes 1 and 2 emerged during analysis of participant responses to Interview Questions 1 and 2/subquestions. Research Question 2 prompted Interview Questions 3-6, with subquestions.

Research Question 2 (“How does dependency affect the adult child/dependent parent relationship?”) led to the development of Interview Questions 3-6 and,

subsequently, to Themes 3-6. Interview Question 3 required participants to return to thinking about the beginning of their caregiving experience: “What were your expectations for this caregiving arrangement? Have your expectations changed over time? Has the real caregiving experience been the same or different from your expectations? How?” This question/subquestions introduced the idea of “expectations” to participants; those who had not already remarked on this topic in earlier responses now were asked to consider whether their original expectations matched their actual caregiving experiences. Participant responses to Question 3 varied, yet all who recognized that their expectations had changed over time provided detailed responses; most discussed several ways in which their original expectations had changed. Four participants responded that they had not expected the caregiving experience to involve so much work (P2, P4, P9, P10). Three participants discussed how they had expected their parent(s) to do more for themselves (P6, P7, P8), two participants described how they had not expected their parent(s) to cling to their independence (P4, P10), and one participant responded that she had expected more help from others (P1). Interview Question 4 introduced the topic of care-recipient dependency to participants.

Interview Question 4 included one subquestion: “Would it be accurate to say your parent(s) depends on you for care? Could you give me some examples of that dependency?” Six participants cited specific ways in which their parent(s) depended on them for care (P1, P2, P3, P6, P7, P10). Two participants described how parent/care-recipient dependency increased over time, citing specific examples (P1, P5). Two participant responses to Question 4 and the accompanying subquestion reported that their

parent depended on them for care yet the parent did not realize he/she was doing so (P4, P9).

Interview Question 5 asked participants to reflect upon the effects of dependency on the relationship with their care-recipient parent: “How do you think dependency has changed your relationship with your parent(s) since you began caregiving?” Three participants reported a change in roles between themselves and their care-recipient parent(s) (P10, P5, P7). Two participants responded that their relationship was a continuation of a positive relationship with their parent and denied a change in that relationship since the parent became dependent (P1, P9). Two participants reported having become closer to their care-recipient parent since dependency added to that relationship (P2, P6).

Interview Question 6 addressed any afterthoughts the participants may have about any of the other interview questions. This final interview question elicited participant data that contributed to emergence of themes. For example, nine out of 10 participants gave substantive responses to Question 6, four of which contributed to theme development (P1, P5, P8, P10). Three participants added more details to their previous descriptions of specific aspects of their caregiving experiences (P2, P7, P9), while two participants provided responses in the form of advice for other caregivers (P6, P7). One participant responded that she had no more to share. Trustworthiness of acquired data is addressed in the next section.

### **Evidence of Quality**

Quality in the current study was maintained by ensuring accuracy of data. The data collection process was undertaken singlehandedly following a procedure that was consistent from one participant contact to the next. Once a participant emailed a response to a flyer describing the current study (see Appendix A), posted by a support group facilitator, I replied to that email with an informed consent (see Appendix C) and a request for a telephone number. Once I received the signed informed consent by email, I called the participant on the telephone and scheduled a tape-recorded interview at a time that was convenient for both of us.

All interviews were conducted from my home telephone, which was connected, through an adapter, to a tape recording device. Each completed interview was then digitally placed into an electronic folder within the operating system of the recording device that I subsequently labeled “A, B, C,” and so on, and the electronic locations of each interview were manually recorded and kept with other field notes. Once audio recordings of all 10 interviews had been compiled on the tape recorder, I downloaded the contents of each interview onto a file in my computer, to provide a password-protected backup system for the data. Field notes in this research consisted of scheduled dates, times, and telephone numbers for each of the 10 participants. Also included were typed transcriptions of each interview, locations of interviews within the tape recording device and the backup system in my computer, and a results matrix developed to display participant responses under each of the six themes that evolved out of the interview data (see Appendix E).

Each participant's responses to interview questions that formed each theme are identifiable on the Results Matrix by color-coding, developed by the researcher for the purpose of clarity. All field notes, signed Informed Consent documents, and all audio recordings will be kept in a locked file cabinet in the researcher's home for five years, as required by Walden University's Institutional Review Board (IRB). All interviews were transcribed verbatim and all audio-recordings remain available for inspection by each participant for 5 years. Individual transcriptions were not presented to participants for perusal prior to inclusion in data analysis. Recording of all data during the collection process and maintenance of acquired data followed Walden University's IRB policies. Table 2 provides the distribution of participant responses matching each theme.

Table 2

*Numbers of Participant Responses to Each Theme*

	Caregiving Evolved On its Own	Not Enough Help	Expectations Changed	Dementia Caused Changes	New Relationship Provided Benefits	Changed Roles
P1	X	X	X	X	X	X
P2	X	X	X	X	X	X
P3	X	X		X	X	X
P4	X	X	X	X		X
P5	X	X		X		X
P6	X	X	X	X	X	
P7	X	X	X			X
P8		X	X	X		X
P9	X	X	X		X	
P10		X	X			X

## Results

This section provides explanations of how themes 1-6 evolved from participant responses to interview questions. This section includes examples from participant data to support the formation of each theme, organized by research questions.

### **Research Question 1: How Do Adult Children Experience Parental Dependency?**

**Theme 1: Caregiving evolved on its own.** Research question 1 prompted interview question 1 and subquestions: “Tell me about your caregiving relationship with your parent(s). When did it begin and where does the caregiving take place?” Eight out of 10 participant responses to this question contributed to the theme that caregiving for their parent(s) followed an evolutionary process. Other responses described logical processions of events that led to the participants assuming caregiving roles; however, participants 8 and 10 did not describe their caregiving experiences as “evolving.” Some examples of participant responses that contributed to the theme of their caregiving experiences as “evolving” are as follows:

I brought her (Mom) here to visit and she didn't want to go back so I've had her about 3 ½ years . . .she begged and cried and pleaded to stay with me and I couldn't send her back [to my sister's]. [With Dad] . . .there was never a question, especially when my dad got to where he couldn't keep a checkbook. (P1)

It's been an evolving thing . . .so there's no single answer to that. [Mom] started calling me . . . like, a couple of times a week, grew to once a day . . . and eventually . . .she would call me in hysterics: 'I don't know what to do . . .' over

trivial things that she had always had been perfectly capable of solving herself.

(P2)

We did get me on her checking account, and she was still pretty . . . alert at that time when all *that* was taking place, so that made it pretty simple, and thank *God* I did *that*, because I had to do that. So, that's when it pretty much started . . .again, she is 85, so it's . . .been over time that she's . . .gotten more and more . . .needy.

(P7)

**Theme 2: Not enough help from family/friends.** All 10 participants contributed responses leading to emergence of the theme of not receiving enough help from family, friends, or both, during the caregiving experience. Each participant described her caregiving circumstances as needful of help from others that had not been forthcoming. While some participants reported receiving some caregiving help from others, all described needing more help in specific areas. For example, one participant described asking her sister for specific help, with a warning that if she didn't provide any help at all, the entire caregiving burden might fall to her. Examples of participant responses contributing to Theme 2 are as follows:

I'm the only one that lives in Texas . . .and my other sisters all live in Tennessee . . .we expected more from the other siblings and it just didn't happen . . . We pastored this church 40 years and you would think after 40 years . . .somebody would have said, 'Why don't . . .you let me sit with your mom for an hour where you can go to the store' . . .but . . .*not once* . . . and *that's sad!* (P1)

. . .the family expected me, being the only one that wasn't married, to move back and take care of Mom . . .and . . .my mom and I had a difficult relationship. My sister would never commit to *anything* . . . it was very frustrating . . . And when she would get sick I would kind of freak out . . .I'm the one non-medical person in the family. (P3)

I told my sister I need her to come and help me, so she would come . . .every three months and give me a break where I would get away, and then she would try to come down as her job permitted once a week, so I wouldn't have to go home at lunch after I started working again . . .just to keep me sane. So . . .I told my sister, explained the situation, and I said it would all fall on *her*, so she helped me out.

(P5)

## **Research Question 2: How Does Dependency Affect the Adult Child/Parent Relationship?**

**Theme 3: Expectations changed.** Eight out of 10 participants endorsed the theme that expectations of the caregiving arrangement with their parent(s) changed over time. While each participant endorsing Theme 3 described entirely different ways in which her caregiving experience “changed over time,” all responses converged around the idea that they had underestimated the sheer amount and, in some cases, the difficulty of tasks they would need to do as caregivers for their parent(s). Some examples are as follows:

I'd expect I'd be less of a caretaker . . .I'm expecting now when they come back from Florida that in time . . .he probably won't recognize me in six more months .

. .I think I'm going to be less of a caretaker as this disease gets worse . . .I don't think I have the facility to deal with it. (P8)

Well, I thought (\*laughs\*) when we brought him down here that this would be this idyllic situation. . .it's been a *lot* harder, a *lot* harder . . .and I thought, because we had them in assisted living instead of in her home, we would kind of have it made . . .and it never ended up being like that. (P9)

I never thought it would be so involved . . .taking care of a parent . . .you just don't think about that . . .on tv . . .people think parents are still pretty spry until they have this lovely bedside 'fading away' and that's not at all how it is. My dad had so many health problems and he just was so uncooperative about anybody helping him out . . . (P10)

**Theme 4: Dementia caused a change in the relationship.** Seven out of 10 participants contributed responses leading to the emergence of Theme 4. These participants described circumstances in which dementia in the parent(s) caused a change in the adult child/dependent parent relationship. Each response included specific instances in which dementia in the parent was evident. Examples are as follows:

Twice a week I would take him out to lunch. He would just stare at me like a zombie . . . it was very, very, sad. He used to be very verbal; he was a stock-broker before having Alzheimer's. He was forced to retire at 70 years old which was the worst thing in the world . . .I would take him twice a week to doctors cause my mother doesn't drive well . . .and . . . he would urinate in his pants . . .this is part of the Alzheimer's thing. (P8)

Like the last time she fell about a month ago . . . went out to get the paper, and she has a Life Alert that we got for her and she wears it around her neck and she didn't press it. She has dementia, among other things. She has a Life Alert on her walker, she can't even walk across the room without her 'buggy' . . . and she didn't press *anything*. She lay on the floor for *hours* until my sister-in-law came over to see how's Grandma today. And then she wouldn't go to the hospital . . .  
 ..(P10)

**Theme 5: Changed relationship provides benefits.** Responses of five out of 10 participants contributed to emergence of the theme that benefits arose from the change in the adult child/dependent relationship. Four out of these five responses described situations in which participants grew closer to their parent, while one discussed the benefit of “giving back” to parents who had given to others in the past. Some examples of contributions to Theme 4 are as follows:

I wouldn't trade it . . . I wouldn't trade it . . . I would remind myself 'I'm paying back . . . a little bit,' and my parents . . . always done for other people . . . so it's just giving back a little bit, a portion of what was given to me . . . And it makes you feel good . . .(P1)

But she gradually came . . . around . . . she gradually began to realize that I actually was helping and that she actually needed the help, and so then she softened up and sweetened up a bit . . . actually, not just a bit, a whole lot, and the strife dissolved and she and I started getting closer—for the first time in my adult life she started treating me like a *peer* at least for awhile there. (P2)

I guess . . . in some ways, that time we had together allowed me to heal some childhood wounds . . .when we'd have issues and then . . .when I would respond differently, then I'd get a different result with her and . . .in some ways we were closer. (P3)

**Theme 6: Changed roles.** Eight out of 10 participants contributed to the emergence of the theme of experiencing a change in roles from roles experienced by participants in the original adult child/parent relationship. All those participants discussed a role reversal in which the parent filled the role of “child” and the adult child filled the role of “parent.” Some examples are as follows:

. . .it's like you do with your own children—‘Here I am doing this for you and you don't even care!’ (\*laughs\*) (P1)

I'm learning to take more of . . . an assertive role in making their appointments . . .whereas before they would . . .make their appointments and see if it would work for me, and now I am actually making the appointments and I'm asking the doctors to call me when they're reporting diagnosis because . . .I'm . . .going to have to talk to them anyway. So I'm doing more of . . .the kind of role that I did with my own children, that my mother did with me when . . .we were in grade school . . .more of that kind of thing . . .(P4)

As time goes by and as they decline, they become like the child and you become like the parent. (P5)

I almost have to treat her with the same kind of care that I treat my almost 2-year-old grandson . . .it . . .is kind of an . . .*odd feeling* to know that the person that was

in charge of you for your whole life can no longer do that, and now you're . . .  
 .pretty much in charge of them, so . . .most of her life she's been a caregiver for  
*us*, and now I find myself in that role as a caregiver for *her*. (P7)

### Summary

This chapter provided results, in the form of participant responses to interview questions, that explored the experiences of 10 adult child caregivers with care-recipient parental dependency. In summary, Research Question 1, “How do adult children experience parental dependency?” was answered through Themes 1 and 2. Theme 1 concerned the way in which the caregiving relationship between participants and their dependent parents originated, with eight out of 10 participants reporting that this process “evolved on its own.” Theme 2 described participant experiences with care-recipient dependency as “not [receiving] enough help from family/friends.” Theme 2 was valid for all 10 participants, making this theme a universally relevant answer to research question 1. Research Question 2, “How does dependency affect the adult child/dependent parent relationship?” was answered through developing Themes 3-6.

Answering Research Question 2 revealed four changes following the addition of dependency to caregiving/care-receiving relationships with parents. Two participants reported changes in four areas (P1, P2), four participants reported changes in three areas (P3, P4, P6, P8), and four participants reported changes in two areas (P5, P7, P9, P10). Thus, all participant data described at least two changes that corresponded to adding dependency to their relationship with a parent(s). Reported changes in relationships with parents included changes in caregiver expectations, changes brought on by parental

dementia, benefits experienced by caregivers, and changes in the child/parent roles. All participants in the current study described changes in the adult child/parent relationship with the addition of care-recipient dependency. Chapter 5 follows this presentation of the current study's results with an analysis of the results, conclusions from the data, implications for social change, and recommendations for future research on this topic.

## Chapter 5: Discussion, Conclusions, and Recommendations

### **Introduction**

The purpose of the current qualitative, phenomenological study was to highlight the interpersonal dynamics of adult children experiencing parental dependency. A focused exploration of the possibility of change, over time, in the caregiving adult child/care-recipient dependent parent dynamic, suggested by both attachment and Bowen's theory, and role conceptualizations, comprised the impetus for developing the research questions: "How do adult children experience parental dependency?" And, "How does dependency affect the aforementioned caregiver/care-recipient dynamic?" To accomplish this exploration, I developed six interview questions, most including subquestions, and posed them in structured interview format to each participant.

The first two interview questions examined participant caregiving experiences in general, including an exploration of when and how the adult child/parent relationship became a caregiving/care-receiving experience: "Tell me about your caregiving relationship with your parent(s). When did it begin? Where does the caregiving take place?" and "Please describe how this caregiving relationship got started. How did you and your parent(s) decide that you would provide caregiving?" The purpose of starting the interview with general questions was to develop a reflective focus that could be expanded with subsequent questions. Two main themes developed from data generated in response to the first two interview questions.

The first main theme evolved from participant responses to Interview Questions 1 and 2 that directly explored the origin of the caregiver/care-recipient relationship. Theme

1, “Caregiving evolved on its own,” was endorsed by 8 out of 10 participants. Typical participant responses reflected on care-recipient behavior that compelled caregiver/participants to spend increasing amounts of time providing assistance to care-recipient parents. The second main theme also emerged from the first research question inviting responses describing general aspects of the caregiving experience.

Theme 2, “Not enough help from family/friends,” evolved from participant responses to Interview Questions 1 and 2 and the subquestions therein. Endorsed by all 10 participants, this theme emerged from responses detailing events and circumstances illustrating the idea that, although other family members or friends could have volunteered to provide caregiving to the particular parent(s), the participant perceived herself as doing almost all of the care provision. The second research question led to the development of four interview questions that addressed the effects of dependency on the adult child/parent relationship.

The second research question, “How does dependency affect the aforementioned caregiver/care-recipient dynamic?” compelled the development of the final four interview questions and subquestions, directing participants to examine the dependency dynamic (if, in fact, one was reported) and its effect on the adult child/parent relationship. The third research question was intended to invite a deeper exploration of participant/caregiver ideas of how the caregiving/care-receiving relationship would manifest from the adult child/parent relationship.

The third interview question introduced the concept of “expectations” for the caregiving arrangement, inviting participants to review the original idea of what they

believed this experience would entail, and then to compare the current status of the caregiving relationship with their parent to the original expectation: “What were your expectations for this caregiving arrangement? Have your expectations changed over time? Has the real caregiving experience been the same or different from your expectations? How?” If a participant answered “no” to the subquestion “Has the real caregiving experience been the same or different from your expectations?” she was not asked the subquestion “How?” The next two interview questions addressed the concept of “dependency,” asking participants to reflect on whether they believed their parent(s) depended on them for care, and if so, what that experience was like for them.

The fourth interview question addressed the possibility of participant-experienced care-recipient dependency with two subquestions: “Would it be accurate to say that your parent(s) depends on you for care? Could you give me some examples of that dependency?” and “How do you think dependency has changed your relationship with your parent(s) since you began caregiving?” If a participant answered “no” to the first part of Question 4 (“Would it be accurate to say that your parent(s) depends on you for care?”), the participant was not asked either the second part of that question (“Could you give me some examples of that dependency?”) or Question 5 (“How do you think dependency has changed your relationship with your parent(s) since you began caregiving?”). The interview process was completed with Question 6, which invited further reflection on caregiving experiences not covered by previous interview questions.

The final interview question provided participants an opportunity to share any other aspect of their caregiving experiences that had not been addressed in the interview:

“Is there anything I have not asked you about your caregiving relationship with your parent that you would like to share?” From transcribed participant responses to all six interview questions, six main themes emerged as I color-coded and categorized the resulting data.

The following are the six themes developed from corresponding interview questions. From the question “How do adult children experience parental dependency?” two themes emerged: first, that the caregiving relationship evolved on its own, and, second, that adult child participants believed they did not receive enough help from family and/or friends. From the question “How does dependency affect the aforementioned caregiver/care-recipient dynamic?” four themes emerged: that caregiver expectations of the caregiving experience changed over time, that dementia caused changes in the adult child/dependent parent relationship, that benefits sometimes resulted when there was a change in the adult child/dependent parent relationship, and that a shift in roles sometimes occurred in the adult child/dependent parent relationship. The numbers of participants endorsing the aforementioned themes are provided in Chapter 4, Table 2.

### **Interpretation of Findings**

This section will supply connections between research questions, corresponding interview questions, and main themes that evolved from the data collection process, with examples from the data. This section will also provide conclusions that link the results of the current study with results from earlier research, and that show how the current study’s grounding theories—Bowen’s theory and attachment theory, with role

conceptualizations—contribute to understanding the data. The aforementioned connections will be presented according to which group of data evolved from what research question.

The first research question, which addressed adult child experiences with parent dependency (“How do adult children experience parent dependency?”), compelled participant responses that led to the theme of the caregiving experience as evolving from one interdyadic interaction to the next (“Caregiving evolved on its own”):

Well . . .mine’s evolving . . .mine started a little bit before my parents moved out of their home . . .it really started much more heavily 6-8 months ago as health changed . . . even more so about two months ago as my father’s “think” processes changed and . . .it . . .paralleled some new intense pain he was having in his legs and feet . . .my parents are 91 and almost 90. (P4)

Mom’s health started to deteriorate a little bit after a fall that she took and . . .she started to become more and more recluse . . . and it just evolved slowly . . .first it was just one little thing, and just got to be a little bit more and a little bit more, so it wasn’t like I just walked in and was inundated with a ton of things. (P6)

The natural evolution of the caregiver/care-recipient relationship from the original adult child/parent relationship was discussed by Bengtsson and Psouni (2008), who pointed out how reciprocity in a caregiving dyad promotes adaptation to, for example, a “maternal” role that guides the caregiver. Attachment theory explains an infant’s need for physical/emotional proximity to a caregiver by pointing out how, in early developmental stages, caregivers supply what is needed until a child is ready to progress to the next

stage. Once a child reaches adulthood, caregivers can abdicate the role of parent and bestow that role onto the child (Byng-Hall, 2008). Role dynamics within a family system are not static; they shift and change according to member circumstances and perceptions.

Lynch (2007) explained how roles are adopted by family members through observation and perception of need. According to Ziemba and Lynch-Sauer (2005), a complete reversal of roles can occur when parents relinquish a supportive role to their children and adopt a dependent role. This concept is addressed more fully as a separate theme later in this chapter. The first research question also compelled the emergence of the second theme, within which participants reported not receiving enough caregiving help from others.

The second theme, “Not enough help from family/friends,” was developed with participant data such as the following:

. . .what I really needed was somebody to . . .show up at like 4 or 4:30 in the morning, wait until Dad got up, . . .monitor Dad, give him his insulin, give him something to eat, *and then leave* . . . . Once my dad had that taken care of, . . he could sit there in his semi-catatonic state until Mom got up . . .it would be fine. So . . . all the caregivers have a minimum of 2 hours . . .and some of them have a minimum of 4, and so, I had to pay for 2 hours whether we used it or not. (P2)

Well, ours was a de facto kind of thing. I have three siblings and none of them live in the state, none of their grandchildren live in the state . . . it just kind of . . .it landed in my lap (\*laughs\*). (P4)

Akin to the theme of not receiving enough help from family/friends, Interview Questions 1 and 2 elicited responses indicating how conflicts had arisen that were related to disparate caregiving responsibilities. According to Bowen's theory, family members contribute to, and are affected by, family dynamics that are followed by continual, systemic changes (Shaffer & Stroufe, 2005). Caregiver burden, as discussed in Kang (2006) and Molloy et al. (2008), is the direct result of feeling overwhelmed by caregiver-related responsibility. A combination of circumstances can lead to caregiver burden, among them in-family conflicts. As stated by one participant,

I think as far as siblings sharing their responsibility, that's more complicated than I realized . . . I have two brothers, one who lives in Dallas so he and his wife get the brunt of the responsibility just because they're nearby, which is not fair, and he has a teenaged daughter, he has a grown son who is married and that family has all kinds of problems, so it's not fair that he . . . is pretty much stuck with the majority of this. And then my other brother lives in California, and financially he's the most secure . . . and he is the least involved, and I think it causes friction between the brothers that the one who really could be doing so much *doesn't*.

(P10)

Another source of conflict reported by some caregiver/participants and discussed in Benefield and Beck (2007) was the financial burden of traveling to and from a care-recipient parent's home or facility in order to provide caregiving. Two of the 10 participants reported traveling from state to state to care for parents (P9 and P10). According to Benefield and Beck, around 5 to 7 million Americans travel long distances

to provide informal caregiving. Role conceptualizations can also be used to characterize some data generated by the third interview question:

I never thought it would be so involved . . .taking care of a parent . . . you just don't think about that . . .on tv . . .people think parents are still pretty spry until they have this lovely bedside "fading away" and that's not at all how it is. (P10)

Accustomed to experiencing a hands-on caregiving relationship with her mother, P10 reported a sharp contrast between how the aging process and subsequent caregiving relationships were represented in the media and what she knew to be true. According to Bengtsson and Psouni (2008) and Lynch (2007), individuals within dyads have ideas of the roles they themselves and the other member of a caregiving dyad should adopt. Other participants' data reflected comparable ideas about how their original expectations as caregivers were dissimilar to what they later discovered was reality.

Theme 3 evolved from participant responses to the third interview question ("What were your expectations for this caregiving arrangement . . .?") and arose from data generated by Research Question 2: "How does dependency affect the aforementioned caregiver/care-recipient dynamic?" Theme 3, endorsed by eight out of 10 participants, reflected the idea that caregiver expectations of the caregiving experience changed over time:

. . .before 2003 I had had the expectation that . . .by living half an hour from my parents' house that I might occasionally need to go sit in the hospital while waiting for a for a parent to get through a procedure, and the time might come when I or my husband or both of us would have to go to their home once a month

or so to do some odd jobs, you know, repair little things that break and . . .that sort of thing. As of 2003, all expectations were cancelled, I never had any kind of expectations *ever again* . . . (P2)

The response from P2 reflected a sense of awakening to the realization that their caregiving experience was not what she had originally thought it would be, similar to data provided by P10. P4's caregiving experience, reflected in her response to the third interview question, revealed a different aspect of the theme of changed expectations:

I . . .quite honestly thought one of them would be gone by this point . . .*one* caregiver, *two* adults . . .and I work full time and . . . must continue to do that. It's much more *intense* than . . . I had realized . . .(P4)

Talley and Crews (2007) explained that Americans are living longer than ever and typically die from complications caused by chronic illness, as opposed to the time period prior to the introduction of antibiotics, when the average life expectancy was around 45 years. Informal caregivers are now providing the bulk of hands-on care provision to adults with chronic illnesses (Montgomery & Kosloski, 2009). P8 referred to her caregiving experience as affected by her parent's dementia:

I'd expect I'd be less of a caretaker . . . I'm expecting now when they come back from Florida that in time . . .he probably won't recognize me in 6 more months . . .I think I'm going to be less of a caretaker as this disease gets worse . . .I don't think I have the facility to deal with it. (P8)

P8's response, while corresponding to the idea of Theme 3 ("Changed expectations"), also fits the concept described by Theme 4 ("Dementia caused changes in

relationship”), which was endorsed by seven out of 10 participants. Participants who provided data that fit into Theme 4 (“Dementia caused changes . . .”) gave accounts of experiences with this condition in one or both parents that were similar across individuals:

Mom was still able to . . .take care of Dad . . .but eventually her dementia got worse and . . .we had to . . .hire somebody . . .Mom’s dementia became *violent* . . .she tried to hurt the grandkids and all kinds of things . . . (P1)

My father doesn’t want to admit he *cannot* balance his checkbook any more . . . went back with him 3 or 4 months and found three or four errors . . .he still doesn’t understand what the errors are . . .He . . . kept talking about, “It must be the bank’s fault” . . . (P4)

At the beginning her brain was fine, and she could . . .help herself get in and out of bed, I just had to lift her . . .onto a chair to wheel her around and . . .she could feed herself and everything and at the end it progressed where she needed assistance getting her out of bed and . . .I had to feed her. [There are] low times where she would . . . curse at me and . . .physically fight me and try and . . .scratch me and hurt me . . . (P5)

Most of the participants who reported experiencing dementia in their care-recipient parents described a series of events that indicated a steady progression of the disease:

During that period before I took them into my house to take care of them . . . something happened to her . . .maybe she had some TIAs . . . I don’t know . . . but

something happened . . .and she's been in cognitive . . . and memory decline ever since. (P2)

Razani et al. (2008) discussed how caregiver burden can result from caregiving experiences with even mild dementia, due to increased physical and emotional stress. The descriptions (above) by P1 and P5, of being physically attacked by care-recipient parents, and witnessing attacks on vulnerable family members (P1), illustrate the claim that higher levels of caregiving are required for patients with dementia (Nguyen, 2009; Razani et al., 2008). Lynch (2007) discussed role conceptualizations that are held by both members of a dyad; when one member's behavior changes, the other's automatically changes to accommodate the new dynamic. While Themes 1 through 4 focused on problems experienced by caregivers, Theme 5 revealed a different side to some caregiver/care-recipient relationships.

Interview Question 5 (“How do you think dependency has changed your relationship with your parent(s) since you began caregiving? ”) elicited a variety of responses, half of which described benefits to the original adult child/parent relationships. Eaves (2006) discussed the compulsion on the part of some informal caregivers to return to the parent the benefit of caregiving they received as children:

I wouldn't trade it . . .I wouldn't trade it . . .I would remind myself, “I'm paying back . . .a little bit, and my parents . . . always done for other people . . .so it's just giving back a little bit, a portion of what was given to me . . .”and it makes you feel good. (P1)

Another participant discussed a beneficial change that took place in their relationship with their parent with the addition of dependency:

But she gradually came . . . around . . . she gradually began to realize that I actually was helping, that she actually needed the help, and so then she softened up and sweetened up a bit . . . actually, not just a bit, a whole lot, and the strife dissolved and she and I started getting closer—for the first time in my adult life she started treating me like a *peer* at least for awhile there. (P2)

Attachment theory explains how the original parent/child bond contains elements that can endure throughout the life of the relationship. P2's caregiving relationship with her mother appeared to reflect multiple changes throughout its lifespan, some that were welcomed by P2 and others that had been difficult to manage. Theme 5 ("New relationship provides benefits") emerged unexpectedly from data that, prior to five responses contributing to that theme, had consisted of descriptions of caregiver struggles with various aspects of the caregiving experience. According to Clukey (2008), the fact of approaching death, with concomitant anticipatory grief, can precede changes in intra-familial dyads. It is possible that intradyadic changes, as reported by Clukey, could explain descriptions of benefits reported by participants of the current study. All the participants in the current study provide caregiving for parents 80 years of age and older, which approximates the current life expectancy for individuals in the United States (Talley & Crews, 2007). It is logical, then, that adult children, providing caregiving to parents nearing the end of their lifespan, would be especially alert to benefits associated with their dyadic relationship. According to Stajduhar et al (2010), caregiver/participants

in recent research reported rewards of caregiving. Other aspects of caregiving experiences, perceived as beneficial to participant/caregivers, included healing from conflicts in childhood:

I guess . . .in some ways, that time we had together allowed me to heal some childhood wounds . . .when we'd have issues and then . . .when I would respond differently, then I'd get a different result with her and . . .in some ways we were closer. (P3)

Another participant reported benefits directly resulting from care-recipient dependency:

She's shared more with me than she would have . . .when she was more independent she wouldn't have necessarily shared . . .it's been kinda nice . . .we've spent more time just chatting and . . . she's shared a lot of memories with me that I didn't know about so that was nice . . .that's been really fun. (P6)

Theme 6 evolved from caregiver/participant data reported in response to Question 5 (“How do you think dependency has changed your relationship with your parent(s) since you began caregiving?”) Eight out of 10 participants reported a change in the original role dynamic between themselves and their parent(s):

It's like you do with your own children—‘Here I am doing this for you and you don't even care!’ (\*laughs\*) (P1)

And so here I am, working my first full-time job since my daughter was born in 1992, and . . .still taking care of a teenaged daughter and trying to take care of my parents, who were resisting care and yet at the same time screaming for help . . .

So I was not putting up with her resistance and I put my foot down and I prevailed but . . .there was a lot of strife involved in doing that . . . . Once she finally acknowledged her dependency and allowed me to take over her finances and get her moved . . .she finally relaxed, and now she's sweet as sugar. (P2)

Keene and Prokos (2007) discussed the concept of caregiving adult children being “sandwiched” (p. 366) between responsibilities to dependent children and to dependent parents, reflected in P2's response (above).

Other participants cited examples of how roles had changed within the child/parent dynamic:

. . .as she got worse . . .I had to take over her finances . . . she trusted me to do that, . . .and then I had to take over her . . .medication distribution . . .because she was using up her inhalers way, way before they were due to be refilled, so I had to hang onto everything and then I had to dole out her pills . . .then I had to convince her to let somebody come in 2-3 times a week . . .'cause I was still working . . .and she didn't want to *pay* for that . . .and I *knew* she had enough money to pay for it. (P3)

I'm learning to take more of . . .an assertive role in making their appointments . . .whereas before they would . . .make their appointments and see if it would work for me, and now I am actually making the appointments and I'm asking the doctors to call me when they're reporting diagnosis, because . . .I'm . . . going to have to talk to them anyway. So I'm doing more of . . . the kind of role that I did

with my own children, that my mother did with me when . . .we were in grade school. (P4)

Role reversal, as discussed by most participants in the current study, is a phenomenon that was also seen in earlier studies. Role reversal, as discussed in Crouch (1987) and in Ziemba and Lynch-Sauer (2005), described a phenomenon in which role dynamics change to accommodate a particular circumstance. Crouch advocated for preserving the original child/parent dynamic, and found that this could be accomplished in a caregiving partnership later on by allowing for role reversal. Ziemba and Lynch-Sauer found that parent/child role reversal was reported by half the participants in a qualitative study of adult child caregivers and dependent parent carerecipients. The finding of parent/child role reversal will contribute to research on the dynamics of the child/parent interpersonal relationship. Quality and trustworthiness of acquired data in the current study is presumed to parallel the original plan for data collection, since that process followed an uninterrupted course, and was completed without problems. Contributions to positive social change are discussed in the following section.

### **Implications for Social Change**

Findings discovered in the current study show how adult children are routinely affected by changes in the adult child/parent relationship over time. All adult child caregivers in the current study reported not receiving enough, if any, help with caregiving tasks they routinely provide their parents. These unpaid caregivers provided detailed accounts of physical, emotional, and psychological challenges to their own well-being that began once they had undertaken caregiving responsibilities to dependent parents.

Eight of the caregiving adult children discussed how their original expectations of the amount of time spent caregiving and the intensity of the changing relationships between themselves and their dependent parents did not match the actuality of the daily experiences they faced. Seven out of the 10 adult child participants needed to manage their parent's progressive symptoms of dementia on top of routine caregiving duties. Eight out of 10 participants in the current study had to manage interpersonal role reversals, in which the adult children became like parents to their own parents whose behavior had changed to such a degree that it resembled that of dependent children. All participants in the current study reported life-affecting changes to their relationships with their parents once dependency was added to the dynamic. This finding will expand existing knowledge of the effects, over time, of dependency in the adult child/parent relationship.

Data from the current study will broaden the qualitative research base on the experience of adult child caregiver dependency explored most recently by Ziembra and Lynch-Sauer (2005), and on changes in the adult child/parent dynamic discussed by van Ecke et al. (2006). Through the current research, individual experiences with the adult child/dependent parent caregiving dynamic will be made available to medical professionals and policymakers, thus giving a concise, collective voice to adult child caregivers of dependent parents. Findings from the current study will also be available to family members and friends of the study's participants by word-of-mouth and, more formally, through a logical procession of research data through professional acquaintances. Theme 2 ("Not enough help from family/friends") reflects a desire on the

part of all this study's participants for relief from at least some burden of caregiving responsibility. Social change at the levels of family could, in turn, impact positive changes in the wider community, as well as both being impacted by changes by policymakers. If, in fact, changes were mandated by legislative bodies that apportioned financial assistance to current unpaid family caregivers, adult child caregivers would obtain relief in this manner.

Positive social change depends on awareness of social problems that affect vulnerable individuals. Awareness of problems, while only the beginning of positive social change, is nonetheless significant and can be accomplished through research that magnifies the effects of social problems, and makes the results of such studies available to professionals responsible for implementing policy and funding changes. The focus of the current study, adult child experiences with parent dependency, will augment prior research on dependency factors in caregiving dyadic dynamics. All the participants in the current study are unpaid caregivers with other existing demands on their time, energy, and personal resources. All of the current study participants reported a lack of available resources, as reflected in participant data comprising Theme 2 ("Not enough help from family/friends").

Each of the current study's participants assume the daily burden of contributing time, energy, and more tangible resources to parental care in a process that, for most, evolved over time (Theme 1: "Caregiving evolved on its own"). A plethora of earlier studies have discussed physical, financial, and other stress-related difficulties inherent in the caregiving experience in mainly quantitative research. Other qualitative and

quantitative research has addressed some implications of caregiver-experienced dependency. The current study will further qualitative research on adult child/caregiver dependency while providing an examination of the effects of dependency on the adult child/parent relationship.

### **Recommendations for Action**

The most common theme that emerged from participant data was “Not enough help from family/friends,” endorsed by all 10 adult child caregivers. This significant finding, a collective cry for help by these vulnerable individuals, cannot be simply assimilated into professional literature and then ignored. While family systems are characterized by continual changes that affect and are affected by changes within and outside of itself, further study of family dynamics is warranted. Most recently, Bailey et al (2010) revealed an appreciable relationship between caregiver stress and caregiver health. More research on this dynamic would further the procession of logical thinking followed by, “Caregiving evolved on its own,” “Expectations changed,” and, “Changed roles,” all of which were endorsed by 8 out of the 10 participants. Following in descending order of collective significance were, “Dementia caused changes,” endorsed by 7 participants, and, “New relationship provides benefits,” endorsed by 5 participants. The current study provided clear substantiation of the need for tangible resources allotted to adult child caregivers who experience dependency in caregiving relationships.

All participants in the current study made the choice to provide caregiving to their parent(s). None of the participants provided data that indicated either they or their parent(s) were experiencing financial poverty, yet all reported having less available

resources than they believed they needed as caregivers to dependent parents. While the current study provided an introduction to an exploration of some specific problems reported by adult children experiencing care-recipient dependency, further research is needed to formulate ideas that could lead to direct solutions. The results of this study, once available to medical and psychological professionals, and those responsible for changing government policies, can lead to practical solutions such as allocating financial and/or human resources to assist adult child caregivers, and/or providing substantial tax deductions to informal caregivers. Most participants in the current study belonged to caregiving support groups, indicating an additional need to augment emotional and/or psychological support. This study exposed some tangible difficulties—and a benefit—reported by adult child caregivers. This knowledge can raise awareness, for example, of some changes over time within the caregiving dyad, expressed by participants within four of the six main categories/themes reported by caregivers experiencing care-recipient dependency.

While change is an accepted factor in human relationships, an understanding of how these changes can manifest in a caregiving/care-receiving dyad—that caregiver expectations can change over time, that dementia can cause changes in relationships, that the new relationship can provide benefits, and that roles sometimes change as a result of dependency—will be an enduring contribution of the current study. In the current study, data are represented by responses to open ended questions by adult child caregivers, as opposed to quantitative representation in researcher designated categories. A useful dissemination of these results could involve inclusion of the data in didactic instruments

used in educational programs of all medical levels and types. In this way, psychotherapists, clinical psychologists, and other medical professionals who work with adult child/dependent parent dyads will have access to phenomenological data that illustrates some effects of care-recipient dependency.

### **Recommendations for Further Study**

The current study briefly examined some effects of care-recipient dependency on an adult child/parent dyad. Further research could include quantitative explorations of specific issues reported by participants in the current study. For example, all 10 participants reported “Not enough help from family/friends.” Quantitative research could focus on certain aspects of “help” that were found to be lacking in the current study participants’ caregiving experiences. All 10 participants in the current study reported at least two changes in the adult child/dependent parent relationship over time; the phenomenon of dyadic dynamic change is supported by both Bowen’s theory and attachment ideology. Not all participant responses, however, were included in the six main themes that evolved from participant data.

Some participant responses were considered secondary to those comprising the six main themes, yet could be topics for future research, as all were discussed by at least two participants. Assuming control over parental finances was considered problematic for four participants; two of those four discussed their concern over abuse and exploitation of their parent’s financial resources. Three participants discussed how their dependent parents clung to their independence to the point that the adult child caregivers were concerned for their safety, and the safety of others. Three participants reported frustration

that state laws sometimes prohibited adult children of dependent parents from assuming legal control despite prominent safety concerns. Two participants reported experiencing significant marital problems they associated with caring for dependent parents. Other research could involve cultural and gender implications of care provision that were not addressed in the current study,

Future research could include examinations of gender and ethnic components of caregiving, specifically sociocultural norms that may lead to certain gender-specific choices of caregiving assistance for aging family members. Since the current research participants were exclusively female, and ethnic information was not elicited, questions of how dependency is experienced from a more diverse sample remain unanswered.

Another avenue for further research that branches out from the current study's focus on the adult child/dependent parent dyadic dynamic is more in-depth research on the effects of the 28 "change experiences" collectively reported by the 10 participants. Mixed-methods research could examine both the number and the quality of discrete experiences of change, such as those reported in the current study involving dementia, caregiver expectations, role changes, and unexpected benefits, within a dyadic relationship. Other reported changes could also come to evidence within established adult child/dependent parent caregiving/care-receiving dyads.

While the current qualitative, phenomenological, study provided 28 discrete experiences of change within an adult child/dependent parent caregiving/care receiving dyad, further qualitative research may reveal more types of changes, and more aspects of

the changes already in evidence. Complete transcripts of the current study's data are available by request from the researcher.

### **Researcher's Experience**

A researcher's personal reflection on all phases of data collection, analysis, and presentation of pertinent data is especially relevant to qualitative, phenomenological research, because of the researcher's intimate relationship with study participants and with the data itself. The current study used a modification of Moustakas's (1994) method of conducting research and analyzing data. The appeal of this method lay in its reliance on allowing a theory to emerge from the data itself.

Interest in this particular research began during my employment as an intake qualifier for a private company that contracts to provide psychotherapy in nursing homes. Many times, I noticed what appeared to be guilt, resentment, doubt, and even despair in family members who were struggling with their decision to commit a parent to the nursing home. It was sometimes difficult to break off conversations with these adult children, as they seemed burdened with feelings that they wanted to share with someone who understood what they were experiencing. As years on this job progressed, I became more and more convinced that these adult children were saying essentially the same things.

My sixth year of employment as an intake qualifier/psychotherapist in nursing homes paralleled the need to choose a doctoral dissertation topic. While it soon became a certainty that the adult child/dependent parent dynamic was to be my topic, it took a little more time to decide that using the exact words of participants was the correct research

method for the study. Once I had decided on the topic of adult child/dependent parent caregiving/carereceiving, I was surprised to learn that friends, colleagues, and other graduate students began sharing their experiences; it turned out that many of them were caregivers of dependent parents, or knew someone in that role. The prevalence of the adult child/dependent dynamic in my own day-to-day experience was behind the choice to use actual voices of adult children in an open-ended interview format. I had come to believe that social justice could best be implemented in this emotionally/psychologically/financially vulnerable population by providing them a literal voice in literature that concerns them.

### **Summary**

The current study elucidated the reported experiences of 10 adult children with dependency added to the interpersonal relationship with a parent 80 years old or older. Each participant described the effects of several specific changes that took place in the course of their caregiving relationships, echoing the Bowenian premise that change not only constantly occurs within relationships, but that change in one family member affects other family members. The current study also validated the possibility of role reversal in the adult child/parent relationship with dependency added to the dynamic; this concept had not been examined in caregiving literature since Brody (1990) and Selzer (1990). Attachment theory's emphasis on dyadic dynamics sharpened the current study's focus on the adult child/dependent parent dyad, while role conceptualizations provided the basis for discovering the theme of role reversal.

Each of the six main themes, “Caregiving evolved on its own,” “Not enough help from family/friends,” “Expectations changed,” “Dementia caused changes in relationship,” “New relationship provides benefits,” and “Changed roles” emerged from participant data; each was endorsed by at least half of the 10 participants. The theme of “Not enough help . . .” was endorsed by all participants, and thus would be the most likely to generate data if this study were replicated, or if quantitative research were undertaken that included a focus on that theme. Three of the six themes reflected participant reports of intrapersonal and interpersonal changes over time within the caregiving dyad. The concept of interdyadic dynamic changes was also prevalent in earlier caregiving research (Aslan, 2009; Benefield & Beck, 2007; Brown, 2007; Butler, 2008; Campbell, 2009; Carek et al., 2010; Carretero et al., 2007; Clukey, 2008; Haley et al., 2010; Keeling et al., 2008; McConigley et al., 2010; Montgomery & Kosloski, 2009; Ostwald et al., 2009; Pierce et al., 2007; Pressler et al., 2009; Sanders et al., 2008; Stephens et al., 2009; Wright et al., 2008). Each participant reported changes in their relationship with their parent(s) once dependency was a factor in the relationship, thus extending prior caregiving research on that dynamic. The current study also broadened the caregiving research base that examines the adult child/parent relationship.

The current study, then, achieved the earlier stated purpose of qualitatively examining adult children’s experiences of dependency within a relationship with a parent who is 80 years old and older. This study also provided an opportunity for future research on the topics of changes in the adult child/dependent parent relationship, specifically, by detailing six changes and some effects of these changes on the adult children. Lastly, and

perhaps most importantly, this study's 10 participants will now be able to extend their voices into the community of professionals who are the most able to affect policy changes on matters that concern them.

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## Appendix A: Recruitment Letter Sent to Support Group Facilitators

Hello there,

My name is Anna (“Katy”) Johnson and I am a doctoral student at Walden University. I am conducting a study of adult child caregivers’ experiences with care-recipient dependency. I need to recruit 10 participants who meet the following criteria:

- 1) Can speak and understand English well
- 2) Have provided informal care to a parent for at least 6 months
- 3) The care-recipient parent is at least 80 years of age

Each participant will be interviewed at a location that is convenient for both the participant and myself. The interview will last 1-2 hours, and will include some general questions about the caregiving experience, as well as specific questions about how care-recipient dependency has affected the adult child/parent dynamic. Would you be willing to post a flyer that I provide to recruit participants for my study?

Please reply to this email with your response. Thank you so very much!

Katy Johnson  
360-556-3210

## Appendix B: Flyers Posted to Support Groups

### **AN OPPORTUNITY TO PARTICIPATE IN CAREGIVING RESEARCH!**

- A Walden University researcher is conducting a doctoral study of care-recipient dependency from the perspective of adult children who have provided informal care to their 80+-year-old parent for over 6 months. Ten participants will be interviewed in person at a convenient location, over the telephone, or over the Internet, for about 1-2 hours. The ability to speak and understand English is required. All interviews will be tape recorded. Interview questions will include a general description of the caregiving experience, and specific questions about how dependency has affected the adult child/parent relationship.
- Anyone interested in participating in this study should contact me by email or by telephone:

Email address: [anna.johnson@waldenu.edu](mailto:anna.johnson@waldenu.edu); or [katyj1048@yahoo.com](mailto:katyj1048@yahoo.com)

Telephone: 360-556-3210

## Appendix C: Informed Consent

You are invited to take part in a research study of informal caregivers' experiences with care-recipient dependency. You were chosen for the study because you have been providing caregiving for six months to a parent who is 80 years of age or older. This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named Anna C. ("Katy") Johnson, who is a doctoral student at Walden University.

### **Background Information:**

The purpose of this study is to find out how informal caregivers to parents experience parental dependency in caregiving relationships, and how dependency affects those relationships.

### **Procedures:**

If you agree to be in this study, you will be asked to:

- Answer a series of questions about your experiences as a caregiver to your parent;
- Answer a few questions about any specific experiences you may have had with being depended upon by your parent in the caregiving relationship.

The interview should not take longer than 1-2 hours to complete.

### **Voluntary Nature of the Study:**

Your participation in this study is voluntary. This means that everyone will respect your decision of whether or not you want to be in the study. If you decide to join the study now, you can still change your mind during the study. If you feel stressed during the study you may stop at any time. You may skip any questions that you feel are too personal.

### **Risks and Benefits of Being in the Study:**

Some questions asked by the researcher may seem personal; while you do not have to answer any questions that cause you discomfort of any kind, you may nonetheless feel uncomfortable or uneasy while considering either the nature or the content of the questions. If at any time during the interview process you appear to feel especially stressed, the researcher may stop the interview and assist you in calling an appropriate support person; this may be your support group leader or a counselor at a local free or reduced-cost agency.

Some possible benefits of being in this study include having an opportunity to share personal experiences with caregiving as someone with authority on the subject, and to have those experiences documented and made available to professionals in fields such as medicine and psychology.

**Compensation:**

There will be no compensation, financially or otherwise, provided to those who participate in this study.

**Confidentiality:**

Any information you provide will be kept confidential, with certain exceptions. If you disclose an instance of possible elder abuse and/or neglect, the researcher, as a mandated reporter in the State of Washington, is required to report the instance(s) to the local Adult Protective Services agency. The researcher will not use your information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in any reports of the study.

**Contacts and Questions:**

You may ask any questions you have now. Or if you have questions later, you may contact the researcher via 360-556-3210 or [anna.johnson@waldenu.edu](mailto:anna.johnson@waldenu.edu). If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is 1-800-925-3368, extension 1210. Walden University's approval number for this study is **10-28-11-0041697** and it expires on **October 27, 2012**.

The researcher will give you a copy of this form to keep.

**Statement of Consent:**

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below, I am agreeing to the terms described above.

Printed Name of Participant

Date of consent

Participant's Written or Electronic\* Signature

Researcher's Written or Electronic\* Signature

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Electronic signatures are regulated by the Uniform Electronic Transactions Act. Legally, an "electronic signature" can be the person's typed name, their email address, or any other identifying marker. An electronic signature is just as valid as a written signature as long as both parties have agreed to conduct the transaction electronically.

## Appendix D: Interview Questions

1. Tell me about your caregiving relationship with your parent(s)..When did it begin? Where does the caregiving take place?
2. Please describe how this caregiving relationship got started. How did you and your parent(s) decide that you would provide caregiving?
3. What were your expectations for this caregiving arrangement? Have your expectations changed over time? Has the real caregiving experience been the same or different from your expectations? How?
4. Would it be accurate to say that your parent(s) depends on you for care? Could you give me some examples of that dependency?
5. How do you think dependency has changed your relationship with your parent(s) since you began caregiving?
6. Is there anything I have not asked you about your caregiving relationship with your parent(s) that you would like to share?

## Appendix E: Results Matrix (Brief Example)

Not enough Help from family/ friends	Dementia Caused Change In Relationship	New Relationship Provides Benefits	Caregiving Evolved on its Own	Expectations Changed	Changed Roles
(P1) I'm the only one that lives in TX . . .and my other sisters all live in TN. . .we expected more from the other siblings and it just didn't happen. . . .We pastored this church 40 years and you would think after 40 years . . .somebody would have said, 'Why don't . . .you let me sit with your mom for an hour where you can go to the store . . .but . . .not once . . .and that's sad!	(P1) Mom was still able to . . .take care of Dad . . .but eventually her dementia got worse and . . .we had to . . .hire somebody. . . .Mom's dementia became <i>violent</i> . . .She tried to hurt the grandkids and all kinds of things . . . <i>That's</i> the hardest part . . .she's cut my arms open with rings . . .she has false teeth . . .she can't bite you . . .she tries but she can't. . . .Mom can't feed herself, you have to feed her . . .she doesn't know when she's going to the bathroom, so you have to get her up and put her on the pot occasionally . . .it's so <i>hard</i> on you physically	(P1) I wouldn't trade it . . .I wouldn't trade it . . .I would remind myself 'I'm paying back . . .a little bit, and my parents . . .always done for other people . . .so it's just giving back a little bit, a portion of what was given to me . . .and it makes you feel good . . .	(P1) (With Mom) I brought her here to visit and she didn't want to go back so I've had her about 3 ½ hours. . . .she begged and cried and pleaded to stay with me and I couldn't send her back [to my sister's] (with Dad) . . .there was never a question, especially when my dad got to where he couldn't keep a checkbook and things that we noticed were happening . . .between my oldest sister and . . .the sister that's two years younger than me and myself . . .we made a pact together. . . .we would take care of Mom and Dad no matter what it takes	(P1) Well, the expectations, even with my dad, was that there were 5 of us girls, and if you split a whole year . . .amongst 5, it wouldn't be so difficult . . .Yes, [my expectations] have changed, . . .especially when it comes to help I . . .learned a lot of things the hard way, I expected more from my friends, I expected more from my church people . . .	(P1) . . .It's like you do with your own children— 'here I am doing this for you and you don't even care! (*laughs*)'
(P2) . . .what I really needed was somebody	(P2) . . .during that period before I took	(P2) But she gradually came . . .around . . .	(P2) It's been an evolving thing . . .so	(P2) I never had expectations; I	(P2) And so here I am, working my

<p>to . . .show up at like 4 or 4:30 in the morning, wait until Dad got up, . . .monitor Dad, give him his insulin, give him something to eat, <i>and then leave</i> . . .Once my dad had that taken care of, . . . he could sit there in his semi-catatonic state until Mom got up . . .it would be fine. So . . .all the caregivers have a minimum of two hours . . .and some of them have a minimum of four, and so, I had to pay for two hours whether we used it or not . . .</p>	<p>them into my house to take care of them . . .something happened to her . . .maybe she had some TIAs . . .I don't know . . .but <i>something happened</i> . . .and she's been in cognitive decline ever since.</p>	<p>.she gradually began to realize that I actually was helping and that she actually needed the help, and so then she softened up and sweetened up a bit . . .actually, not just a bit, a whole log, and the strife dissolved and she and I started getting closer—for the first time in my adult life she started treating me like a <i>peer</i> at least for awhile there . . .</p>	<p>there's no single answer to that. [Mom] started calling me . . .it started off, like, a couple of times a week, grew to once a day . . .and eventually . . .she would call me in hysterics: '<i>I don't know what to do...</i>' over trivial things that she always had been perfectly capable of solving herself. . .so I just wound up spending gobs and gobs of time over there . . .but it was never enough.. . .There was nobody but me . . .I was it! I'm an only child</p>	<p>basically just . . .I reacted to the situation from . . .one moment to the next . . .I suppose that before 2003 I had had the expectation that . . .by living half an hour from my parents' house that I might occasionally need to go sit in the hospital while waiting for a parent to get through a procedure, and the time might come when I or my husband or both of us would have to go to their home once a month or so to do some odd jobs, you know, repair little things that break and . . .that sort of thing. As of 2003, all expectations were cancelled, I never had any kind of expectations <i>ever again</i> . . .from then on it was just <i>react to the situation</i>.</p>	<p>first full-time job since my daughter was born in 1992, and . . .still taking care of a teen-aged daughter and trying to take care of my parents, who were resisting care and yet at the same time screaming for help. In the case of my mom, it's been a really stormy, rocky ride . . .since Mom has always been such a fundamentally independent and capable person . . .she spent a lot of time in denial, as my story illustrates, and . . .it . . .caused a great deal of strife between us . . .like when she was demanding to have my dad come home with no care in the home, I was really afraid that she would accidentally <i>kill him!</i> So I was not putting up with her resistance and I put my foot down and I</p>
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					prevailed but . . .there was a lot of strife involved in doing that. . . Once she finally acknowledged her dependency and allowed me to take over her finances and get her moved . . .she finally relaxed, and now she's sweet as sugar . . .
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## Appendix F: Sample of Interview Transcripts

## Responses to Interview Question #1:

I've done caregiving with both parents. My father passed away and this coming June will be 6 years ago. And so, there are 5 of us girls . . .and I'm the Only one that lives in TX, we pastor a church, . . .and my other sisters all live In TN . . .I'm the oldest and my sister that's two years younger than me . . . Have basically been the caregivers . . .(P1)

Oh gee . . .it's been an evolving thing, uh, so there's no single answer to that . . .The present arrangement, which has been in effect since September, uh, my Mom . . .let's see . . .I live in Swathmore, PA, uh, my mother is in a senior living community in the independent living section, uh, in, uh, Wallingford, so she is two miles from my home. (P2)

The caregiving relationship really began emotionally um when I was a child . . .and my dad was an alcoholic and my mother was um codependent and I was sort of the person that tried to smooth everything over . . .so I would try to comfort my mother . . .(P3)

Well, mine's evolving . . .if you polled most of the participants from the group that you contacted I'm I think the newest member of the group and . . .mine started much more heavily 6-8 months ago as health changed . . .(P4)

Well, we bought a house together, and it . . .started on February 23, . . .2006 . . .My mom was getting out the . . .garbage cans to the street for collection and her . . .she'd . . .been sort of on the thin and frail side and . . .her bone broke at her . . .femur broke and . . .she was out on the street . . .(P5)

Well, at first it started probably about, oh, about 5 or 6 years ago . . .Mom's um health started to deteriorate a little bit after a fall that she took, and uh she started to become more and more recluse . . .she was a very social person prior to that . . .(P6)

Well, my mother . . .had a stroke in . . .I believe it was 2008, and she was still able to live in her home . . .until last November. At that time, we gave her lots of support in her home, but then the dementia . . .became so severe . . .(P7)

I've been very successful on a good note. I started to tell my mother that . . .she has to put my dad in what you'd call 'Adult Day Care' for folks who have Alzheimer's cause she was really overwhelmed and she fought me on it: 'Oh, he'll be around *old people*,' so I sat down with her, I said, 'Mom, taking care of him and me taking care of him is not getting hin better; (P8)

With my father, it . . .started when my mother died in 2005 . . .but he lived in a different state so . . .I . . .had to drive up there and my . . .brother was living with him so I knew that he was . . .sort of safe . . .(P9)

My . . .mother lives in Dallas, TX. My father passed away . . .2 years ago, he had multiple health problems then also. So, I have two brothers, one who lives in Dallas and gets a lot of the responsibility and then . . .I used to go every month to help take care of them also. (P10)

## Curriculum Vitae

Anna (“Katy”) Johnson

### Education

10/2005 – Present	Clinical Psychology PhD program, licensure track Walden University, Minneapolis, MN
6/2002	Master of Arts and Counseling Saint Martin’s University, Lacey, WA
6/1999	Bachelor of Arts The Evergreen State College, Olympia, WA

### Professional Experience

12/2010-Present	Counselor HopeSparks (Formerly Family Guidance Center), Tacoma, WA
2/2003-Present	Mental Health Associate and Team Coordinator Senior Connections, Vancouver, WA
12/2002-12/2003	Social Service Provider Evergreen Convalescent Center, Lacey, WA
12/1999-12/2001	Residential Counselor Community Youth Services, Olympia, WA

### Professional Memberships

Since 2006	Psychologists For Social Responsibility (PSY-R)
Since 2005	American Civil Liberties Union (ACLU)
Since 2005	American Psychological Association (APA), Student Affiliate
Since 2013	Washington State Psychological Association (WSPA)

### Current License

WA Mental Health Counselor  
#LH 00010343