FEMALE CAREGIVERS’ PERSPECTIVES AND PLANS FOR THEIR OWN AGING

By

NATALIE D. POPE

(Under the Direction of Stacey Kolomer)

ABSTRACT

In the coming decades, millions of older adults will be living with chronic, life-threatening diseases that require ongoing care, also referred to as long-term care. Consequently, planning ahead for long-term care needs is crucial to health and well-being in later life. Women are at high risk for needing long-term care as they age, and women in midlife represent the majority of unpaid caregivers to older adults. Previous research has identified structural and individual barriers to planning for later life yet little is known about how caregiving for a parent influences one’s perspectives and plans for later life. The purpose of this study was to understand how providing care for aging parents shapes informal female caregivers’ beliefs about and desires for their own aging. The following research questions guided this study: (a) how did the participants come to be caregivers? (b) how does being a caregiver affect their perspectives and subsequent decision making about their own late life (c) what desires and plans do caregivers have for their own aging?

This qualitative study utilized an interpretive design and included in-depth interviews with 15 participants who were selected using criterion sampling. The sample included female
caregivers between the ages of 50 and 65 who self-identified as the primary caregiver to a parent or parent-in-law with an illness and disability.

Interview transcripts were analyzed individually and then collectively using open and focused coding, constant comparison, and memo-writing. First, analysis revealed that assistance provided to parents was initiated by one or more triggering event, after which participants became caregivers in either an emergent or deliberate manner. Second, caregiving for a parent influenced daughters in five ways including making them aware of aging and provoking age-related fears. Lastly, caregivers’ plans for later life related to finances, living arrangements, health, and social network. Caregivers also discussed preference for long-term care and these preferences concerned where they would prefer to receive care, who they would want to give care, and the desired traits of the care provider. Implications based on these findings were presented and future research recommendations were made.

INDEX WORDS: Caregivers, Mid-life, Women, Planning, Long-Term Care, Preferences, Late Life, Aging, Family Processes, Women
FEMALE CAREGIVERS’ PERSPECTIVES AND PLANS FOR THEIR OWN AGING

by

NATALIE D. POPE

B.A., University of Georgia, 2001

MSW, University of Georgia, 2003

A Dissertation Submitted to the Graduate Faculty of The University of Georgia in Partial Fulfillment of the Requirements for the Degree

DOCTOR OF PHILOSOPHY

ATHENS, GEORGIA

MAY 2010
DEDICATION

This dissertation is dedicated to my parents, Charles “Papa” Joseph Durrance and Carolyn “Mimi” Templeton Durrance. I certainly would not be here without their emotional, intellectual, and financial support. Thank you for always believing in me.
ACKNOWLEDGEMENTS

First and foremost I want to thank Stacey Kolomer who encouraged and guided me through this process. She unselfishly gave her time and energy to meet with me and read many, many drafts of this manuscript. She was always confident in my abilities to complete this journey; her believing in me made all the difference. Additionally, thanks are due to my committee members, Drs. Betsy Vonk, Anne Glass, and Jude Preissle. Dr. Vonk’s personal and professional experiences were a source of wisdom and encouragement for me in this research. Dr. Glass shared with me not only her expertise, but also her passion for older adults and their families. Dr. Preissle provided specific expertise in qualitative research and took the time to meet with me about data analysis, read drafts, and offer invaluable feedback.

I would also like to thank other faculty and staff at The University of Georgia School of Social Work who contributed to my rich educational experience. I am especially grateful for Dr. Ed Risler, Dr. Kevin DeWeaver, Dr. Jim Gaudin, Dr. Bert Ellett, and Kat Farlowe.

I would not have reached this point with my sanity intact if not for the other doctoral students in the School of Social Work. I am incredibly grateful to the rest of my Ph.D. cohort, Josphine Chaumba and Latrice Rollins. With kind and gentle words, Josphine always calmed me down and reminded me to be faithful. Latrice’s friendship was so effortless and she provided me with much needed encouragement as I finished this study. Thanks go to Drs. Sandra Yudilevich, Denise Levy, Kareema Gray, and Byungdeok Kang, for their advice and support while in the doctoral program. I am grateful to Jennifer Hadden for cheering me on through this process. I appreciate also my new friendships with Jacquelyn Lee and Ann Gowdy. Jacquelyn always
makes me and “Tad” laugh, brightening my day. Ann generously shared her snacks and her wisdom with me.

Thank you also to my dear friends, Sarah Davis, Lacy Armstrong, Angela Bewley, and Brianne Whitworth who listened to my rantings about school yet always reminded me that there is more to life than research and publications and Ph.Ds.

In addition to my parents, I am grateful to my family. My sister, Suzanne, and her husband, Ronnie, have provided much needed support since I have been in Athens. Thanks also go to Emma and Caroline who are always willing to share with their aunt their Polly Pockets and video games. I appreciate also my mother-in-law, Tammy, for help with editing and Ron, for his encouragement. Thank you also to Jesse and Scout for keeping me company during those endless hours in front of the computer.

Finally, to my husband and partner, Jeremy Pope, I owe a lifetime of gratitude. He supported my decision to go back to school and stuck with me throughout this process. Even when I was being a P.I.B., Jeremy showed me patience and understanding. I could not ask for a better friend and partner to share this life with.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>v</td>
</tr>
<tr>
<td>LIST OF TABLES</td>
<td>x</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>xi</td>
</tr>
<tr>
<td>CHAPTER</td>
<td></td>
</tr>
<tr>
<td>1 INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>Background of the Problem</td>
<td>1</td>
</tr>
<tr>
<td>Statement of the Problem</td>
<td>9</td>
</tr>
<tr>
<td>Purpose Statement</td>
<td>10</td>
</tr>
<tr>
<td>Significance of the Study</td>
<td>10</td>
</tr>
<tr>
<td>Definitions</td>
<td>12</td>
</tr>
<tr>
<td>Chapter Summary</td>
<td>15</td>
</tr>
<tr>
<td>2 REVIEW OF THE LITERATURE</td>
<td>16</td>
</tr>
<tr>
<td>Introduction</td>
<td>16</td>
</tr>
<tr>
<td>Older Adults</td>
<td>17</td>
</tr>
<tr>
<td>Well-Being of Older Adults</td>
<td>19</td>
</tr>
<tr>
<td>Older Women</td>
<td>35</td>
</tr>
<tr>
<td>Long-Term Care of Older Adults</td>
<td>42</td>
</tr>
<tr>
<td>Middle Adulthood</td>
<td>60</td>
</tr>
<tr>
<td>Planning for Later Life</td>
<td>63</td>
</tr>
<tr>
<td>Chapter</td>
<td>Title</td>
</tr>
<tr>
<td>---------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td>3</td>
<td>CONCEPTUAL FRAMEWORK</td>
</tr>
<tr>
<td></td>
<td>Introduction</td>
</tr>
<tr>
<td></td>
<td>Traditional Theories of Midlife Development</td>
</tr>
<tr>
<td></td>
<td>Alternative Theories of Midlife Development</td>
</tr>
<tr>
<td></td>
<td>Theoretical Approaches to Planning for Later Life</td>
</tr>
<tr>
<td></td>
<td>Caregiving as a Factor in Planning for Later Life</td>
</tr>
<tr>
<td></td>
<td>Chapter Summary</td>
</tr>
<tr>
<td>4</td>
<td>METHODOLOGY</td>
</tr>
<tr>
<td></td>
<td>Introduction</td>
</tr>
<tr>
<td></td>
<td>Study Design</td>
</tr>
<tr>
<td></td>
<td>Sample Selection</td>
</tr>
<tr>
<td></td>
<td>Data Collection</td>
</tr>
<tr>
<td></td>
<td>Data Analysis</td>
</tr>
<tr>
<td></td>
<td>Ethical Considerations</td>
</tr>
<tr>
<td></td>
<td>Validity and Reliability</td>
</tr>
<tr>
<td></td>
<td>Role of the Researcher</td>
</tr>
<tr>
<td></td>
<td>Chapter Summary</td>
</tr>
<tr>
<td>5</td>
<td>INDIVIDUAL PROFILES</td>
</tr>
<tr>
<td></td>
<td>Introduction</td>
</tr>
<tr>
<td></td>
<td>The Participants</td>
</tr>
<tr>
<td></td>
<td>Chapter Summary</td>
</tr>
<tr>
<td>6</td>
<td>FINDINGS</td>
</tr>
</tbody>
</table>
# Table of Contents

- **Introduction** ........................................................................................................... 148
- **Overview of the Findings** ..................................................................................... 148
- **Chapter Summary** ................................................................................................ 192

## 7 CONCLUSION AND DISCUSSION, IMPLICATIONS AND RECOMMENDATIONS ................................................................................................................................. 194

- **Introduction** ........................................................................................................... 194
- **Summary of the Findings** ..................................................................................... 194
- **Conclusions and Discussion** ................................................................................ 195
- **Limitations of the Study** ...................................................................................... 218
- **Implications for Practice** ...................................................................................... 219
- **Implications for Policy** ......................................................................................... 225
- **Recommendations for Future Research** ................................................................. 227
- **Chapter Summary** ................................................................................................ 229

**REFERENCES** .............................................................................................................. 231

**APPENDICES**

- **A** RECRUITMENT FLIER .......................................................................................... 278
- **B** PRE-SCREENING INTERVIEW ............................................................................ 279
- **C** INTERVIEW GUIDE .......................................................................................... 281
- **D** CONSENT FORM .............................................................................................. 286
LIST OF TABLES

Table 1: Older Population by Gender in 2006 ................................................................. 35
Table 2: Profile of Women in Late Midlife ................................................................. 63
Table 3: Participant Characteristics ................................................................. 119-120
Table 4: Description of Caregiving Situation ....................................................... 121
Table 5: Care Recipients’ Ability to Perform Activities of Daily Living ................. 123-124
Table 6: Care Recipients’ Ability to Perform Independent Activities of Daily Living .... 125-126
Table 7: Categories and Properties ...................................................................... 149
**LIST OF FIGURES**

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 1</td>
<td>Five Stages of Proactive Coping</td>
<td>81</td>
</tr>
</tbody>
</table>
CHAPTER 1
INTRODUCTION

Background of the Problem

“Every woman is a nurse,” Florence Nightingale proclaimed in the opening paragraph of her book, *Notes on Nursing*. “Every woman must at some time or other [in] her life, become a nurse” (Nightingale, 1860, p. 1). This statement by Nightingale captured the significance of caregiving in women’s lives during the nineteenth century. It was common for women to spend a considerable amount of time attending to the needs of the sick, the injured, and the terminally ill (Abel, 1994; Rothman, 2004).

Catherine Beecher’s book, *A Treatise on Domestic Economy* (1841) provides another perspective on the history of women’s responsibility to others. Beecher’s book became the leading handbook of the “cult of domesticity”, a phrase coined by historians to describe what became, and in many ways, still is a cultural standard for women. This ideology asserted that women belonged in the home and their primary responsibility was to look after the needs of their husbands, children, and other family members. In times of war, women even organized formal efforts to care for their husbands and sons, who were fighting on the battlefield. During the Civil War, for example, thousands of northern women assisted with the United States Sanitary Commission, which organized medical relief and other services for men serving in the military (Tindall & Shi, 1992).

The context of caregiving has gone through many transformations since the late 1800s, when Nightingale and Beecher published their commentaries on the role of women. Between 1890 and 1930, industrialization increased the availability of commodities such as electricity,
indoor plumbing, and store-bought food; these things often made the individual tasks of caregiving easier. However, urbanization and mobility resulted in a weakening of family and community structures that had in many ways, sustained women as they cared for others (Abel, 1991). During the late 19th and early 20th centuries, there were also changes in the types of care needed by individuals. Many infectious diseases, such as typhoid and dysentery, were under control and “chronic diseases replaced acute ailments as the major cause of death” (Abel, 1991, p. 48).

Today, a common type of caregiving done by family members involves assistance to older adults. Approximately 8.5 million people over age 70 have limitations either in activities of daily living (ADLs) or instrumental activities of daily living (IADLs). While they may not be disabled to the point of needing institutional care, these older adults do require some help to function in the community (National Alliance on Caregiving [NAC] & AARP, 2005). Older adults with activity limitations receive approximately 83% of their care from family members. Adult children provide most of the assistance to family members (49%), followed by spouses (6%). Family caregivers help with managing medication and personal finances, transporting to doctors appointments, and assist with everyday tasks such as laundry, grocery shopping, and meal preparation (NAC & AARP, 2005).

Women provide most of the unpaid family caregiving to older adults (Brody, 2004; NAC & AARP, 2005; NAC & AARP, 2009; Stone, Cafferata, & Sangl, 1987; Takamura & Williams, 2006). As the population ages, it is estimated that women could spend more years caring for their aging parents than they did caring for their children (Wold, 2004). Social and demographic changes since the 19th and early 20th centuries have greatly affected the context of women as family caregivers. For example, women have benefited in many ways from the civil rights and
women’s movements of the 1960s and 1970s. Women currently outnumber men in college completion rates (DiPrete & Buchmann, 2006). Most women today pursue careers and are employed in the paid labor force (U.S. Census Bureau, 2008). The percentage of employed women caregivers closely mirrors the percentage of non-caregiving women in the labor force. In general, unemployed women and employed women provide the same amount of unpaid care to family members (Takamura & Williams, 2006).

Although employment opportunities for women outside the home have increased, responsibilities of caring for home and family are often still based on traditional gender roles. Women are frequently just expected to do more. Declines in birth rates and overall family size mean older adults typically have fewer adult children to share the responsibilities of parent care. Consequently, more demands fall on adult daughters and daughters-in-law (Brody, 2004; Koerin & Harrigan, 2002; Marks, 1996).

The “sandwich generation” has been given a lot of attention in both popular and research literature. This concept refers to the situation of being caught in the middle of two (or more) generations. Brody (1981) provided early evidence of women having both dependent children at home, as well as responsibilities to assist aging parents. Due to growing divorces rates, women are now increasingly the single heads of households (Brody, 2004; Weiss, 2005). In spite of further evidence indicating the sandwich generation may not be as common as once thought, it certainly is stressful for those who do experience these dual responsibilities (Loomis & Booth, 1995; Rosenthal, Matthews, & Marshall, 1991).

Life expectancies have increased considerably since the early 1900s. As more people survive into very old age, adult children in midlife will continue to play a significant role in caring for aging family members. The U.S. Census reported in 2000 that in the previous decade,
middle aged adults represented the fastest growing segment of the population — 50 to 54 year olds increasing 55% and the 45 to 49 year old group increasing 45% (Lachman, 2004). The population of the oldest-old, is also increasing in number. Lachman (2004) points out that the third fastest growing group of Americans, those over age 90, will “have a profound impact on the lives of those in midlife” (p. 308).

**Future Care Needs of Older Adults**

The 65 and over population is growing exponentially, in large part because of the aging baby boomers. From 2007 to 2030, the number of older adults will increase by 89%, compared with the population as a whole increasing 21% (Houser, Fox-Grage, & Gibson, 2009). Life expectancy is also increasing. In 1950, men and women living in the U.S. could expect to live to age 66 and 72 respectively; in 2000, life expectancy was 74 for men and 80 for women (Kinsella & Velkoff, 2001).

In recent decades, the U.S. has also seen widespread improvements in disease prevention and medical care. Evidence suggests that disability rates among older adults have decreased over the past few decades (Federal Interagency Forum on Aging [FIFA], 2008; Spillman and Pezzin, 2000). However, focusing only on the lengthening of life and reduction of functional decline does not provide an accurate portrayal of the needs of the aged population. According to Mor (2005):

> It is critical to understand that, even if the rate of functional decline has dropped several percentage points over the last decades, the sheer numerical increase in the size of the aged population over the next 30 years will mean that the number of older persons who are dependent, disabled, and suffering the functional consequences of multiple chronic
conditions will be larger than it has ever been, far larger that most countries are prepared to manage. (p. S309)

In the coming decades, millions of older adults will be living with chronic, life-threatening diseases that require ongoing care — also referred to as long-term care. Long-term care is needed when individuals require hands-on assistance with daily activities such as bathing or eating, over a significant period of time (Friedland, 2004). Approximately 7.3 million older Americans reported long-term care needs in 1995 (Stone, 2000). By 2030, however, some 21 million older adults may need help with activity limitations (Shirley & Summer, 2000).

Health care trends like early discharge of hospital patients and the move toward home- and community-based care are expected to result in more reliance on family caregivers (Feinberg, Wolkwitz, & Goldstein, 2006). Rising health care costs will make it difficult for uninsured and underinsured elders to access formal medical and long-term care (Sinclair, 2008). As Coleman and Pandya (2002) point out, “Family caregivers are the backbone of the long-term care system in the United States” (p. 1) and they will continue to play an integral role in the health and well-being of older Americans. In 2002, national spending on long-term care totaled $180 billion, approximately 12% of total health care (including medical and long-term care) expenditures (Komisar & Thompson, 2004). In the U.S., the value of unpaid family caregiving provided each year is estimated at nearly $375 billion (Houser & Gibson, 2008).

The availability and accessibility of long-term care is an especially relevant issue for aging women. They are the fastest growing segment of the older adult population, particularly among the oldest-old (those 85 and over) (U.S. Census Bureau, 2006). Women continue to have a longer life expectancy than men, outliving men by an average of five years. Those who reach age 65 can expect to live an average of 20 more years and those who reach age 75 an additional
13 years (National Center for Health Statistics, 2007). Women also represent the majority of long-term care consumers. Houser (2007) reports:

Among people age 75 or older, women are 60% more likely than men to need help with one or more activities of daily living, such as eating, bathing, dressing, or getting around inside the home. One in nine women age 75 or older, and one in five age 85 or older, needs assistance with daily activities. (p. 1)

More than 70% of nursing home residents are women with an average age of admission of 80 years (Houser, 2007).

Not only are women at high risk for needing long-term care as they age, but women are the overwhelming majority of care providers, both paid and unpaid. Nearly 90% of nursing, psychiatric, and home health aides, the front line workers in both institutional and home- and community-based settings, are women (Houser, 2007). Most of the responsibility of providing assistance to aging family members falls on female relatives, specifically daughters (Brody 2004; NAC & AARP, 2009; Stone, 2000; Stone, Cafferata, & Sangel, 1987; Wolff & Kasper, 2006).

According to the Older Women’s League (OWL) (2001):

The typical informal caregiver is a married woman in her mid-forties to mid-fifties — a baby boomer who is herself aging and increasingly likely to need long-term care and support. She is employed fulltime and also spends an average of 18 hours per week on caregiving. In addition to juggling her career with caring for a parent, partner or spouse, she may be the primary caregiver for her children. (p. 9)

Compared with men, female caregivers typically provide more hours of care and higher levels of assistance to their care recipients; they also experience more negative consequences as a result of caregiving. Negative consequences reported by female caregivers include physical strain,
emotional stress, and depression (NAC & AARP, 2005; Pinquart & Sorenson, 2006; Takamura and Williams, 2006; Yee & Schulz, 2000).

Planning for Later Life

Planning ahead for the possibility of needing long-term care is imperative because the vast majority of people over age 65 will require some type of long-term care assistance (U.S. Department of Health and Human Services [USDHHS], 2008b). In general, people do not proactively plan for long-term care needs, that is obtain information and make concrete decisions in the absence of a crisis (AARP, 2007; McGrew, 2000; Sorenson & Pinquart, 2001). In their research with older adults, Steele, Pinquart, and Sorenson (2003) describe four styles of preparation for future care needs. Most older adults can be categorized into avoiders, ruminators, conformers, and planners. Avoiders try not to think about future care issues and have low levels of awareness of potential future care needs and low levels of planning ahead. Ruminators (or “thinkers”) are highly aware of future care needs, but do not make concrete plans. Conformers are those who try not to think about future risks but adopt a plan supplied by others, usually family members. Finally, planners think about and make concrete, specific plans regarding their future care needs (Mahoney, Finn, Bloom, & Anderson, 1996; Pinquart, Sorenson, & Peak, 2004; Steele et al., 2003).

Early preparation for the possibility of needing long-term care assistance has been associated with having more options and more control over one’s options (USDHHS, 2008c). Therefore, adults in midlife would benefit from thinking about and making plans for their aging. The middle years of adulthood are often characterized by the “negotiation of changes in roles and statuses within family and work” (Hunter, Sundel, & Sundel, 2002, p. 5). Experiences typical of midlife include children leaving home, reaching a peak in one’s career, menopause,
grandparenthood, retirement, onset of chronic illness, and widowhood (Neugarten, 1968). For adult children and daughters in particular, providing care to aging parents is an increasingly common midlife task (Brody, 2004; Magai & Halpern, 2001). Therefore, caregiving is an experience that might coincide and influence a woman in midlife planning for her own aging.

**Gaps in the Literature**

Studies on older adults and their families is a priority for gerontological social work research. Advances in biomedical, behavioral, and social research have certainly increased opportunities and improved the lives of many older adults (Burnett, Morrow-Howell, & Chen, 2003). However, “continuation and further enhancement of this progress will depend in part on decisions about priorities in the field of aging” (Burnett et al., 2003, p. 828). Demographic projections indicate that the population of older adults will continue to increase rapidly. Longer life expectancies are associated with higher disability rates; thus planning for the possibility of long-term care is an increasingly important concern for the health and well-being of future elders.

In reviewing the literature, much of the research on how individuals think about and prepare for their future aging focuses on older adults. Early planning enables people to have more options and more control over their options; thus, planning for later life is important not only for older adults, but also for adults in late midlife. Studies on factors influencing planning have focused on structural and individual barriers to planning. Planning ahead for aging is influenced by contextual factors such as access to resources, the cultural emphasis on acute rather than chronic conditions, and quality of family relationships (Pinquart, Sorenson, & Peak, 2004, Roberto, Allen, & Bleiszner, 2001; San Antonio & Rubinstein, 2004). However, caring for an aging parent is one contextual factor that has been given limited attention in the research
on planning for old age. It has been suggested that women’s familiarity with family caregiving might make them more likely to prepare for old age (Cannon, 1988; Robinson & Moen, 2000; Roberto et al., 2001). Previous research has not sampled caregivers in particular or specifically examined how caregiving influences perceptions and planning for later life. This study fills a gap in the literature by looking specifically at female caregivers in late midlife and how caregiving shapes their perspectives and plans for their aging.

**Statement of the Problem**

Planning ahead for long-term care needs is vital to health and well-being in later life. Most people who live beyond age 65 will need some type of assistance in their daily functioning. In fact, about 70% of older adults require some long-term care services and the likelihood of needing help increases with age (USDHHS, 2008b). Research shows that most Americans do not plan for their own aging and the possibility of needing long-term care assistance (AARP, 2007; McGrew, 2000; Sorenson & Pinquart, 2001). Demographic trends and changes in health care delivery make it increasingly necessary for individuals to plan ahead for the likelihood of disability in late life.

Preparing for the possibility of long-term care needs is especially significant for older women. Because of their longer lives, higher rates of disability and chronic health conditions, and lower incomes than men on average, many older women need long-term care services but have limited resources to pay for them (Houser, 2007). Research has identified factors that promote planning for future care needs and factors that act as barriers to such planning. Although a great deal of research exists about contextual factors that influence preparation for later life, no literature was found regarding the influence of caregiving on planning. Although women in midlife represent the majority of caregivers for older adults, little is known about how
caregiving affects them, what they learn from it, or how that learning affects their plans for aging. Therefore, the effect of caregiving on female caregivers’ beliefs and desires about their late life needs was the focus of this study.

**Purpose Statement**

The purpose of this study was to understand how providing care for aging parents shapes informal female caregivers’ beliefs about and desires for their own aging. The following research questions guided this study: (a) how did the participants come to be caregivers? (b) how does being a caregiver affect their perspectives and subsequent decision making about their own late life (c) what desires and plans do caregivers have for their own aging?

**Significance of the Study**

The social work profession emphasizes drawing upon clients’ knowledge, skills, values, and personal experiences to support their physical and psychological well-being. Psychosocial assessments are typically strengths-based, highlighting clients’ past instances of coping and success in order to support their capacity to make future life changes (Austrian, 2002; Cowger & Snively, 2002). Major life experiences, such as caregiving for an aging parent, are potential sources of positive change in people’s lives. This research sheds light on how caregiving influences women in midlife with regard to their self-perceptions and preferences about later life. A qualitative research design results in richly descriptive data. Practitioners can use the data to transfer findings to similar client situations, providing entry into dialogue with clients about planning for the likelihood of disability in late life.

In the future, this area of research should be expanded to examine planning behaviors in a national sample of female caregivers. If caregivers do in fact plan for their aging, factors related to their motivation to plan can be communicated and made relevant to women who are not
caregivers. Also needed are interventions designed to increase awareness and help women to begin planning for the possibility of long-term needs. Evaluation studies would further assist practitioners in making better decisions about social service programs designed to help women plan for later life.

According to a 2006 report by the Department of Health and Human Services, between 36,100 to 44,200 professional social workers were employed in long-term care settings, including nursing facilities, home health, and selected community-based settings. The report projected that approximately 110,000 social workers would be needed to work in long-term care settings by 2050 (National Association of Social Workers, 2008). Crewe and Chipunga (2006) note that a key role social workers have in working with older adults and their families is to raise awareness about dialogue within families regarding preparing for care needs in late life. Social work practitioners can benefit from continued research regarding personal and contextual factors that influence planning for later life. This research provides a deeper understanding of the processes by which women in midlife reflect on and make plans for their aging.

This study also offers an alternative perspective on the well-documented negative consequences of caregiving, especially for women (NAC & AARP, 2005; Pinquart & Sorenson, 2006; Yee & Schulz, 2000). Rather than focusing on the problems caregivers face, this study suggests that caring for an aging parent can foster psychological growth and proactive planning for late life. For some women, caregiving during midlife may trigger an awareness of mortality and a change in priorities resulting in activities or preparation that promotes successful aging. This research contributes to a more comprehensive understanding of the caregiving experience.

The baby boom generation is entering midlife and late life in record numbers. Many have noted how this cohort is vastly different than the current cohort of older adults (Davies &
Therefore, studies of adults in midlife and how they enter old age is an important area of study, particularly for women who are often underrepresented in research of mature human development (Clark & Schwiebert, 2001; Lippert, 1997; McQuaide, 1998). Another goal of this study was that through the interview process, the research participants would be encouraged to reflect on and articulate how caregiving has influenced their concept of self and aging.

**Definitions of Terms**

Definitions that are significant to this study are presented in this section and some others will be discussed further in Chapters II, III, and IV.

*Activities of Daily Living (ADLs)*: ADLs are skills people use and rely on everyday and are a frequently used measure of functional health status (Morgan & Kunkel, 2007). Such skills include ambulating (walking), transferring (getting up from a chair), dressing, eating, drinking, personal hygiene, and taking medication.

*Caregiving*: The Encyclopedia of Social Work defines caregiving as “custodial or maintenance help or services rendered for the well-being of individuals who cannot perform such activities themselves” (Hooyman & Gonyea, 1995, p. 953). Caregiving includes not only instrumental support, but emotional support as well. It is often provided by family members to other family members, regardless of age (Price & Rose, 2007). Informal caregiving refers to unpaid assistance provided by friends and family while formal caregiving involves paid assistance, usually by nursing assistants.

*Decision-making*: Decision-making is typically viewed as a cognitive process which involves selecting among various choices and ending in a course of an action. Based on existing decision-making and problem-solving models, Sorenson and Pinquart (2001) outline four steps
in the process of preparing for future care needs: 1) becoming aware; 2) gathering information; 3) deciding on preferences; and 4) making concrete plans. It appears that decision-making with regard to future aging occurs after an individual becoming aware of the need to plan. For this study, decision-making included reflecting on preferences and options for aging, evaluating the feasibility of these preferences, and choosing among these preferences.

**Future Plans:** This study explored the future plans of caregivers, specific to their own aging. Planning has been defined as the degree to which people make plans for the future and set goals as opposed to focusing on just one day at a time (Prenda & Lachman, 2001). Future plans might include making arrangements for the possibility of health problems or dependency. Planning for future aging might also entail saving for retirement and communicating preferences with family. Based on the literature, the most important areas of planning for aging are in the areas of social resources, finances, and housing. In this study, future plans included any actions defined by the participants as having an outcome for their future aging.

**Instrumental Activities of Daily Living (IADLs):** IADLs are secondary level activities that are not necessarily done everyday, but are nonetheless important for living independently. Examples of IADLs are driving, doing housework, preparing meals, shopping, managing personal finances, managing medication, and using the telephone.

**Long-Distance Caregiving:** Long-distance caregiving describes a situation in which a caregiver and care recipient are separated by geographic distance. Long-distance caregiving is said to define caregivers residing at least out hour away or more than 50 miles from the care recipient (Schoonover, Brody, Hoffman, & Kleban, 1988; Wagner, 1997).

**Long-term Care:** Long-term care encompasses a wide range of assistance and supportive services provided to individuals with chronic illness or disability unable to function
independently on a daily basis. Long-term care is provided for an extended period of time, and attends to the social and environmental needs rather than only the medical needs that dominate acute care. Long-term care takes place in a range of settings and depends on the care recipient’s needs and preferences, the availability of informal support, and the source of financial reimbursement. Services and housing considerations are necessary to the development of long-term care policies and systems (Hooyman & Kiyak, 2005; Stone, 2000).

Long-term Care Planning: Long-term care planning has been defined as “actions of preparation for a future time when help with activities of daily living may be needed because of decrements in functional capacity” (Friedemann, Newman, Seff, & Dunlop, 2004, p. 521).

Midlife: Early developmental theories suggested that midlife began somewhere between the age of 25 and 40 (Erikson, 1963; Levinson, Darrow, Klein, Levinson, & McKee, 1978). As life expectancies increase, midlife is considered to be later in the life span and last longer than proposed by early theorists. Middle adulthood is often viewed as a period covering approximately 30 years of the life span, roughly from 35 to 65 years old (Stewart and Vandewater, 1999). This study conceptualized midlife as the years between age 40 and 65; late midlife is further distinguished as spanning from age 50 to 65 (Vandewater & Stewart, 2006).

Old Age: Old age is typically viewed as beginning around age 65. Older adults are further separated into young-old (age 65 to 74), old-old (age 75 to 84), and oldest-old (age 85 and over) (U.S. Census Bureau, 2006).

Possible Selves: These are the “the future-oriented representations of self that guide and motivate our behavior” (Wald & Frazier, 2003, p. 252). Possible selves are those elements of the self-concept that represent what we could become, what we would like to become, and what we are afraid of becoming (Cross & Markus, 1991).
**Self-concept:** Self-concept centers on the way individuals view themselves. Herzog & Markus (1999) define self as “a multifaceted, dynamic system of interpretive structures that regulates and mediates behavior” (p. 228). A person’s self-concept is active and is shaped by how a person interprets and organizes “self-relevant experiences” (Markus & Nurius, 1986, p. 955).

**Self-development:** Self-development, also referred to as adult development, psychological development, psychosocial development, and personal growth, is a process of learning and evolving — physically, intellectually, socially, professionally, and spiritually (Hughes, 2003).

**Chapter Summary**

Being in the role of caregiver to an aging parent is a common event for many women during their life course. However, little is known about how caring for a parent or parent-in-law might impact one’s decision-making about their own aging. The present study fills a gap in the literature by examining how being a caregiver influences women’s beliefs and desires about their own aging. To set the context for the study, Chapter II presents a review of the literature. Relevant to this study is research on the health and well-being of older adults, long-term care, family caregiving, middle adulthood, and planning for later life.
CHAPTER 2

REVIEW OF THE LITERATURE

Introduction

The purpose of this study is to understand how providing care for aging parents shapes informal female caregivers’ beliefs about and desires for their own aging. The following research questions guided this study: (a) how did the participants come to be caregivers? (b) how does being a caregiver affect their perspectives and subsequent decision making about their own late life? and (c) what desires and plans do caregivers have for their own aging? To provide context for the study, this chapter is comprised of four sections. First, I discuss the current experiences of older adults, as well as the projected needs of future elders. Second, I describe long-term care provided to older adults with illness and disability. Unpaid care from family members comprises a large proportion of long-term care, so family caregiving is highlighted, including factors related to the caregiving experience. This is followed by a third section discussing middle adulthood and late midlife women in particular. Finally, I review preparation for late life, including areas of planning and factors related to planning.

The literature that contributes to the current knowledge of how caregiving for older adults influences planning for late life comes from various disciplines including psychology, social work, adult education, public health, women’s studies, sociology, and gerontology. Online searches via GIL and GALILEO were conducted. The following databases were used: Academic Research Complete, Ageline (Ovid), ProQuest Dissertation Abstracts, Medline, Medline Plus, Google Scholar, Social Work Abstracts (Ovid), PsychINFO, and Census data. Search terms included combinations of the following descriptors: older adults, elders, aging, caregiver burden,
caregiving, midlife, family processes, late life planning, preferences, long-term care, women, gender, identity, self, and development.

**Older Adults**

The aging population is the fastest growing group in the United States (U.S.). Advances in health care and medical technology, which contribute to longer life expectancies, as well as the baby boom generation, are leading to increasing numbers of older adults. The baby boomers have been identified as one of the largest and most dynamic generations in American history (Keegan, Gross, Fisher, & Remez, 2006). In 2004, about 36 million people 65 years and older lived in the U.S., representing just 12% of the population. In 2011, the baby boomers (those born between 1946 and 1964) will begin turning 65 and the number of people in the country age 65 and older will grow to 71.5 million in 2030 (Centers for Disease Control [CDC], 2003; Federal Interagency Forum on Aging [FIFA], 2006). This will be an increase of almost 50% since 2005 and will mean one in five Americans will be 65 or older (Administration on Aging [AOA], 2007).

The population of oldest-old, those 85 years of age and older, will also see a marked increase in the coming years. In 2000, the 85 and older population numbered 4.2 million, however, when the baby boomers move into this age group in 2030, the number will increase to 9.6 million (AOA, 2007). By 2050, there will be 20.9 million adults age 85 and older (FIFA, 2000). Centenarians, individuals age 100 and older, are another important segment of the oldest-old population. In 1980, there were approximately 15,000 centenarians. This number nearly doubled by 1990 (28,000). By 2050, there could be as many as 834,000 centenarians living in the U.S. (Velkoff, 2000).
**Diversity among older Americans.** The population of older Americans is expected to become more racially and ethnically diverse in the future. In the year 2000, 83.6% of those 65 and over were White, but by the year 2050, they will only comprise 61% of older adults (FIFA, 2008). In 2006, approximately 19% of those 65 and over were people of color, including African Americans, Hispanic Americans, and Asian/Pacific Islanders. These groups will represent 23.6% (12.9 million) of the older population in 2020 (FIFA, 2008; U.S. Department of Health and Human Services [USDHHS], 2007).

Among people aged 65 and over, the ethnic groups projected to grow the most are Hispanic and Asian Americans (Morgan and Kunkel, 2007). The population of older Hispanics will grow the fastest, from about 2 million in 2005 to 15 million in 2050. By 2028, older Hispanic Americans will outnumber older African Americans (FIFA, 2008). In 2006, there were a little over 1 million older Asians in the U.S., but by 2050, this population is expected to be almost 7 million (FIFA, 2008). Thus, the composition of future elders will be significantly more racially and ethnically diverse than the 65 and older population of 2010.

**Education of older Americans.** Elders of today are better educated than in previous decades. In 1965, 24% of older adults were high school graduates, but by 2007, 76% had finished high school (FIFA, 2008). Each succeeding generation has been better educated than the one preceding it. Nearly one-third of all people under age 60 have a college degree, compared to only 17% of people over age 75 (U.S. Census Bureau, 2005b). 

Despite these encouraging statistics, racial disparities still exist in education levels of older adults. Currently, 81% of Whites age 65 and over have completed high school. Older Asians are also highly educated; 72% have a high school diploma and 32% have at least a bachelor’s degree (making them the racial group with the highest percentage of college degrees).
In contrast, only 58% of older African Americans and 42% of older Hispanics have finished high school (FIFA, 2008). In 2003, only 10% of older African Americans and 6% of older Hispanics had a college degree (U.S. Census Bureau, 2004). As Hooyman (2006) points out, “Because educational level is closely associated with economic well-being, these differences impact poverty levels of persons of color across the life span, and particularly in old age” (p. xxxiv).

Well-Being of Older Adults

Quality of life for older persons is dependent on a variety of factors, including health and life expectancy, financial resources, living arrangements, and social support. These issues affect the well-being of older adults today, as well as individuals entering old age in the coming years.

Health Status

Health status is typically defined by researchers and health care workers as 1) the presence or absence of disease and 2) the degree of disability in level of functioning (Hooyman, 2006; Hooyman & Kiyak, 2005). The World Health Organization (1948) views health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (p. 100). This conceptualization of health recognizes both the integration and interaction of the body, mind, and spirit and the interdependence of the person and environment (Hooyman & Kiyak, 2005; Morgan & Kunkel, 2007). Thus, the following sub-sections offer a comprehensive review of health status among older adults today. Physical manifestations of health (causes of death, chronic illness, and functional ability), social factors related to health (health insurance), and emotional well-being (mental health) in older adults are discussed.

Causes of death. The Census Bureau’s population estimates suggest that by 2050, more than 40% of older adults can expect to live to at least age 90 (U.S. Census Bureau, 2003). The average life expectancy at birth has increased to 77.5 years with most deaths now occurring from
chronic illness (Hooyman & Kiyak, 2005; National Institutes of Health, 2007). In 2004, the leading cause of death among people 65 and older was heart disease (1,418 deaths per 100,000 people), followed by cancer (1,052 per 100,000), stroke (346 per 100,000), chronic lower respiratory diseases (284 per 100,000), Alzheimer’s disease (171 per 100,000), diabetes (146 per 100,000), and influenza and pneumonia (139 per 100,000) (FIFA, 2008). Regardless of gender or race, heart disease and cancer cause significantly more deaths in older adults than other illnesses (FIFA, 2008).

Differences exist in mortality rates based on race and gender and these differences in health are a combination of social, economic, and cultural factors. According to Morgan and Kunkel (2007):

In the United States there is a strong relationship between race and socioeconomic status, and there is a strong relationship between socioeconomic status and a range of health variables, including prevalence of chronic conditions, obesity, lack of preventative health care, and early mortality. (p. 206)

According to the 2000 Census, White females could expect to live 80 years compared with 74.8 years for African American females. Furthermore, the life expectancy for White males was 74.5 years while African American males could expect 67.6 years of life (as cited in Hooyman & Kiyak, 2005).

**Chronic illness.** Chronic conditions are “health problems that last for an extended period of time and are not easily or quickly resolved” (Morgan & Kunkel, 2007, p. 248). The prevalence of chronic disease increases with age and causes most of the deaths of older adults (Morgan & Kunkel, 2007; National Center for Health Statistics, 2002). These illnesses also have a significant impact on one’s quality of life and contribute to declines in functioning and the
inability to remain in the community (FIFA, 2008). Increased longevity will likely mean more people living with chronic illness (Gonyea, 2006). Currently, 80% of older Americans are living with one chronic condition; 50% have at least two (CDC & Merck Company Foundation [MCF], 2007). Some of the most common chronic diseases facing older Americans are heart disease, diabetes, high blood pressure, and arthritis (FIFA, 2008; Gist, Beedon, & Southworth, 2006).

The prevalence of many chronic conditions and diseases also varies by race and ethnicity. In 2006, more African American than White elders reported hypertension (70% compared with 51%) and diabetes (29% compared with 16%) (FIFA, 2008). Other reports indicate that African Americans experience higher rates of not only diabetes and hypertension, but also heart disease, arthritis, and stroke (CDC & MCF, 2007). Similarly, Hispanic Americans suffer from diabetes more than non-Hispanic Whites (25% compared with 16%), but have similar levels of hypertension and lower levels of arthritis (FIFA, 2008). Controlling for race and ethnicity, older adults with lower incomes are more likely to experience multiple chronic health conditions than those with higher incomes (Center on an Aging Society, 2003a).

**Functional ability.** In addition to causes of death and chronic illness, the degree of limitation in people’s ability to perform activities of daily living is another important indicator of health status in older adults (Morgan & Kunkel, 2007). Takamura and Williams (2006) define functional disability in older adults as:

The inability to perform, without human and/or mechanical assistance, one or more of six basic Activities of Daily Living (ADLs) including bathing, dressing, moving around indoors, transferring from bed to chair, using the toilet, or eating and/or one or more of nine Instrumental Activities of Daily Living (IADLs) including light housekeeping, meal
preparation, grocery shopping, laundry, taking medicines, managing money, telephoning, outdoor mobility, and transportation. (p.13)

Of primary concern is an older person’s ability to function independently at home (Hooyman & Kiyak, 2005). In 2005, 42% of older adults reported a functional limitation. Twelve percent had difficulty performing one or more IADLs (but no ADL limitation). Eighteen percent had difficulty with 1 to 2 ADLs, 5% had difficulty with three to four ADLs, and 3% had difficulty with 5 to 6 ADLs (FIFA, 2008).

Frailty in late life is defined by severe limitations in ADLs (Hooyman & Kiyak, 2005). Indicators of frailty include age-related declines in balance, activity level, strength, and walking ability. Frail older adults are at higher risk for hospitalizations, institutionalizations, and falls (Fried et al., 2001). Health and long-term care costs are also especially high for frail elders (Houser, 2007).

Although disability rates for older adults have declined in the past few decades (Pandya, 2005; Spillman & Pezzin, 2000), the declines have been smaller for the least advantaged socio-economic groups like those with less income and education and elders of color (Schoeni, Martin, Andreski, & Freedman, 2005). Older African Americans continue to have higher disability rates than Whites (Dunlop, Song, Manheim, Daviglus, & Chang, 2007; FIFA, 2008).

Mental health. A fourth aspect of health status is mental health. Mental health status of older Americans encompasses cognitive, emotional, and behavioral issues, including anxiety, cognitive impairment, and mood disorders (Morgan & Kunkel, 2007). It is estimated that approximately 20% of older adults experience some type of mental health concern (CDC and National Association of Chronic Disease Directors [NACDD], 2008; Kerson, 2001). A complete discussion of the prevalence of mental disorders in various groups of elders, and their causes,
consequences, and treatment is beyond the scope of this paper. However, depression and dementia in the 65 and over population are described, as these are two of the most common mental health concerns in this population.

Contrary to popular notion, depression is not a normal part of aging. In fact, research indicates that older adults are less likely than other age cohorts to have depression (Hooyman & Kiyak, 2005; National Institute of Mental Health [NIMH], 2008). However, those over age 85 experience depression more often than the younger-old (FIFA, 2008). Symptoms of depression often coexist with other illnesses such as diabetes, heart disease, and cancer (U.S. Census Bureau, 2005a).

Depression is often associated with suicide which disproportionately impacts older adults. Older adults represent only 13% of the population yet 20% of all suicide deaths (American Psychological Association, 2003; NIMH, 2008). Compared with all groups based on gender, age, and race, White men age 85 and over present the greatest risk for suicide, averaging 50 suicide deaths per 100,000 people (FIFA, 2008). Even more disturbing is that almost 75% of older adults who die by suicide visited a physician within a month before death. This suggests that depression in older adults is largely ignored and goes untreated (NIMH, 2008).

Risk factors for developing depression after age 65 are similar to those in younger populations and include being female, unmarried, poor, socially isolated, and having a history of depression at a younger age (Krishnan et al., 1998). The prevalence of major depression increases as one moves from community settings (1% to 3%) to primary care (6% to 9%) to institutional settings such as nursing homes (12% to 30%) (Unützer, Katon, Sullivan, & Miranda, 1999). Older adults in community settings and nursing homes are more likely to have situational or reactive depression than major depression (Hooyman & Kiyak, 2005). As individuals age,
they often experience physical illness which puts them at risk for becoming depressed. Losses in late life such as the death of a spouse, other family members, and close friends are also said to contribute to depression in this age group (Fiske, Gatz, & Pedersen, 2003).

The mental health of older adults also depends on their cognitive functioning. Normal declines in cognitive functioning that occur in old age include a slower pace of learning new things and slower retrieval from one’s short-term memory (Quadagno, 2008). Dementia is a second type of mental illness prevalent in late life and represents more severe cognitive decline (Quadagno, 2008). However, dementia is not “universal and inevitable” in late life (CDC & MCF, 2007, p. 5).

Dementia is defined as “the loss of mental capacity for higher-level mental functioning; memory loss, confusion, disorientation, and loss of ability to care for oneself are some symptoms of cognitive impairment” (Morgan & Kunkel, 2007, p. 258). In 2002, about 2.5 million Americans had a dementia diagnosis and by 2030, the number of Americans with dementia is expected to more than double to 5.2 million (CDC & MCF, 2007). Causes of dementia in older adults include Alzheimer’s disease, vascular dementia, neurological diseases such as Parkinson’s and Huntington’s disease, and infection (Ohio State University Medical Center, 2006; Quadagno, 2008). The two most common causes of dementia among people age 65 and older are Alzheimer’s disease and vascular, or multi-infarct, dementia (National Institute on Aging [NIA], 2002; Quadagno, 2008).

Approximately two-thirds of people with dementia have Alzheimer’s disease, the sixth leading cause of death in the U.S. (Alzheimer’s Association, 2008; CDC, 2008). As many as 5.2 million Americans are living with Alzheimer’s, and by 2050, the number of people in the U.S. with Alzheimer’s could reach 16 million. Symptoms of Alzheimer’s such as poor or impaired
judgment, changes in mood or personality, and disorientation to time and place can be overwhelming challenges for family caregivers (Alzheimer’s Association, 2008).

**Health insurance.** An older person’s health is also impacted by the availability of health care services and access to these services (Morgan & Kunkel, 2007). Access to health care services is closely tied to health insurance. Lack of health insurance substantially increases the likelihood that those with chronic conditions will delay or not receive care. Costs of health care services tend to increase with age as does the risk of illness (Center on an Aging Society, 2003b).

On a national level, health care costs have increased dramatically in the past few decades. The U.S. spends more on health care than other industrialized countries (Cutler & Hendricks, 2001; Reinhardt, Hussey, & Anderson, 2004). In 2007, the U.S. spent 16% of its gross national product on health care and will likely spend 20% by the year 2016 (National Coalition on Health Care [NCHC], 2008). Individuals are also paying more in health insurance premiums. Increasing health care costs have contributed to fewer companies offering health insurance, more Americans being underinsured or uninsured, and rising numbers of people with medical debt (Sinclair, 2008). It is estimated that couples entering retirement need between $200,000 and $300,000 in savings to pay for basic medical coverage (NCHC, 2008).

Medicare is a federally funded health insurance program for people 65 and older, people under 65 with certain disabilities, and people of all ages with end-stage renal disease (Center for Medicare and Medicaid Services, 2005). In 2006, almost all (94%) of non-institutionalized persons 65 and older were covered by Medicare (AOA, 2007). Although most Americans have the benefit of Medicare coverage in later life, disparities in access to health insurance and medical care across the life course often result in accumulated health problems in old age (Morgan & Kunkel, 2007). Medicare is the principal payer of skilled home health services for
older people, but coverage of other long-term care services is limited (Johnson & Uccello, 2005). It also does not pay for medical care such as routine physical exams and eye exams, hearing aids, routine foot care, and most immunizations (Quadagno, 2008).

Because many health care services are not covered by Medicare, older adults frequently purchase Medigap policies from private insurance companies (Quadagno, 2008). The Administration on Aging (2007) found that in 2006, about 87% of non-institutionalized Medicare beneficiaries had some form of supplementary coverage. Other reports indicate that as many as one-fourth of people 65 to 74 have only Medicare, with no Medigap private insurance coverage. Among those 85 and older, the numbers are even higher (U.S. Census Bureau, 2005a).

Medicare’s prescription drug benefit, added in 2003, might help alleviate some of the burden of health care expenses, but elders will continue spending a substantial proportion of their monthly income on health care costs. In 2003, out-of-pocket expenses for non-institutionalized Medicare beneficiaries age 65 and older averaged $3,455, or 22% of their income (Caplan & Brangan, 2004). Elders who are uninsured or have only Medicare coverage may postpone seeing a doctor when they have a health problem or go without medical care entirely (Quadagno, 2008; U.S. Census Bureau, 2005a). Early diagnosis and treatment of health conditions contribute to quality of life and longevity in older adults (Morgan & Kunkel, 2007).

Although much attention is given to Social Security’s funding crisis, Medicare’s financial difficulties will come earlier and will be more severe. Medicare is not only affected by increasing numbers of people moving into old age and living longer, but also by rising health care costs (U.S. Social Security Administration, 2008). In the near future, an aging population, an increased life expectancy, and a decline in the number of workers per beneficiary will present fiscal challenges for Medicare. From 2010 to 2030, the number of people on Medicare is
Projected to grow from 46 million to 78 million, while the number of workers to support beneficiaries is will decline from 3.7 workers per beneficiary to 2.4 workers per beneficiary. Medicare provides much needed health coverage and enjoys broad public support; therefore, ensuring the program’s financial stability over the long-term without transferring additional costs onto beneficiaries is an urgent challenge for the nation (Kaiser Family Foundation, 2008).

Medicaid also plays a significant role in financing health care for some older people. Funded by states and the federal government, it has long been available for low-income elders. However, two important changes in Medicaid have taken place over the past few decades (Morgan & Kunkel, 2007). First, a greater proportion of Medicaid expenditures are going toward health care for older people rather than low-income parents, children, and people with disabilities. Second, more and more of these expenditures for older people are going toward long-term care rather than acute care (Flowers, Gross, Kuo, & Sinclair, 2005). In fact, Medicaid is the major source of public funding for long-term care; about half of the older adults receiving long-term care in nursing homes are covered by Medicaid (AOA, 2007; Stone, 2000).

Medicaid is a “safety net” not only for those with limited financial resources, but also for middle-income Americans (AARP, 2008; Johnson & Uccello, 2005). Even individuals who save for their retirement years might need to rely on Medicaid for long-term care (Johnson & Uccello, 2005). The high costs of long-term care services force many older adults to deplete their assets paying for care — when impoverished, they may turn to Medicaid for assistance. The average private cost of nursing home care in 2008 was about $76,000 per year for a private room and $68,000 for a semi-private room. For assistance in the community, the average rate for a home health aide in 2008 was $19 per hour (AARP, 2008).
For elders of color, gaps exist in the ability to pay for health and long-term care services. The availability of health insurance has important implications for health service access and utilization (Hooyman & Kiyak, 2005). African Americans over age 65 have less access to health care than Whites; postponement of medical treatment due to cost of health services is highest among African Americans (FIFA, 2000). Older Blacks are often dependent on Medicaid, are less likely to have private supplemental health insurance, and therefore not as likely as White elders to receive sufficient medical care (Chadiha, Brown, & Aranda, 2006; Hooyman & Kiyak). Older Hispanics also are likely to miss doctor visits and often are dependent on Medicaid. Compared with non-Hispanics, a substantially large portion of their health care expenditures are paid for by Medicaid (Center on an Aging Society, 2004).

**Financial Resources**

Well-being in late life is associated with one’s capacity to meet one’s physical, nutritional, medical, and safety needs. Financial security is a key element in an older person’s ability to meet these needs. At the societal level, the financial security of older Americans is impacted by factors such as the current economic downturn and financial crisis. Future elders are also expected to face increased competition for resources as the extremely large cohort of baby boomers moves into late life (Lachman, 2004).

**Retirement funding.** For American baby boomers, employment has been a defining feature of their cohort, working 130 hours more per year than workers in Japan and 499 hours (over 12 weeks) more per year than German workers (Freedman, 2003). In a nationally representative sample of workers age 45 to 74, 84% said they would work even if they were financially secure for life and 69% planned to work into their so-called retirement years. Whereas the “need for extra money” was one motivation for working in retirement, other reasons
included desires to “work for enjoyment,” “have something interesting to do,” and “to stay physically active” (Montenegro, Fisher, & Remez, 2002).

While many baby boomers will continue to work because of personal satisfaction, many will work out of financial necessity. A significant concern for older adults is the possibility of outliving financial resources (Montenegro et al., 2002; Ohlemacher, 2007). With increased age, older adults are more likely to face poverty. Nine percent of individuals age 65 to 74 are poor, compared with 10% of those 75 and over (FIFA, 2008).

In recent decades, older Americans have had to take more responsibility for financing their own retirement (Gist et al., 2006). Defined contribution plans [401(k) and 403(b)] are currently being used more than pensions. Although employer-based retirement plans have many financial advantages, a 2007 study by AARP found that regardless of access to employer-based retirement plans, most households are not financially prepared for retirement (Thayer, 2007). In 2005, the major sources of income for older adults were Social Security (reported by 89% of older persons), income from assets (55%), private pensions (29%), government employee pensions (14%), and earnings (24%) (AOA, 2007).

The large cohort of retiring baby boomers raises concerns about the decreasing ratio of workers to retirees. In 2001, there was one person over age 65 for every 5.2 people of working age, but in 2025, there will be one older person for every 3.1 people of working age (Merlis, 2004). In 2011, Social Security's annual surpluses of tax income over expenditures will begin to decline and then develop into rapidly growing deficits as the baby boom generation retires (U.S. Social Security Administration, 2008).

**Poverty rates.** By and large, the financial well-being of older Americans has improved over the past several decades. Based on 2007 Census data, the overall poverty rate of individuals
65 and older has dropped from 35% in 1959 to 9% in 2006 (FIFA, 2008). However, these numbers do not tell the whole story. As Morgan and Kunkel (2007) point out, “The approach to calculating the poverty threshold is to keep that threshold artificially low, meaning that people have to be extremely poor in order to be categorized as living in poverty” (p. 229).

According to the Current Population Survey (CPS) conducted in 2007 by the U.S. Census Bureau, in 2006, 96.9% of persons age 65 and older had a median personal income of $16,902 (Wu, 2008). Considering that the national poverty line in 2006 for a single person under age 65 was $10,787 and $9,944 for someone older than 65 — many older adults are close to living in poverty (Institute for Research on Poverty, 2008). “Poor” as defined by the federal government assumes an older person can survive on 8 to 10% less income than those under 65 (Anti-Ageism Taskforce at the International Longevity Center, 2006). This means that “hundreds of thousands of older people who are not categorically poor according to the official poverty threshold are nonetheless economically vulnerable” (Morgan & Kunkel, 2007, p. 230).

For certain groups of old Americans, namely people of color, financial security in late life is even more challenging. In 2006, older Whites were much less likely than African Americans and Hispanics to be living in poverty. One out of every 14 older Whites (7.0%) was poor, in contrast to 22.7% of African Americans, 12.0% of Asian Americans, and 19.4% of Hispanics (AOA, 2007; FIFA, 2008). In 2005, the median net worth of older White households was six times that of older African American households (FIFA, 2008).

Social Security is the predominant source of income for people of color age 65 and older. Yet, Social Security was designed only to be one source of financing retirement and was not intended to be the sole source of income in retirement (Cutler & Hendricks, 2001). Of African Americans and Hispanics who receive Social Security, almost 80% depend on it for more than
half of their total income and almost 50% of African Americans depend on Social Security for 90% or more of their income (Beedon & Wu, 2004; Wu, 2007). The proportion of African American men receiving pensions is slightly higher than that for all older persons (27.2%). Income from interest and dividends is much lower for African American elders than other groups; less than a quarter receive income from interest and only 5.2% receive dividends in retirement (Beedon & Wu, 2004; Wu, 2007).

Poverty rates among older persons also differ based on geographic location. Elders living in central cities and rural communities face the highest poverty rates (Hooyman, 2006). In 2006, elders living in major cities had a higher than average poverty rate at 12.7%. Older adults residing outside metropolitan areas, such as in rural areas and small towns, had poverty rates of 11.0%, and approximately 11.7% of elders in the southern U.S. lived in poverty (AOA, 2007). Elders living in metropolitan areas, rather than central cities and rural communities are reported to have the most financial security (Biegal & Leibrandt, 2006).

Living Arrangements

Living arrangements are another important component of the well-being of older adults. Demographic factors (gender, race/ethnicity, and cohort factors), early life course events and achievements (historical factors, financial situations, family histories, etc.), and the community environment (neighborhood characteristics, availability of formal and informal care, and health services) all affect with whom elders live and where they reside (Hayes, 2002).

Lawton and Nahemow’s (1973) environmental press theory puts forward a way to understand the fit between an older person and his or her environment. Environmental press consists of the demands of a social and physical environment which force an older person to respond, adapt and change (Lawton & Nahemow, 1973). Based on this perspective, “Individuals
perform at their maximum level when the environmental press slightly exceeds the level at which they adapt” (Hooyman & Kiyak, 2005, p. 8-9). A poor fit between an older person and her environment can result in extreme stress and burden on the one hand, or sensory deprivation, learned helplessness, and dependence on others on the other. “The ultimate goal of any modification [of the living environment] should be to maximize the older person’s ability to negotiate and control the situation, and to minimize the likelihood that the environment will overwhelm the person’s competence” (Hooyman & Kiyak, 2005, p. 385).

The majority of older adults desire to “age in place.” This “refers to individuals growing old in their own homes with an emphasis on using environmental modification to compensate for limitations and disabilities” (Alley, Liebig, Pynoos, Banerjee, & Choi, 2007, p. 2). More than 80% of older persons express a desire to remain in their own home, and in 2002, 81% of older Americans owned their own home (AARP, 2000; U.S. Census Bureau, 2003). Home modifications such as installing grab bars in showers, widening doorways, and changing door handles can increase independence, ensure safety, and reduce the need to relocate to institutional settings (Putnam & Stark, 2006). However, many of these home modifications are not covered by health insurance plans; more than 80% of improvements made to age in place are funded by personal savings (Kopen, 2008).

In 2006, more than half (54.8%) of older community dwelling adults lived with their spouse (AOA, 2007). More Black men live alone compared with other groups of older men; almost 30% live alone compared to approximately 19% of Whites and less than 10% of Asian or Hispanic older men (He, Sengupta, Velkoff, & DeBarros, 2005). The extended family has traditionally been a source of emotional support for older Hispanics (Quadagno, 2008). In later life, Hispanic men are more likely than men of other races and ethnicities to live with relatives.
other than a spouse. Older Hispanics are more than five times as likely as Whites between the ages of 65 and 74, and more than twice as likely as those 74 years and older to live with their adult children (Choi, 1999; Quadagno, 2008).

Living alone has negative consequences for well-being in late life. Elders living alone have less security and are more likely to fear a safety or health emergency; they are also at higher risk of placement in a nursing home (Lawler, 2001; Quadagno, 2008). A person’s financial status in late life is also associated with her living arrangements. Older adults living alone are much more likely to be poor (16.9%) than are older persons living with families (5.6%) (AOA, 2007). Elders who have outlived family members and friends, and live alone, are more likely to experience loneliness and isolation (British Columbia Ministry of Health, 2004; Victor, Scrambler, Bond, & Bowling, 2000).

Social Support

The physical and mental health benefits of social support have been extensively documented (House, Landis, Umberson, 1988; Kawachi & Berkman, 2001; Seeman, 1996) and for the older population in particular (Moren-Cross & Lin, 2006; Yoon & Kropf, 2004). Elders with various types of relationships have lower risk of morbidity and mortality (Bosworth & Schaie, 1997; Ceria et al., 2001; Litwin & Shiovitz-Ezra, 2006). Friendship networks in particular have been associated with longevity in older adults (Giles, Glonek, Luszcz, & Andrews, 2005; Rasulo, Christensen, & Tomassini, 2005). For elders living alone, living in rural areas, or confined to the home because of physical limitations, it can be challenging to establish and maintain relationships with others.

The related concepts of social networks and social supports have been differentiated in the literature. Social networks refer to objective characteristics of a person’s social ties,
including the size, density, intensity, reciprocity, frequency of contacts, and geographic mobility (Lubben & Gironda, 2003). Social support on the other hand, describes the more subjective traits of social ties, particularly the quality and nature of interactions between members of one’s social network (Lubben & Gironda, 2003). Berkman (1984) has defined social support as “the emotional, instrumental, and financial aid that is obtained from one’s social network” (p. 415). Thus, an older person’s social networks are not uniformly supportive in the sense of contributing to his or her well-being (Berkman, 1984).

Research shows that as age increases, the size of social networks decreases. Yasuda and colleagues (1997) found that contact with children, contact with close relatives, and attendance at group organizations were less for women over age 75 than for women 65 to 74. However, developing smaller social networks in late life might be an adaptive strategy. According to Baltes and Carstensen (1999) the “reduction in the breadth of older people’s social networks and social participation reflects, in part, a motivated redistribution of resources by the elderly person” (p. 215). In later life, individuals proactively select and focus on social partners who are emotionally satisfying, disregarding more peripheral relationships (Baltes and Carstensen, 1999; Carstensen, Issacowitz, & Charles, 1999). This motivational shift comes when older adults perceive limitations on their time and choose to focus on goals and tasks that are emotionally meaningful (Carstenson et al., 1999; Carstensen, Fung, & Charles, 2003).

In summary, the heterogeneity of life circumstances for older adults is largely the result of decisions and circumstances based earlier in the life course (Crystal & Shea, 1990). Factors related to health, financial security, living arrangements, and social support individually and in their intersection affect quality of life for older adults. However, the experience for older women is further impacted by personal and environmental factors related to their gender.
Older Women

Women represent the fastest growing segment of the older population, especially among the oldest-old (those 85 and older). As shown in Table 1, in 2006 there were 21.4 million older women compared with 15.6 million older men (U.S. Census Bureau, 2006). Women outnumber men significantly in the 100 and older age group; in 1990, about four out of five centenarians were women (Krach & Velkoff, 1999). In both the U.S. and worldwide, the aging society, primarily women, will face a unique set of concerns in old age (Hooyman, 2006).

Table 1

*Older Population by Gender in 2006*

<table>
<thead>
<tr>
<th></th>
<th>All ages</th>
<th>Young-Old&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Old-Old&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Oldest-Old&lt;sup&gt;c&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
<td>15,628</td>
<td>8,699</td>
<td>5,308</td>
<td>1,621</td>
</tr>
<tr>
<td>Women</td>
<td>21,427</td>
<td>10,182</td>
<td>7,750</td>
<td>3,495</td>
</tr>
<tr>
<td>Total</td>
<td>37,425</td>
<td>19,162</td>
<td>13,174</td>
<td>5,090</td>
</tr>
</tbody>
</table>

*Note.* Numbers are in thousands

<sup>a</sup> Young-old are age 65 to 74.  <sup>b</sup> Old-old are age 75 to 84.  <sup>c</sup> Oldest-old are age 85 and over.

Well-Being of Older Women

The cumulative disadvantage of women over the life course is relevant for research on women and aging (Dannefer, 2003). In many ways, the well-being of women in old age stems from gender inequalities across the life course. This section describes how demographic and social trends affect the economic situation and health of older women. Living arrangements and social support are also discussed as these influence the physical and mental well-being of older women.
**Financial resources.** Financial resources, particularly a concern about one’s economic situation, are a major determinant of older women’s life satisfaction and perceived quality of life (Choi, 2001). Many older women live in relative financial security during their lifetime, only to experience poverty, near poverty, or the threat of poverty when they age. Financial hardship, often the result of longevity, widowhood, and divorce, is compounded for older women of color who face disproportionately higher rates of poverty (Lewis, 1997).

Older women are more likely than men to face financial challenges in late life. In 2006, the median income of older males was $23,500 compared to only $13,603 for older females. A greater proportion of older women are poor — approximately 11.5%, compared with 6.6% of older men (AOA, 2007). As with men, the majority of income for older women comes from Social Security benefits; 91% of White women, 88% of African American, and 76% of Hispanic women receive Social Security (Rix & Beedon, 2003). However, in 2007 the average annual Social Security income received by older women was $10,685, compared with $14,055 for men (Social Security Administration, 2008). Benefits for formerly employed women average 77% of that for men (Lewis, 1997).

Family and employment patterns across the life course have implications for women’s financial status in late life. Although gender norms are becoming less rigid, women still occupy most caregiving roles in families. Mothers often do the majority of child rearing and domestic work in a family. Wives, daughters, and daughters-in-law provide more of the direct, day-to-day care for older adults. Although more and more women are pursuing paid employment outside the home, traditional gender roles in the family have financial costs for women. Work interruption due to caregiving has long-term consequences such as lower incomes and smaller retirement savings (Cruikshank, 2003). Time spent in caregiving and out of the workforce is
calculated as zero earnings and results in lower Social Security benefits (Cruikshank, 2003; Hooyman & Kiyak, 2005). Although wage disparities based on gender are decreasing, income disparities across the life span — particularly for women of color — can make it more difficult to save for retirement (Weichselbaumer & Winter-Ebmer, 2005).

Social Security operates so that that while both members of a married couple are living, they are entitled to benefits based on their own earning history or a spouse's benefit equal to 50% of the higher earner's amount (Brandon, 2008). In each cohort since the 1950s, women have increased participation in the labor force and have spent a greater percentage of their adult years in the labor force (Morgan & Kunkel, 2007). However, enduring gender norms of women not working outside the home or taking breaks from full time employment to assume caregiving responsibilities will continue to have implications for their Social Security benefits. Women are more likely to earn less income than men over their lifetime, either due to income disparities or work interruption, and often receive exactly the same survivor benefit they would have received had they never worked outside the home (Older Women’s League, n.d.). Evidence also suggests that women more often delay retirement due to work patterns across the life course and resulting financial insecurity (Morgan & Kunkel, 2007).

**Health status.** A key factor in the health of older women is their long life expectancy; women outlive men by approximately five years on average. Women who reach age 65 can expect to live an average of 20 more years, and those who reach age 75 an additional 13 years (National Center for Health Statistics, 2007). Like older men, the leading causes of death for older women are heart disease, cancer, and stroke (CDC, 2004). Despite their longevity, women have higher rates of illness — both acute and non-fatal chronic conditions. Women who are economically disadvantaged have even higher health risks (Calasanti & Slevin, 2001).
In later life, women are more likely than men to experience chronic illness (Cruikshank, 2003; Morgan & Kunkel, 2007). Women have higher rates of arthritis, osteoporosis and hypertension than men (FIFA, 2008; Hooyman & Kiyak, 2005). They are also more likely to experience frailty in late life (Hooyman & Kiyak, 2005). In general, “older men have higher rates of the most life-threatening conditions, but older women have higher rates of illness and disability overall” (Morgan & Kunkel, 2007, p. 248). Differences in chronic illness and disability might be due to women living longer than men, women’s propensity to seek medical treatment more often than do men, or multiple roles and responsibilities across the life course accumulating into health concerns in later life (Cruikshank, 2003; Morgan & Kunkel, 2007).

Given that women can expect to live longer than men and have higher rates of disability than men — long-term care is a significant issue for older women. They are more likely to need care than men (79% compared to 58%), and on average need care for longer (3.7 years compared to 2.2 years) (Houser, 2007). Almost two-thirds of paid and unpaid home care recipients are women and more than 70% of nursing home residents are women. Among the 75 and older population, women are 60% more likely than men to need assistance with one or more ADLs such as bathing, dressing, or getting around the house (Houser, 2007).

Mental health is also essential to the overall health and well-being of older women. Women’s vulnerability to mental health issues in late life is not necessarily a result of their longevity, but more so because longevity can cause a woman to outlive her financial and social resources (Kerson, 2001). Older men and women report similar rates of life satisfaction (CDC & NACDD, 2008). However, among all age groups, women are more likely to report clinically-relevant symptoms of depression; this pattern persists in older women. In 2004, 11% of men over age 65 reported depressive symptoms compared with 17% of women (FIFA, 2008). A
greater proportion of women than men also experience dementia in later life as the prevalence of dementia increases with age (Toseland & Parker, 2006).

Because of their lower socioeconomic status, older women are more likely to depend on Medicaid than older men (Hooyman & Kiyak, 2005). Women represent 70% of Medicaid beneficiaries over 65 and spend more out-of-pocket on health care costs. On average, women pay about $400 more per year out-of-pocket on health care than men. Moreover, older women spend a greater proportion of their income on health care. Compared with men, who spend an average of 19% of their income, women spend 24% of their income (Caplan & Brangan, 2004; Kaiser Family Foundation, 2007).

Although more women are working outside the home and have access to health care through their employers, many women working as homemakers are only able to enroll in insurance plans as a dependent. Divorced and widowed women, unable to rely on their husband’s insurance, are more likely to be uninsured (Hooyman & Kiyak, 2005). Women in this position might hope they stay healthy until qualifying for Medicare at age 65 or take advantage of COBRA (Consolidated Omnibus Budget Reconciliation Act), which requires insurance companies to offer temporary coverage to people who retire early, become divorced or widowed, or become unemployed (Hooyman & Kiyak, 2005; Quadagno, 2008).

Living arrangements. Compared with men, women are more likely to live alone in old age. Nearly half of older women (48%) age 75 and older live alone (AOA, 2007). In very old age, the likelihood women will be living alone increases significantly. Gender differences in living arrangements in old age are partially explained by women’s longer life expectancy and the fact that many women outlive their husbands. Only 9% of men aged 65 to 74 are widowed compared with 29% of women in this age group. Among those 85 and older, 59% of men are
married as compared to only 14% of women (U.S. Bureau of the Census, 2004). Widowed men are seven times more likely to remarry than widowed women (Quadagno, 2008). However, older women of color (Hispanic, Asian, and African American) are much more likely to live with relatives (about 35% of women of color compared with less than 14% of older White women) (FIFA, 2008; He, Sengupta, Velkoff, & DeBarros, 2005).

As previously mentioned, elders living alone face particular challenges with regard to their health and well-being. Women living alone are at a higher risk of living in poverty (Hardy & Hazelrigg, 1993; Smeeding & Sandstrom, 2004). Older adults living alone are also more likely to be malnourished. A poor diet might be due to high poverty rates among elders living alone or because they do not experience the social function of meals to help them eat regularly (Hooyman & Kiyak, 2005). Bosworth and Schaie (1997) point out that isolated older adults may also suffer health consequences because “they lack the environmental support, social ties and assistance by others that become critical factors in the maintenance of their independence later in life” (p. 197). Cruikshank (2003) suggests that instead of living alone or living with family, communal or group living would be a viable option for older women. For many women, their lives center around their families rather than on friendships; unfortunately, “families are not organized to meet the needs of older women” (p. 195). As women tend to outlive partners and other potential family resources, housing options for older women need to be expanded to include non-relatives (Cruikshank, 2003).

**Social support.** Women can expect to live alone for nearly one-third of their lives, from age 60 and on. For the never-married, the percentage of women living alone is even higher (Hooyman & Kiyak, 2005; Velkoff & Lawson, 1998). Therefore, establishing and maintaining social networks is particularly important for older women. Strong social networks are believed
to have a protective influence on the cognitive functioning of aged women (Barnes et al., 2007; Crooks, Lubben, Petitti, Little, & Chiu, 2008). Men often have a larger number of non-kin networks, perhaps because of employment patterns over the life course. However, in general men “are less resourceful in planning social get-togethers and building networks that substitute for the sociability in marriage” (Hooyman & Kiyak, 2005, p. 581).

Widowed women living in retirement communities generally take part in social activities and have frequent and intimate contacts with friends. Retirement communities provide women with peers at the same life stage and offer shared activities (Roberto, 1996). Older women living in rural areas also take part in social activities such as bingo, volunteering, and church attendance. Telephone calls provide an important connection to family and friends (Arbuthnot, Dawson, & Hansen-Ketchum, 2007). However, women living alone in rural areas, especially those without family nearby, have more barriers to establishing and preserving social networks in late life. Access to transportation is often a key element in maintaining contacts with others, as well as independence and quality of life (Arbuthnot et al., 2007). More recently, researchers are examining online communities and Internet use as a resource in helping older adults maintain connections with others (Freese, Rivas, & Hargittai, 2006; Furlong, 1997; Sum, Matthews, Hughes, & Campbell, 2008).

Research on the lives of older GLBT individuals is limited, but growing (Richard & Brown, 2006; Shankle, Maxwell, Katzman, & Landers, 2003). Several studies suggest that friends, neighbors, and communities are significant in the lives of older lesbians (Dorfman et al., 1995; Grossman, D’Augelli, & Hershberger, 2000; Nystrom & Jones, 2002). Supportive, committed friendships often develop within the context of a lesbian social group. Although being partnered is often associated with receiving greater social support (Grossman et al., 2002;
Waymnet & Peplau, 1995), a strong sense of social support is not experienced by all older lesbians in a committed relationship (Richard & Brown, 2006).

In summary, women represent the majority of current and future older adults. With longer life expectancies, higher rates of disability and chronic health problems, and lower incomes than men on average, affordable long-term care services are an integral part of the health and well-being of older women. The following sections describe the system of long-term care for older adults, including types of care provided and funding for these services. Not only do many older women have a need for long-term care services, but women also play an integral role as primary providers of long-term care. Therefore, the role of women as unpaid, informal caregivers to older adults is also highlighted.

**Long-Term Care of Older Adults**

In 2006, the 65 and older population numbered 37.3 million, an increase of 3.4 million since 1996 (AOA, 2007). It is estimated that these numbers will grow to 71.5 million by 2030 when one in five Americans will be over 65 (CDC, 2003; FIFA, 2006). Not only is America experiencing growth in the population of older adults, but advances in medical procedures and increased lifespan mean that people are living longer. People aged 85 and older are the fastest growing segment of older adults. The U.S. Census Bureau (as cited in Gonyea, 2006) projects that by 2050, more than 40% of adults age 65 and older can expect to live to at least 90 years old.

Technological advances in medicine have created a paradox in that, while people can expect to live into old age, they are also living with chronic, life-threatening diseases that require ongoing care (Hooyman & Kiyak, 2005). The U.S. Department of Health and Human Services (USDHHS) (2008c) estimates that approximately 70% of individuals over age 65 will require at
least some type of long-term care services during their lifetime. Long-term care, according to the U.S. Senate, Special Committee on Aging (2000) is described as follows:

[Long-term care] differs from other types of health care in that the goal of long-term care is not to cure an illness, but to allow an individual to attain and maintain an optimal level of functioning….Long-term care encompasses a wide array of medical, social, personal, and supportive and specialized housing services needed by individuals who have lost some capacity for self-care because of a chronic illness or disabling condition. (p. 154)

Determining whether individuals are in need of long-term care usually comes from their ability to perform basic ADLs or IADLs.

Long-term care consists of “supportive services and assistance” to individuals “unable to function independently on a daily basis” (Hooyman & Kiyak, 2005, p. 527). These services include help with ADLs such as bathing, dressing, eating, toileting, or transferring. Long-term care services might also help a person with IADLs like household chores (meal preparation and cleaning) and shopping. This assistance encompasses a broad range of services “designed to minimize, rehabilitate, or compensate for loss of independent physical or mental functioning” (Stone, 2000, p. 2).

Older adults who need long-term assistance can obtain these services in institutional and non-institutional settings. Long-term care services are provided in nursing homes, home and community-based settings, non-institutional settings such as congregate care and residential care (assisted living, board and care, and adult family homes), and adult day centers. In home and residential care settings, services helping older adults include personal assistance (home-delivered meals, chore services, in-home respite, and visits from nurses or social workers),
assistive devices (canes, walkers, and home modifications), and technology (electronic medication reminders and emergency alert systems) (Hooyman & Kiyak, 2005; Stone, 2000).

Most of the long-term care for older adults takes place in the community, rather than in institutions. Less than 5% of Americans 65 and over are residing in nursing homes at any one time (Stone, 2000). Among the 5.5 million older adults who received long-term care in 1999, only 30% were in institutions and 70% were residing in the community (Uhlenberg & Cheuk, 2008). Other estimates, taken from the National Long-Term Care Survey (NLTCS), put the prevalence of institutional use in the aged population at only 5% in the years 1984 and 1994 (Spillman & Pezzin, 2000). Informal caregivers provide most of the assistance to elders living in the community — 65% rely solely on informal care, and an additional 30% rely in part on informal care. In other words, 95% of elders not living in institutions who depend on others for daily assistance are receiving that care, entirely or in part, from unpaid sources (Knickman & Snell, 2002).

Research indicates that overall disability among older adults has decreased over the past few decades (FIFA, 2008; Spillman and Pezzin, 2000). Between 1992 and 2005, the proportion of people age 65 and over with a functional limitation declined from 49% to 42% (FIFA, 2008). However, increased age is associated with a need for long-term care services. Thus, the growing number and proportion of older adults will likely affect the demand for long-term care services in the coming years. Stone (2000) points out:

Despite a trend toward declining disability rates among the elderly, the sheer volume of the old-old in the first half of the twenty-first century suggests that we must continue our quest for more effective and efficient ways to finance and deliver long-term care. (p. 50)
There are several reasons why most of the long-term care for older adults takes place in community rather than institutional settings. The traditions of caregiving and expectations for family care might prevent older adults from planning for and taking advantage of formal support services (San Antonio and Rubinstein, 2004). The growth of alternative housing options like assisted living and home based care have provided elders and their families with more long-term care options. However, research suggests that consumers are unaware of the different residential care options and have a tendency to group or label them negatively as “nursing homes” (Gibler, Lumpkin, & Moschis, 1997).

Another reason that unpaid, informal assistance comprises most long-term care of elders is because of the fragmented system in place for payment for services. In 2002, the nation spent $180 billion on long-term care for older people. Nearly two-thirds of long-term care expenditures went toward institutional care (Komisar & Thompson, 2004). The largest percentage of long-term care is paid for by Medicaid, and nursing home care makes up the greatest proportion (75%) of this Medicaid spending (Hooyman & Kiyak, 2005; Morgan & Kunkel, 2007). Medicaid also pays for home health services and non-medical home- and community-based care aimed at helping persons with disabilities remain in the community (Johnson & Uccello, 2005). However, Medicaid eligibility is restricted to elders with limited financial resources or those who become eligible by spending down resources paying for care (Hooyman & Kiyak, 2005; USDHHS, 2008c).

Second to Medicaid, out-of-pocket payments by care recipients and their families fund most long-term care for elders (Komisar & Thompson, 2004). Considering the high costs of some long-term care options (a one bedroom unit in an assisted living facility at approximately
$2,700 per month or a semi-private room in a nursing home at $181 per day), the ability to pay out-of-pocket for services is limited to a small proportion of older adults (USDHHS, 2008c).

Medicare and private health insurance provide limited coverage for home health and nursing home care (Komisar & Thompson, 2004). Skilled home health services are primarily funded by Medicare, but coverage for other long-term care services is limited (Johnson & Uccello, 2005; Morgan & Kunkel, 2007). Few older adults have private long-term care insurance, although the number is growing (Komisar & Thompson, 2004).

Recently, there have been changes in public funding for long-term care. Between 1990 and 2004, funding for long-term care came more often from public sources and home and community-based care increasingly comprised most of the long-term care services. In 2000, 22% of long-term care expenditures went toward home- and community-based services; this grew to 36.7% of spending in 2004. This trend is largely the result of increased spending within the Medicaid program toward these types of services (Tritz, 2006).

Although most of the care for community-dwelling elders has taken place within the family, demographic changes are expected to affect the availability of family caregivers in coming years. Women’s participation in the workforce has increased over the past several decades, family size is decreasing, and more marriages are ending in divorce (U.S. Census, 2008). Data from the National Long-Term Care Surveys (NLTCS) indicate that a large group of primary caregivers are spouses and children aged 65 to 74. There also appears to be an increase in the proportion of caregivers who are aged 75 and older, nearly one-quarter of all primary caregivers in 1994 (636,000 persons), up from 18% in 1984 (Spillman & Pezzin, 2000). Family caregivers who are also aging might be experiencing their own age-related health problems.
A decrease in the number of family or friends able to provide care to older adults will probably lead to higher need and use of formal services. Recent studies indicate many elders would prefer formal support (Roberto, Allen, & Blieszner, 2001) or a combination of formal and informal support (Eckert, Morgan, & Swamy, 2004). National spending in 1997 for nursing home care was $83 billion and spending on paid home health care was $32 billion (Arno, Levine, & Memmott, 1999). In comparison, the value of (unpaid) informal caregiving provided in 2007 is estimated at nearly $375 billion (Houser, Fox-Grage, & Gibson, 2009). Market surveys conducted by MetLife Mature Market Institute (2002; 2005) report that the average nursing home cost per day increased from $168 in 2002 to $203 in 2005. The likelihood that formal care services will be utilized more in the coming years and is getting more expensive has repercussions for public spending and the ability of older adults to pay for these services out-of-pocket.

The estimate of risk for nursing home use at some point during the life course ranges from 25 to 63% (Cohen, Tell, & Wallack, 1986). The possibility of needing long-term care is influenced by several factors. First, the risk for requiring long-term care generally increases with age. Single older adults are more likely to need formal support services. Primarily because they live longer than men, women are at a higher risk for needing long-term care. Finally, lifestyle factors such as poor diet and exercise habits, as well as health and family history, affect risk of long-term care usage among older adults (USDHHS, 2008a).

**Informal Caregiving**

This study sought to learn from women providing unpaid care to older relatives. The following sections will review relevant literature on the caregiver population and the challenges facing caregivers. Research indicates that factors related to the caregiver, such as gender, race,
and employment status, influence their personal experience with caregiving. Other characteristics unique to the care recipient affect caregiving outcomes, such as health status or impairment and relationship to the caregiver. Consequently, attention is given not only to the general condition of caregivers, but also to issues facing particular sub-groups of caregivers and care recipients.

Approximately 52 million Americans provide informal (unpaid) care to a family member or friend who is disabled or ill. People of all ages receive and provide informal care. The most common informal caregiving relationship is that of an adult child providing assistance to an aged parent; 38% of informal caregiving is children caring for older parents. Spouses provide 11% of informal caregiving, to their aging wives or husbands. Disabled children receive 7% of informal care, most often middle-aged parents providing assistance to adult disabled children. Finally, approximately 20% of informal care is provided to other relatives such as siblings, grandparents, aunts, and uncles and about 24% is assistance given to friends and neighbors (Takamura & Williams, 2006).

Informal caregivers are individuals who provide unpaid assistance to family or friends with functional disabilities. The most typical informal caregiving in the U.S. involves care to older adults who require assistance due to chronic illness and/or functional disability (Takamura & Williams, 2006). The primary forms of care provided by informal caregivers are instrumental activities inside and outside the home (such as meal preparation, transportation, and shopping), emotional support, personal care (such as bathing, dressing, and feeding), and communicating with agencies for services (Hooyman & Kiyak, 2005). Older adults requiring assistance from family and friends typically receive help in order to maximize their independence and functioning.
Family Caregiving to Older Adults

The majority of care for frail, older adults comes from family members (NAC & AARP, 2009; Stone, 2000; Stone, Cafferata, & Sangel, 1987). There are more than 22.4 million households in the U.S. reported to be in family caregiving roles for persons over the age of 50 (USDHHS, 2003). Adult children and spouses provide most of the long-term care to family members (Quadagno, 2008). Caregivers are evenly divided between those providing care eight hours or less per week (approximately 50%) and those who report spending nine hours or more per week providing care (50%). The average amount of time spent by caregivers providing assistance is 21 hours per week. However, one in five caregivers (17%) provide more than 40 hours of care per week (NAC & AARP, 2005). The average duration of care is 4.3 years. Caregivers are typically juggling other responsibilities such as work and family commitments; nearly six in ten caregivers are currently employed (NAC & AARP, 2005). Caregivers of adults as well as their care recipients are now older than their counterparts were five years ago. There are fewer younger caregivers, those under the age of 50, and an increased number of caregivers age 50 to 64 (NAC & AARP, 2009).

A 2005 report by the National Alliance for Caregiving (NAC) and AARP stated that the “typical” caregiver is “a 46 year old female with some college experience and provides more than 20 hours of care each week to her mother” (p. 7). Although women do most of the caregiving to older adults, men do represent a significant proportion of caregivers. It is estimated that about 33% of caregivers are men (Kramer, 2002; NAC & AARP, 2005). There are also growing numbers of family members providing help from a distance; there are between 5 and 7 million long-distance caregivers in the U.S. (Metropolitan Life, 2004; National Institute on Aging, 2008).
Transition to caregiving role. When illness or disability arises, older adults often receive both emotional and practical assistance from family members. Adult children provide most of the unpaid care to older family members (NAC & AARP, 2005; Takamura & Williams, 2006). Research on adult children’s motivation to become caregivers centers around three themes: fulfilling social roles and familial expectations, emotionally-based motivation, and accomplishing a normative developmental task (Radina, 2007). For many adult children, providing care to an aging parent is rooted in early family interactions and “guided by an implicit social contract that ensures long-term reciprocity” (Silverstein, Conroy, Wang, Giarrusso, & Bengtson, 2002, p. S12). A second motivation to become a caregiver comes from an internal, emotionally-based desire to provide this assistance. The notion that “sensitivity to others” and “responsibility for caring” are central themes of women’s self-concept and moral identity supports this perspective (Gilligan, 1982). Thus, women might be more likely to be internally motivated to be caregivers because of their emotional attachment to care recipients (Allen & Walker, 1992; Walker, Pratt, & Oppy, 1992). Lastly, because caring for an aging parent most commonly takes place during middle adulthood, caregiving is sometimes viewed as a normative, midlife task, particularly for women (Brody, 1985; Magai & Halpern, 2001). Pillemer and Suitor (2006) also suggest several factors influencing whether a child will provide care to his or her parent; these include parent-child similarities (e.g., gender, values), emotional closeness, past history of exchange, and children’s availability.

The path by which women and men become caregivers has an impact on their experience as a caregiver. In their national sample of caregivers, the National Alliance for Caregiving (NAC) and AARP (2005) found that caregivers who felt they had to assume the role of caregiver were more likely to experience negative consequences such as stress and strain. Nearly four in
ten caregivers (39%) reported they felt they had no choice in assuming the role of a caregiver, and half of these people felt their situation was emotionally stressful. More women (42%) than men (34%) reported that they did not have a choice in becoming a caregiver (NAC & AARP, 2005). Conversely, just a quarter of those who felt they did have a choice in becoming a caregiver reported experiencing high levels of emotional stress (NAC & AARP, 2005).

**Long-distance caregiving.** Growing numbers of family members are providing help from a distance; there are between 5 and 7 million long-distance caregivers in the U.S. (Metropolitan Life, 2004; National Institute on Aging [NIA], 2008). According to the NIA (2008):

> Long-distance caregiving takes many forms — from helping manage the money to arranging for in-home care; from providing respite care for a primary caregiver to helping a parent move to a new home or facility. Many long-distance caregivers act as information coordinators, helping aging parents understand the confusing maze of home health aides, insurance benefits, and durable medical equipment. (p. 4)

Although there has been extensive research on informal caregiving, less is known about long-distance caregiving (Koerin & Harrigan, 2002; Parker, Church, & Toseland, 2006).

Long-distance caregiving has often been conceptualized in terms of miles or travel time separating the caregiver and care receiver. The National Council on Aging (NCOA) and Pew Charitable Trust Fund study described these caregivers as residing at least one hour away from the care receiver (Wagner, 1997). Another study of parent care and “geographically distant children” defined this population as caregivers living “more than 50 miles” from their aging parents, “a threshold point at which visiting and face-to-face interaction between children and elderly parents decreases significantly” (Schoonover et al., 1988. p. 472). Research suggests that
most long-distance caregivers live much farther away than one hour from their aged parent, which makes it much more challenging to respond to crises (Parker et al., 2006).

The NCOA and Pew Charitable Trust Fund One (1997) reported that travel time for long-distance caregivers averaged 4 hours (Wagner, 1997), and MetLife (2004) found that travel distance averaged 450 miles and more than seven hours of travel one way. These caregivers typically provide assistance with instrumental activities of daily living, such as transportation, shopping, and managing finances (Koerin & Harrigan, 2002; MetLife, 2004) and spend approximately 22 hours a month on this assistance (MetLife, 2004). More men provide care at a distance and these caregivers also tend to have high levels of education (Koerin & Harrigan, 2002). Long-distance caregivers often rely on a sibling who lives near the care recipient. Between one-half and one-fourth of long-distance caregivers report to be the only or primary caregiver (Koerin & Harrigan, 2002; MetLife, 2004).

Geographically distant caregivers face unique challenges in providing care to aging parents. Distance makes it difficult to assess the needs of the care receiver and to know when one’s assistance is needed. Reports from the care recipient, family, or neighbors may be inaccurate, either because of exaggeration or concealment of important information (Koerin & Harrigan, 2002). Another communication challenge arises when health care professionals “disregard your opinions because you’re out of town” (AARP, 1994, p. 17). Family relationships can be strained due to long-distance caregiving. Hooyman and Lustbader (1986) point out that local siblings often “resent out-of-town siblings for not doing more” (p. 51). Other stressors for these caregivers include time away from work, costs of travel and long-distance phone calls to assess needs and arrange care, and guilt and anxiety for not being more available
to the care recipient (Koerin & Harrigan, 2002). Increasing geographic mobility will likely mean more adult children will be caregiving from a distance.

Tasks performed by caregivers. Approximately 12 million people in the U.S. have some long-term care needs, specifically assistance with ADLs and IADLs. Fifty percent of individuals requiring assistance with daily living are over age 65. Caregivers of both genders provide help with daily activities (NAC & AARP, 2009; Stone, 2000). Wives provide a median of 28 hours of care per week, husbands 15; daughters and sons differed less with 13 hours per week for daughters and 10 hours for sons (Center on an Aging Society, 2004). There do appear to be gender differences regarding the type of care provided to older adults. Some authors assert that women provide more hands-on assistance with IADLs — tasks such as doing laundry, grocery shopping, and food preparation that are frequently needed. Men, on the other hand, more commonly perform duties like household repairs, home maintenance, and help with legal matters (Brody, 2004; Montgomery, 1992; Navaie-Waliser, Spriggs, & Feldman, 2002). Other reports indicate that men and women describe similar caregiving responsibilities having to do with IADLs such as grocery shopping, transportation and housework (Metropolitan Life, 2003). However, there is evidence that male caregivers are more likely to manage finances for the care recipient (Metropolitan Life, 2003; NAC & AARP, 2005).

A primary difference in caregiving tasks performed by men and women is in the area of personal care, or ADLs. Women more frequently provide assistance with hands-on needs such as dressing, bathing, using the toilet, feeding, transferring, and continence help (Metropolitan Life, 2003; NAC & AARP, 2009; Thompson, 2002). These differences in caregiving tasks might be a result of social norms in which women are assumed to be more naturally suited for domestic tasks. The reluctance of a son to perform personal care tasks, especially for his mother,
might also be to “accommodate his mother’s modesty needs and her preference for another woman to do the hands-on work of bathing and toileting” (Thompson, 2002, p. 30). Men caring for their spouse, on the other hand, commonly perform these personal care tasks (Chang & White-Means as cited in Thompson, 2002). Research also indicates caregiving experiences differ based on factors related to the care recipients.

The diagnosis of care recipients affect the duration and type of assistance needed from caregivers. Compared with non-dementia caregivers, dementia caregivers typically spend more hours per week providing care and assist with more activities (both ADLs and IADLs) (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). A recent study using a nationally representative sample found many similarities between cancer and dementia caregivers. These two groups were comparable in their experiences of burden, stress, and physical and emotional strain. Cancer and dementia caregivers also provided assistance for similar numbers of ADLs and IADLs (Kim & Schulz, 2008).

**Consequences of caregiving.** Although several authors note the positive rewards associated with caregiving (Chen & Greenberg, 2004; Kramer, 1997; Tarlow et al., 2006), there is strong evidence that caregivers often experience strain and burden. Objective burden is “the daily physical demands and behavioral phenomena of caregiving” (Hooyman & Kiyak, 2005, p. 351). This includes the care recipient’s symptomatic behavior, disruptions of work and family life, and legal and health problems (Hooyman & Kiyak, 2005). In contrast, subjective burden is defined as “the caregiver’s feelings toward or perception of the caregiving experience” (Montgomery, Gonyea, & Hooyman, 1985, p. 21). Objective burden is tangible, whereas subjective burden is the caregiver’s appraisal and feelings toward the tangible changes that come from providing care (Harris, Thomas, Wicks, Faulkner, & Hathaway, 2000).
There appear to be gender differences with regard to negative consequences of caregiving. Female caregivers report more stress, burden, and depression than their male counterparts (NAC & AARP, 2005; Pinquart & Sorenson, 2006; Yee & Schulz, 2000). While male caregivers are more likely than women to work outside the home, females generally provide more hours of care and higher levels of care (NAC & AARP, 2005). Therefore, differences in objective burden (such as caregiving tasks and time spent caring) appear to influence subjective experiences of burden felt by sons and daughters (Brody, 2004; Montgomery, 1992).

Caregivers who provide constant care to an older person, more than 40 hours a week, face particular challenges (NAC & AARP, 2005). Most of these caregivers are caring for someone with Alzheimer’s or dementia and live with the care recipient. They are often in poor health themselves. Caregivers providing 40 hours or more care per week typically have a high school education or less and have lower income than other caregivers (NAC & AARP, 2005). Research suggests that caregivers residing with the care recipient, in poor health, and with less income, experience more burden than other caregivers (Hughes, Gobbie-Hunter, Weaver, Kubal, & Henderson, 1999; NAC & AARP, 2005; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007).

Approximately 23% of caregiving for older adults is for an individual with Alzheimer’s, dementia, or other mental confusion (NAC & AARP, 2005). A person with dementia often has mood, personality, and behavior changes that can be puzzling, discouraging, and frustrating for the caregiver (Mace & Rabins, 2001). A person with Alzheimer’s may fluctuate on a daily basis in his or her level of functioning, which can be challenging for a caregiver (Quadagno, 2008). Caregivers and other family members may feel they are losing their loved one a little at a time.
because of the progressive cognitive decline accompanying Alzheimer’s and other dementias (Mace and Rabins, 2001). In general, dementia caregivers report higher levels of emotional and physical strain than non-dementia caregivers (Ory et al., 1999).

There appear to be some differences in the caregiving experience based on race and ethnicity. Hispanic caregivers tend to be younger than caregivers in other ethnic groups; they are more likely to be parents and grandparents at earlier ages than the non-Hispanic population (Magaña, 2006). Compared with other ethnic groups, African American caregivers are more likely to report financial challenges as a result of caring and more often have a child under 18 living in the household (Fredrickson-Goldsen & Farwell, 2004; NAC & AARP, 2005). Asian Americans report high household incomes, are well-educated, and are the least likely to be stressed by caregiving (NAC & AARP, 2005).

**Use of supportive services.** Informal caregivers for older adults have a variety of responsibilities and tasks, often depending on the severity of the illness and the care recipient’s level of impairment. Caregivers typically balance other work and family commitments and experience emotional and physical strains as a result of these compounding responsibilities. A 2005 study revealed that caregivers’ top unmet needs were finding time for self, managing emotional stress, keeping the care recipient safe at home, and balancing work responsibilities (NAC & AARP, 2005).

The National Family Caregiver Support Program (NFCSP) was authorized by the Older Americans Act (OAA) amendments of 2000 and is administered by the Administration of Aging within the U.S. Department of Health and Human Services (USDHHS). The purpose of this program is for states to work in partnership with the area agencies on aging and local community service organizations to provide five basic services for family caregivers. These services
include: 1) information, 2) assistance gaining access to services, 3) individual counseling, support groups and training, 4) respite care, and 5) supplemental services (Li & Rafferty, 2006). Individuals eligible for services are family caregivers of older adults (age 60 and older) who are physically frail or cognitively impaired, grandparents (age 60 and older) who are primary caregivers of children under age 18, and relative caregivers of an adult child (age 19-59) with a disability (not including parents) (U.S. Administration on Aging, n.d.).

For caregivers to make meaningful decisions about their caregiving situation, they need complete and adequate information. Caregivers can benefit not only from information about available services, but also from increased knowledge about the care recipient’s disease, care needs, costs of care, and how to plan for future care needs (Whittier, Coon, & Aaker, 2004). Secondly, caregivers need help in accessing services available to them; “information about available services does not necessarily translate into caregiver service utilization” (Whittier et al., 2004, p. 51). An integral role of social workers in supporting caregivers is that of resource management which “fosters or stimulates exchanges with existing and undeveloped or unrecognized resources” (Crewe & Chipunga, 2006, p. 542).

A third service provided to family caregivers under the NFCSP is counseling, organization of support groups, and caregiver training to caregivers to assist them in making decisions and solving problems relating to their caregiving roles. Counseling may take place in an individual, group, or family setting and typically aims to alleviate caregiver depression and/or anxiety, address conflict between the caregiver and care recipient, and improve overall family functioning (Whittier et al., 2004). Counseling and support services via telephone hotlines are also provided by many agencies, including the Alzheimer’s Association (Ruffin & Kaye, 2006). These services are particularly helpful for caregivers and older adults who are limited in their
ability to access services in-person because of making arrangements for an alternate caregiver or worrying about being away from the care recipient. Telephone counseling also provides a way to reach isolated or rural caregivers with few or no available services (Skipwith, 1994; Smith & Toseland, 2006; Smith, Toseland, Rizzo, & Zinoman, 2004).

Support groups are the most popular and prevalent intervention available to caregivers of older adults (Whittier et al., 2004). In fact, one of the 10 tips for family caregivers offered by the National Family Caregivers Association (n.d.) is to “seek support from other caregivers” (p. 1). Support groups are designed to offer informal peer support, information about care recipient’s disease and disability, and referral information (Crewe & Chipunga, 2006; Whittier et al., 2004). Education and training programs strive to assist caregivers by educating them about resources and by teaching specific problem solving and coping techniques (Toseland & Smith, 2001). Programs offering a combination of counseling, support, and education services have been found to be especially effective. Evidence shows that multi-component interventions are most useful in reducing caregiver burden and negative reactions to care recipient’s disruptive behaviors (Acton & Kang, 2001; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999; Sorenson, Pinquart, & Duberstein, 2002).

Since some older adults require care 24 hours a day over an extended period of time, many caregivers also benefit from concrete support services, such as respite. Respite care is “the use of short-term temporary services that use trained sitters to provide relief for caregivers” (Crewe & Chipunga, 2006, p. 544). Finally, supplementary services are loosely defined and encompass other services which complement the care provided by caregivers (Li & Rafferty, 2006). These services can help sustain caregivers and include home-delivered meals,
transportation assistance, legal assistance, personal care, and homemaker/chore services (Crewe & Chipungu, 2006; Naleppa & Reid, 2003; Whittier et al., 2004).

Evidence suggests that male and female caregivers utilize support services differently. Compared with women, men are less likely to seek formal support but more likely to seek informal help with caregiving from friends and family (Kaye & Applegate, 1990; Pinquart & Sorenson, 2006). Less utilization of formal support service might be because “men may be less comfortable discussing their caregiving activities with others and may also be reticent or uncomfortable seeking support for the emotional aspects of caregiving” (MetLife Mature Market Institute, 2004, p. 3). Likewise, Pruchno & Resch (1989) found that male caregivers are more likely to employ problem-focused coping while women more often used emotion-focused coping strategies. Compared with female caregivers, male caregivers also tend to make more time for preventative health behaviors such as rest, exercise, and making time for personal doctor’s appointments (Yee & Schulz, 2000).

Research suggests that other factors such as race and ethnicity, socioeconomic status, and care recipient characteristics influence strategies for coping with caregivers stress and burden. Compared with White caregivers, African American and Hispanics use spirituality, particularly praying, as a way to manage caregiver burden. African Americans also often cope with caregiving stress by speaking with a professional or spiritual counselor. Caregivers who are the most likely to use formal supplementary services are older, college educated, upper income, and caring for someone with Alzheimer’s or dementia (NAC & AARP, 2005). Caregivers of individuals with dementia (compared with non-dementia caregivers) more often participate in support groups and utilize other supportive services (Ory et al., 1999).
**Future of caregiving.** Caregiving for older adults will continue to be an important societal issue for several reasons. Several interrelated trends will increase the need for long-term care services to older adults. First is the growing proportion of adults age 65 or older, which will reach 20% of the population by 2030 (AOA, 2007). Although disability rates are decreasing, the sheer number of adults surviving into old age will necessitate the need for long-term care assistance (FIFA, 2008; Spillman and Pezzin, 2000). Managed care restrictions on hospital care and home health services have increased demands placed on family caregivers (Koerin & Harrigan, 2002). Changes in health care delivery such as the early discharge of hospitalized patients mean caregivers frequently have to provide skilled nursing care that is often beyond the scope of their knowledge and comfort level (Kim & Schultz, 2008; Levine & Murray, 2004).

In the future, there also might be fewer available family caregivers to share the duties of long-term care. Women’s increased participation in the workforce as well as demographic changes (such as declining birth rates and increased longevity) have decreased the pool of potential caregivers. Geographic mobility of retirement-age parents and adult children has affected the availability of local caregivers (Koerin & Harrigan, 2002). The decline in overall family size means there will be fewer family members to share the responsibility of caring for aging parents (Marks, 1996; U.S. Census Bureau, 2005c).

Many of the competing responsibilities facing caregivers are associated with being in the middle years of adulthood. As many caregivers are in midlife or late midlife, the discussion now turns to middle adulthood and women in midlife.

**Middle Adulthood**

Midlife has not always been viewed as a distinct period of the life course; more recently, however, the middle years of adulthood have been recognized as a significant and complex part
of adult development (Quadagno, 2008). A specific mid-life cohort — the baby boomers — are receiving much attention in both popular media and academic literature. Consider a few recent headlines from newspapers and magazine articles about adults in mid-life: “The Candidates Face the Baby Boomers” (Hoffman, 2008), “No Country for Young Men” (McArdle, 2008), and “Older Baby Boomers Caught All the Breaks” (Waggoner, 2008). There is a great deal of interest in how boomers, the oldest of whom turned 62 in 2008 and the youngest, 45 years old, will traverse from their middle years into late life.

**Definitions of Midlife**

There are several ways to conceptualize age, with chronological years being the most common approach in Western society. For many, objective age is not an accurate representation of how old they might *feel* or *look*. Karp (2000) interviewed 72 professionals in their 50s and 60s about their self-concept related to aging. For many, acknowledging their chronological age felt foreign to them; identity with their numerical age was like a “stranger” with whom they had not yet become familiar. Karp’s participants described a contradiction between how old they felt and the age others perceived them to be. May Sarton (1973) uses a similar metaphor: “The trouble is, old age is…a foreign country with an unknown language to the young and even to the middle-aged” (as cited in Pipher, 1999, p. 15).

The general view in the United States is that middle adulthood begins roughly around age 40 and ends between 60 and 65. Late midlife has been distinguished from early midlife as spanning from age 50 to 72 (Robinson & Moen, 2000) as well as characterizing individuals in their late 50s and early 60s (Vandewater & Stewart, 2006). Those in midlife are not a monolithic group; considering a woman could potentially become a first-time mother or grandmother at 40 suggests the endless personal (and professional) options for individuals in this age group.
Hunter, Sundel, and Sundel (2002) note that increased life expectancies might result in the entrance into and exit from middle adulthood being pushed beyond these standard ages.

Chronological conceptualizations of midlife are not necessarily relevant for non-Western individuals. Wray (2007) studied cultural and ethnic differences in how 38 women viewed being middle-aged. There was a marked difference between the English/British women and women from other ethnicities. For instance, while English women acknowledge midlife as a distinct life phase, the African Caribbean women were less likely to notice it. For them, there was less significance attached to becoming middle-aged. For Muslim women, midlife was a period between “being young and getting older” that did not extend into the 60s as suggested in current literature on aging; one participant defined middle-aged as being 30 to 40 years old (Wray, 2007, p. 37). Consequently, current definitions of midlife need to be extended to include diverse conceptions rather than just Western established notions of how midlife is defined.

Profile of Women in Late Midlife

This study sought to understand how female caregivers in late midlife were influenced by the assistance they provide to aging parents. For the purposes of this study, late midlife encompassed the period in the life course from age 50 to 65. Table 2 presents demographic information on late midlife women based on Census data from the years 2000, 2006, and 2007.

In 2007, there was an estimated 152,962,000 women living in the U.S. Approximately 18% of women were between the ages of 50 and 64 (27,658,000) (U.S. Census Bureau, 2008). The vast majority of women in late midlife are married and have a high school diploma or higher (U.S. Census Bureau, 2006). In 2014, a greater proportion of women in this age group are predicted to participate in the labor force, 78.1% of women age 45 to 54 and 61.9% of women 55 to 64 (up from 76.0 and 58.2 respectively in 2006) (U.S. Census Bureau, 2006). More women
live alone now than in previous decades, 14.2% in 2000 compared with 11.1% in 1970 (U.S. Census Bureau, 2000).

Table 2

Profile of Women in Late Midlife

<table>
<thead>
<tr>
<th></th>
<th>50 to 64 years</th>
<th>45 to 54 years</th>
<th>55 to 64 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female Population (2007)</td>
<td>27,658,000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital Status (2007)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>69.6%</td>
<td>66.0%</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>3.0%</td>
<td>9.0%</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>17.1%</td>
<td>18.4%</td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>10.3%</td>
<td>6.6%</td>
<td></td>
</tr>
<tr>
<td>Participating in Labor Force (2006)</td>
<td>76.0%</td>
<td>58.2%</td>
<td></td>
</tr>
<tr>
<td>Education (2006)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school graduate or higher</td>
<td>87.5%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bachelor’s degree or higher</td>
<td>27.1%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living alone (2000)</td>
<td></td>
<td></td>
<td>14.2%</td>
</tr>
</tbody>
</table>

In summary, midlife is a complex and dynamic period in the life course. Experiences characteristic of middle adulthood include children leaving the home, retirement, health crises, and providing care for aging parents. The following sections review previous research on planning ahead for late life needs, which is an important issue for individuals in midlife.

Planning for Later Life

Planning for late life, particularly for the possibility of needing long-term care, can include a variety of different areas. McGrew (2000) identifies three planning areas: financial, social/environmental, and comprehensive. Friedemann and colleagues (2004) outline three
planning domains: financial, wellness and functional ability, and social and environmental (Friedemann, et al., 2004). Planning for the financial aspects of late life include reviewing current insurance coverage and investigating other resources to help cover long-term care expenses, such as long-term care insurance and reverse mortgages. Since most older adults prefer to age in place and prefer to be cared for in a home/community setting (Eckert, Morgan, & Swamy, 2004), housing adjustments should be included in planning for late life. These environmental changes include home modifications, downsizing to a smaller home requiring less maintenance, or moving close to family or a support network. Other aspects in planning include gathering information, deciding on preferences, and communicating with family members about these preferences (McGrew, 2000; Pinquart, Sorenson, & Peak, 2004; USDHHS, 2008b).

**Successful Aging and Planning for Later Life**

Preparation and planning can help individuals age well. Early on in gerontology, Paulos (1951) observed that “successful aging must be prepared [for] long in advance, a happy old age is the criterion and reward of a well conducted life” (as cited in Ouwenhand, de Ridder, & Bensing, 2007). Baltes and Carstensen (1996) suggest that successful aging should be viewed as a lifelong process, rather than a prescriptive list of outcomes. Successful aging is multi-dimensional and includes aspects of social functioning, life satisfaction, psychological resources, as well as health and functioning (Bowling, 2007). Similarly, there is no one way to plan for late life. Preparation for old age will differ based on personal resources (such as knowledge about services and available options) and psychological resources (such as a conception of a future dependent self and an internal locus of control) (McGrew, 2000; Pinquart & Sorenson, 2002a; Pinquart, Sorenson, & Davey, 2003; Pinquart, Sorenson, & Peak, 2004; Sorenson, 1998).
Research indicates that in general, older adults do not proactively plan for long-term care needs, that is, obtain information and make concrete decisions in the absence of a crisis (AARP, 2007; McGrew, 2000; Sorenson & Pinquart, 2001). Considering the benefits of planning and the possible harm in not planning, this trend is unfortunate.

In their research with 573 older German adults, Pinquart and Sorenson (2002b) found that thinking about the future but not making concrete plans was associated with lower psychological well-being, specifically higher levels of worry and depression. Research suggests that early planning is beneficial because one typically has more options and more control over one’s options the earlier they plan (USDHHS, 2008c). Elders who communicate their preferences and plan ahead have a better chance of receiving the type of care they prefer (Brechling & Schneider, 1993; Holden, McBride, & Perozek, 1997). Planning ahead for future care also means less stress on family members by giving them time to prepare for the caregiving role and relieving them of the burden of making decisions for the care recipient (Pinquart, Sorenson, & Peak, 2004; USDHHS, 2008b).

Factors Related to Planning for Late Life

Based on the literature, there is general consensus that Americans do not plan for late life, and particularly do not prepare for long-term care needs (McGrew, 2000; Sorenson & Pinquart, 2001). From a macro perspective, this may be because of Western cultural values and attitudes toward aging and issues related to long-term care. San Antonio and Rubenstein (2004) outline five themes that provide a context for understanding the “American culture of long-term care planning” (p. 36). These concepts are: 1) the independent versus dependent self, 2) the dueling discourse of youth versus decline, 3) the cultural emphasis on acute versus chronic illness, 4) traditions of caregiving, and 5) the view that long-term care planning is a woman’s issue.
Other social barriers to planning are access to resources and knowledge about services. Research shows that adults with higher socioeconomic status and more contact with adult children are likely to have concrete plans in place to help in case assistance is needed in the future. This is probably because they have more options to choose from, such as more family members available as potential caregivers and more access to high-quality formal services. Lower perceived knowledge about services is associated with less concrete planning in older adults (Pinquart & Sorenson, 2002a; Pinquart, Sorenson, & Davey, 2003).

**Chapter Summary**

This chapter presented an overview of extant literature relevant to the present study. The first section of this review described the current experiences of older adults and older women in particular. Factors such as health and life expectancy, financial resources, living arrangements, and social support were discussed as they relate to quality of life for older adults. Risk of chronic illness and disability increases with age so many older adults need assistance from others to maintain an optimal level of functioning. Thus, formal and informal long-term care options were reviewed. Informal caregiving was also discussed since unpaid assistance from family members, primarily daughters and wives, comprises most of the long-term care to older adults. This was followed by a third section describing middle adulthood. A profile of women in late midlife was provided to set the context for the women who are central to this study. Finally, I reviewed preparing for later life, including areas of planning and factors related to planning. In the next chapter, middle adulthood and planning for later life are discussed further. Chapter 3 outlines the conceptual framework of the study and uses theory to situate caregiving as a relevant experience in midlife development and planning for later life.
CHAPTER 3
CONCEPTUAL FRAMEWORK

Introduction

The purpose of this chapter is to outline the conceptual framework of the present study. This study rests on the assumption that caregiving is a significant experience for women in late midlife. Central to this research are theories related to midlife development and planning for aging. As most caregivers are in middle adulthood, this chapter first reviews theories of adult development, including tasks and transitions associated with midlife. Both traditional and alternative perspectives on midlife development are discussed. This is followed by a section describing theoretical approaches to understanding planning behavior, specifically planning for one’s aging. Finally, using these theories, as well as observations made by others, a case is made for how caregiving might influence proactive planning for later life.

Traditional Theories of Midlife Development

Several perspectives exist on psychosocial development across the life course. “Most of the work in adult development has been driven by the psychological tradition and focuses on the individual’s internal process of development” (Merriam & Caffarella, 1999, p. 94). Consistent with this tradition, early developmental theories “often have been conceptualized as a patterned or ordered progression tied to chronological time” (Merriam & Caffarella, 1999, p. 94). Some of the most significant theoretical approaches examining the midlife experience are stage models which assume development occurs when normative, sequential tasks are resolved (Lachman & Bertrand, 2001). The following section describes four traditional theories of midlife development: Jung’s (1954) work on midlife, Erikson’s (1963) theory of generativity in midlife,
as well as Valliant (2002) and Levinson and colleagues (1978) who applied and extended Erikson’s ideas on midlife development.

**Jung (1954; 1960).** Some of the earliest literature on midlife development comes from Carl Jung, who believed individuals do not become fully mature until the middle years of adulthood (40s and 50s) (Whitbourne & Connolly, 1999). While developmental tasks in young adulthood are more outward focused (such as mastering social roles), tasks in the second half of life require an inner focus and search for self-integrity (Arnold, 2005; Jung, 1960).

According to Jung (1954; 1960), satisfaction in midlife is related to “being able to accept one’s age, find meaning and purpose, and not yearn for the activities of youth” (McQuaide, 1998, p. 22). From his research Jung concluded that individuals have three responses when facing midlife: 1) facing the reality of aging which leads to erosion of attachment and disillusionment, 2) rebelling, which alarms others and can lead to depression, and 3) transitioning into an acceptance of middle age, which allows a person to use his or her unique gifts (Jung, 1954; Stein, 1983).

Vickers-Willis (2002) observed that “Jung’s psychology appeals to women because it is a ‘meaning making’ psychology” (p. 32). From this perspective, midlife is a time of increased introspection and self-evaluation which lead to personal changes and a shift toward authenticity (Marston, 2001; Ogle & Damhorst, 2005). Research on women in midlife supports the notion that this time involves increased self-awareness, reflection, and acceptance of self (Arnold, 2005; Picard, 2000). However, “not all women can attend to the inner promptings of midlife for self-reflection or have the capacity to steer a different course as they enter their fifties” (Arnold, 2005, p. 648). For many women in midlife, stressful life events and personal crises necessitate
attention to immediate concerns. Others have never been self-reflective, having little interest or motivation in contemplating meaningful life changes (Arnold, 2005).

Erikson (1959; 1963). According to Erikson’s (1959; 1963) eight stage model of psychosocial development, every life stage includes a conflict that serves as a turning point in development. The general theme of middle adulthood is generativity versus stagnation, and relies on successful completion of earlier developmental tasks (Lachman, 2004). Generativity is a concern for establishing, nurturing, and guiding the next generation. It requires widening one’s social circle and giving one’s self away to the next generation (Greene, 2005). Although raising offspring is typically associated with generativity, other behaviors include transmitting values, mentoring younger workers, or contributing to the world through art or literature (Lachman, 2004).

Erikson’s theory of personality development has been criticized because it is based on studies conducted primarily on men although it was generally assumed to apply to both men and women (Gergen, 1990; Gilligan, 1982; McQuaide, 1998). Some research suggests that women are not particularly concerned with generativity (Ryff and Migdal, 1984; Stewart, Ostrove, & Helson, 2001). However, other studies of men and women support the importance of generativity not only during midlife, but as an important aspect of personality throughout adulthood (Ackerman, Zuroff, & Moskowitz, 2000; Fisher, 1991; McAdams, St.Aubin, & Logan, 1993).

Erikson posited that identity formation is a task occurring in adolescence and early adulthood. However, identity is not formed permanently during adolescence, remaining unchanged throughout one’s life. McAdams (1993) says:
I do not see identity formation as confined to late adolescence and young adulthood…. Once an individual realizes that he or she is responsible for defining the self, the issue of self definition remains a preoccupation through most of the adult years. (p. 95-96) Indeed, identity formation appears to still be an issue for individuals in midlife (Barrett, 2005; Josselson, 1996; Whitbourne & Connolly, 1999).

**Valliant (2002).** Erikson’s model was extended by George Valliant (2002) to include two other developmental tasks: 1) career consolidation, which follows the task of intimacy and precedes the task of generativity and 2) keeper of the meaning, the second to last task of the life cycle. Career consolidation “involves expanding one’s personal identity to assume a social identity within the world of work” (p. 47). Valliant concluded that without developing one’s sense of self, typically through work, a person has nothing to give away (generativity). The final developmental task involves becoming a keeper of the meaning. Valliant distinguishes the task in this way, “The generative individual cares for an individual in a direct, future-oriented relationship…. In contrast, the Keeper of the Meaning speaks for past cultural achievements and guides groups, organizations and bodies of people toward the preservation of past traditions” (p. 48-49).

Valliant’s (2002) work provides further support for Erikson’s theory of psychosocial development without portraying the stages as a one-size-fits-all model. He states:

One life stage is not better or more virtuous than another. Adult development is neither a footrace nor a moral imperative. It is a road map to help us make sense of where we are and where our neighbors might be located. (p. 50)

**Levinson and Colleagues (1978; 1986; 1996).** From their research, Levinson and colleagues (1978) proposed a theory of adult development based on a series of transitions and
stable periods throughout adulthood (Levinson, Darrow, Klein, Levinson, & McKee, 1978). A key concept in Levinson’s theory is life structure, which is “the underlying pattern or design of a person’s life at a given time” (Levinson, 1986, p. 6). Transitional phases that occur throughout the life cycle are a time when one evaluates their existing life structure and explores the possibility of change. An outcome of transitions is a committed choice around which a new life structure is built and a phase of stability begins. Levinson (1986) asserted that “the life structure develops through a relatively orderly sequence of age-linked periods during the adult years” (p. 7).

Levinson’s research (1996) led him to conclude that women’s midlife experience was similar to that of men, except that the excitement and vitality was missing for women. He reasoned that because most women were homemakers and viewed marriage, homemaking, and family as more important than career, their opportunity for person growth was restricted. A major limitation of Levinson’s research is that although he defined midlife as occurring between ages 40 and 65, his study of women’s development only included participants up to age 45, compared with his earlier inclusion of male participants up to age 65 (Arnold, 2005). Consequently, it is questionable how applicable his theoretical assumptions are to women in midlife.

**Tasks and Transitions in Midlife**

A consistent theme in the literature on adult development and transition for midlife women is that women’s development does not adhere to predictable stages and is non-linear in nature (Belenky, Clinchy, Goldberger, & Tarule, 1986; Gilligan, 1993; Jordan, Kaplan, Miller, Stiver, & Surrey, 1991; McQuaide, 1998; Miller, 1996; Rossiter, 1999). Many of the studies of midlife development have been conducted by male researchers using male participants (Gergen,
More relevant to this study are views of midlife development that involve a cognitive component, giving attention to how individuals appraise and learn from personal experiences. The following section describes experiences typical of middle adulthood and other theories of adult development pertinent to how providing care for an aging parent shapes adult daughters’ perceptions of themselves.

Just as midlife has been labeled by its chronological boundaries, this time period is also defined by its content (Hunter et al., 2002). According to Neugarten (1968), events characteristic of midlife are children leaving the house, reaching a peak in one’s career, menopause, grandparenthood, retirement, onset of chronic illness, and widowhood. Clearly, being at the peak of one’s career might be more typical of adults in early midlife whereas retirement often occurs in late midlife.

The midlife experience is also characterized by the negotiation of changing roles and statuses (Hunter et al., 2002). “Although most persons enter midlife with jobs, young children, and living parents, they usually leave this period with no children still at home, widowed parents or no living parents, and retired from work or anticipating retirement” (Hunter et al., 2002, p. 5-6). It can certainly be an adjustment for men and women to have no children in the home after 18 years or more or to assume the caregiving role for an ill parent.

Providing care to aging family members is an increasingly common midlife task for women in particular. Adams’ (2006) study of “family members embarking on the dementia caregiving career” revealed several challenges associated with this transition. Caregivers not only have to assume tasks formerly done by the care recipient, but also have to negotiate “how much to do for the person with the memory loss, when to take over, how much to push, how much to limit” (p. 11). These difficult decisions are made, reassessed, and made again
throughout the caregiving career. Caregivers also experience significant changes in their relationship with the demented family member; role reversal is most typical for adult daughters caring for aging parents. When women transition to be a caregiver for family members with dementia, they can experience sadness, frustration, impatience, loss, and anger (Adams, 2006).

Oftentimes, midlife is also associated with a “midlife crisis” that marks the end of youth and the imminence of old age. Crises occurring in midlife represent a prominent cultural stereotype of this time period since only a small proportion of adults report actually experiencing a midlife crisis (Moen & Wethington, 1999). Similar to midlife crises however, and relevant to this time of life are turning points, which are “significant changes in the trajectory of life or an experience or realization that causes someone to reinterpret the past” (Lachman, 2004, p. 315) (also noted by Clausen, 1995 and Rosenberg, Rosenberg, & Farrell, 1999). Ogle & Damhorst (2005) observe that “theory about the midlife transition suggests that this life stage often is marked by a revision of the meanings used to understand the self and the surrounding world” (p. 5). Other authors have also noted these changes: Gould (1978) calls them “transformations”, Levinson (1996) refers to them as “transitions”, and Sheehy (1976) labels them “passages”.

Moen and Wethington (1999) define transitions as “objective changes in roles and relationships” (p. 14). Midlife transitions include children leaving the home, retirement, health crises, and caring for aging parents. With transitions often come changes in identity or status, both personally and socially and thus create opportunities for behavioral change (Elder, Johnson, & Crosnoe, 2004). Not all life transitions affect a person’s behavior or sense of self. However, transitions can be turning points for a woman when they are particularly salient and change the direction of her life (Moen and Wethington, 1999). In his research, Clausen (1990) found that psychological turning points occur after a particular experience or realization causes someone to
reinterpret past experiences in a way that revises long-held, fundamental assumptions (as cited in Moen and Wethington, 1999). For women in midlife, caring for an aging parent might be a turning point in which they view themselves differently and become aware of their own aging and future plans for later life.

**Alternative Theories of Midlife Development**

Compared with traditional, stage-based models of midlife development, more relevant to how caregiving might impact a woman’s sense of self are studies of adult development and old age involving personal growth from significant life experiences and relationships with others. Two descriptions of development based on how a person organizes life experiences are Whitbourne’s identity process theory (1987) and the possible selves construct (Markus and Nurius, 1986). These perspectives on development in adulthood offer “more detailed descriptions of the content of the self in adulthood, its role in influencing behavior, and the processes through which the self changes in response to life experiences” (Whitbourne and Connolly, 1999, p. 34). Additionally, the relational model of women’s development provides an alternative to traditional development theories by suggesting that women learn and grow in the context of their connections to others (Jordan, 1995; Jordan et al., 1991; Miller, 1996).

**Identity Process Model**

Whitbourne (1987; Whitbourne & Connolly, 1999) describes the process by which individuals interpret and respond to life experiences in adulthood. As defined by Whitbourne and Connolly (1999), identity is “the individual’s self-appraisal of a variety of attributes along the dimensions of physical and cognitive abilities, personal traits and motives, and the multiplicity of social roles including worker, family member, and community citizen” (p. 28).
Identity comes from the transactional relationship between the individual and her intrapersonal and interpersonal experiences (Whitbourne, 1987).

Whitbourne (1987) puts forward two identity processes to describe how individuals respond to life experiences: assimilation and accommodation. Identity assimilation “is the process through which individuals incorporate life events and new experiences into their identity” (Lachman & Bertrand, 2001, p. 300). Assimilation helps individuals to maintain a sense of self-consistency even in the face of inconsistent experiences or information (Whitbourne & Skultety, 2006). In contrast, identity accommodation “is the process through which individuals change their identity to conform to new experiences” (Lachman & Bertrand, 2001, p. 300).

Whitbourne (1987) proposes that equal use of assimilation and accommodation is the optimal way to adapt to physical and cognitive aging. Assimilative individuals may deny age-related changes such as physical or cognitive limitations. Individuals with a propensity for assimilation are perceived as rigid and inflexible. Denial and rationalization are protective in helping assimilative individuals “avoid recognizing weakness or inadequacies in the self” (Whitbourne & Connolly, 1999, p. 31). Conversely, persons with a strong accommodation style have a weak and incoherent identity; they tend to overreact to age-related changes. This person may take on the identity of an old person at the first sign of gray hair (Lachman & Bertrand, 2001; Whitbourne & Connolly, 1999). A balanced identity style involves being stable in personal goals and inner purpose yet flexible enough to adapt to changing circumstances in midlife (Whitbourne & Connolly, 1999). A balanced identity style “implies a stage of optimal adjustment to aging” (Whitbourne, 1987, p. 209).
Previous research suggests that identity processes are related to physical and psychological well-being in midlife and old age. In middle-aged and older adults, self-esteem is positively associated with identity assimilation (rigidly maintaining an existing identity) and identity balance (the flexible use of identity assimilation and accommodation) and negatively associated with identity accommodation (making structural changes in identity) (Sneed & Whitbourne, 2001). While an assimilative identity style positively influences self-esteem, it can negatively affect a person’s physical health. Denial of early warning signs of disease or impairment, such as cardiovascular disease or physical limitations, can lead to critical health problems later (Whitbourne, 1987).

Possible Selves

Another influence on development in adulthood is a person’s self-representations. Possible selves are the specific, personalized, future-oriented representations of self that motivate and guide behavior (Cross & Markus, 1991; Markus & Herzog, 1992). Markus and Nurius (1986) state, “Possible selves represent individuals' ideas of what they might become, what they would like to become, and what they are afraid of becoming, and thus provide a conceptual link between cognition and motivation” (p. 954). Possible selves include hoped-for and feared selves. Individuals’ hoped-for selves might include closeness with others, active, and independent. Feared future selves might include thoughts of loneliness, disability, or dependence. Possible selves are said to have two primary functions — they serve as incentives for future behavior and function as standards for comparison or evaluation of the current self (Markus & Nurius, 1986).

Possible selves represent a cognitive approach to the study of adult development since possible selves are created, maintained, and adjusted according to a person’s self-knowledge.
From this perspective, “the self-concept is viewed as a system of affective-cognitive structures (also called theories or schemas) about the self that lends structure and coherence to the individual’s self-relevant experiences” (Markus & Nurius, 1986, p. 955). Self-knowledge comes from how a person interprets their past and current experiences, as well as future scenarios (Markus & Herzog, 1992).

Cross and Markus (1991) found that compared with younger people, older adults exhibited more behavioral commitment to possible selves and had fewer possible selves within a more limited range of categories (e.g., physical, occupational, relational). From an assimilation perspective, having fewer possible selves might be an adaptive response to aging by maintaining a consistent view of self and protecting life satisfaction. When a person realizes personal goals may be at risk, the recalibration of possible selves can be likened to the process of accommodation (Whitbourne & Connolly, 1999).

**Relational Model of Women’s Development**

Most psychological studies of women’s development in midlife are from a loss perspective; this period is often depicted as a time of deterioration, barrenness, and asexuality (Gergen, 1990; Lippert, 1997). Greene (2005) notes, “Included in the descriptions of midlife are gloomy accounts of the growing emotional awareness of mortality, and now limited opportunities for reaching one’s life goals” (p. 123).

The relational model, also called self-in-relation theory, presents an alternative to traditional models of development and posits that women grow in and toward relationships rather than toward self-sufficiency and separation (Jordan, 1995; Jordan et al., 1991; Miller, 1996). This theory is founded in feminist writings about gender differences, particularly the debates between an essentialist position — the belief that sexual differences are innate, natural, and
eternal — and a social constructionist position that views gender as constructed through social and cultural processes (Kolmar & Bartkowski, 2005). For example, one might reason that more women than men provide care to older adults because women tend to value nurturance, connection, and selflessness. Some view this gender difference as natural (Chodorow, 1978), while others see it as resulting from gender socialization (Gilligan, 1982).

Some feminists believe that women not only have different traits than men, but that women’s concept of self is unlike men’s and is defined and negotiated in relation to others (Jordan, 1995; Jordan et al., 1991; Miller, 1996). In her longitudinal study of women’s development, Josselson (1996) observed that from college to midlife, women continued to define themselves in connection with others. “Identity in women cannot simply be named, for it resides in the pattern that emerges as a woman stitches together an array of aspects of herself and her investments in others” (p. 9). While traditional models of development emphasize autonomy, independence, and self-reliance (Erikson, 1959; Levinson, 1996), the relational model emphasizes the centrality of relationships in women’s lives (Chodorow, 1978; Gilligan, 1982; Jordan et al., 1991; Miller, 1996). Relationships and connection to others are believed to be particularly significant for women’s learning and development. From this perspective, an adult daughter providing care to an aging parent will likely be influenced by this relationship with reference to how she views herself and her own aging.

**Theoretical Approaches to Planning for Later Life**

This section describes three theoretical perspectives on planning for later life. In reviewing previous research on preparing for the possibility of long-term care needs, three theories emerge as central to understanding planning behavior. First is a theory that comes out of the stress and coping literature in psychology. The theory of proactive coping examines how
people anticipate future events or stressors (e.g., aging, long-term care needs) and prepare in advance for them. This is followed by further discussion of the possible selves construct, which has also been linked to planning for future care needs. Finally, I describe the theory of unrealistic optimism which suggests that people underestimate their risk for needing long-term care assistance and overestimate the likelihood of not needing care in late life.

**Proactive Coping**

Several authors have explored the relationship between proactive coping and “successful aging” (Bode, deRidder, Kuijer, & Bensing, 2007; Ouwehand, de Ridder, & Bensing, 2007) with the assumption that success in late life comes from preparing ahead of time and investing in one’s future. Proactive coping theory has also been used in research specifically looking at middle-aged and older adults’ plans for future care needs (Friedemann et al., 2004; Pinquart & Sorenson, 2002b; Pinquart, Sorenson, & Peak, 2004).

The theory of proactive coping informs this research by examining how people anticipate future events or stressors (e.g., aging, long-term care needs) and prepare in advance for them. Proactive coping is defined by Aspinwall and Taylor (1997) as “efforts undertaken in advance of a potentially stressful event to prevent it or modify its form before it occurs” (p. 471). This type of coping differs from coping as traditionally conceptualized in the stress and coping literature. Coping is the cognitive and behavioral efforts to manage (master, reduce, or tolerate) specific external and/ or internal demands (stress) that are appraised as taxing or exceeding the resources of the person (Folkman & Lazarus, 1980; 1985; Folkman, Lazarus, Dunkel-Sheffer, DeLongis, & Gruen, 1986). Coping strategies are typically viewed as reactive and evaluated by how individuals respond to stressors that have *already occurred* (Ouwehand et al., 2007).
Also important is a person’s ability to evaluate the likelihood of future threats and use strategies ahead of time that may minimize the problems at an early stage. Proactive coping is temporally prior to reactive coping and involves the gathering of resources and acquisition of skills designed to face potential threats (Aspinwall, 1997; Aspinwall & Taylor, 1997). Because future stressors are only potential threatening, they are often ambiguous in nature (Ouwehand, de Ridder, & Bensing, 2006). Even for stressful events or life changes that cannot be avoided (such as aging) and are still uncertain, proactive coping can be a helpful strategy. For example, studies show that older adults who plan are more likely to receive the type of care they prefer and be less of a burden on family members and friends (Brechling & Schneider, 1993; Pinquart & Sorenson, 2002b; USDHHS, 2008b).

There are differing opinions on how proactive coping is defined and explicated. Some researchers (Greenglass, 2002; Schwarzer & Taubert, 2002) view proactive coping as “creating opportunities for personal growth and building up resources that facilitate the pursuit of challenging goals” (Ouwehand et al., 2006, p. 809). Others define proactive coping as a psychological process where efforts are made to identify and prevent possible stressors that would threaten personal goals (Aspinwall, 1997; Aspinwall & Taylor, 1997). One main difference in the two is the source of motivation. Greenglass, Schwarzer, and Taubert view proactive behavior as motivated by perceiving situations as challenging and stimulating rather than potentially stressful or risky. Thus, proactive planning for old age might be motivated both by a desire to experience personal growth in late life and a desire to avoid, detect, and manage potential stress in the future. Aspinwall and Taylor (1997) delineate the proactive coping process into five stages: 1) resource accumulation; 2) recognition; 3) initial appraisal; 4) initial coping efforts; and 5) elicitation and use of feedback (Figure 1).
Figure 1

*Five Stages of Proactive Coping*

![Diagram showing the five stages of proactive coping]

Figure 1. The five stages of proactive coping, their component tasks, and the potential feedback loops among them.

(Aspinwall & Taylor, 1997)

The first stage of the process is *resource accumulation*, which involves the building up of skills and resources in advance of particular anticipated stressors. Proactive coping makes use of planning and organizational skills, time, money, and social support. Stage two of the process involves *recognition* of a potential stressful event and “…depends on the ability to screen the
environment for danger and to be sensitive to potential signs of threat” (Aspinwall, 1997, p. 283). After a potential stressor has been identified, the initial appraisal takes place. This consists of two related tasks: defining the problem and regulating arousal. Factors such as salience, accessibility, strength, expertise, and past experience help to establish the stressor as something requiring action. A cognitive process that is crucial during this phase is the ability to move the potential stressor forward in time to anticipate its likely consequences or course for the future. Thus, the individual must have a “future temporal orientation” (Aspinwall & Taylor, 1997, p. 424). In this stage, there must also be a balance between managing negative arousal and maintaining an accurate appraisal of the problem. Negative arousal can interfere with a person’s ability to engage in coping efforts (Aspinwall, 1997; Aspinwall & Taylor, 1997).

The next step involves preliminary coping efforts, activities aimed at preventing or minimizing a recognized or suspected stressor. At this stage, proactive coping is almost always active rather than avoidant; it can involve cognitive activities, such as planning mentally, or behavioral activities, such as information seeking and taking preliminary action. The final phase in the proactive coping process is the elicitation and use of feedback, which consists of acquiring and making use of feedback on the success of preliminary coping efforts. Questions one may ask at this stage include: Has the situation advanced, changed, or improved? Was I successful at avoiding the stressful event? Did I overreact? These five stages are not necessarily sequential but are interrelated tasks. Several feedback loops exist, particularly between resource accumulation, attention, appraisal, and regulation of negative emotional arousal.

Possible Selves

The construct of possible selves has also been tied to planning for future care needs. McGrew’s (2000) research uses the possible selves construct and self-efficacy beliefs to
understand psychological barriers to long-term care planning. Theoretically, imagining a vital and active older self would encourage physical activity and good nutrition. On the other hand, fearing a frail, disabled older self would encourage planning for that possible self. Based on her research with individuals 64 to 90 years old, McGrew (2000) identified four challenges in “overcoming inertia” (p. 6) about planning for the possibility of long-term care needs. To plan for late life, she asserts that individuals must have:

1. A conception of a future self as dependent
2. A perception of the effects (costs) of dependency
3. A concern today about possible dependency
4. Realistic beliefs about personal capacity (self-efficacy) to control the risk of dependency, to cope with its effects, and to plan for its possibility. In most cases, this would require the balancing act of deflating beliefs about the capacity to reduce risk and cope with effects, while inflating beliefs about the capacity to plan. (p. 6)

The first psychological barrier to planning has to do with the ability of individuals to envision a frail or impaired possible self (McGrew, 2000). Possible selves are the “the future-oriented representations of self that guide and motivate our behavior” (Wald & Frazier, 2003, p. 252). In their research, Pinquart & Sorenson (2002a) found that “a number of respondents felt that planning for [future care needs] is not necessary (yet) because they are too young, too healthy, or because family members died without becoming so sick that they needed care over a longer period” (p. 735). McGrew (2000) claims this overconfidence is due to faulty self-efficacy beliefs and is a form of inaccurate self-knowledge. Four sources of self-efficacy beliefs (and areas for social work intervention) are identified by Bandura (1977; 1997): mastery experiences, vicarious experiences, verbal persuasion, and physiological or affective states.
Visualizing a frail or dependent possible self will likely generate some thoughts about the effects or costs of dependency, the second challenge to planning. The need for long-term care has costs which impact family, friends, personal finances, and self (McGrew, 2000). Regarding just the monetary costs of long-term care, consumer surveys reveal that many individuals are not aware that health insurance, Medicare, and/or disability coverage does not pay for most long-term care services. Although Medicaid pays for some long-term care services, eligibility criteria require limited income and financial resources (USDHHS, 2008c). For some in McGrew’s (2000) study, the anticipated costs of dependency produced proactive coping strategies, but others assumed they would cope with difficulties as they came. This suggests that some older adults have “inflated self-efficacy beliefs about coping with dependency” (p. 13). For these individuals, the ability to cope with future dependency came from relying on previous personal successes, the strength and success of others, and even the possibility of governmental assistance (McGrew, 2000).

A third psychological barrier inhibiting planning is a concern today about possible dependency, and specifically the belief that a future dependent self is not worthy of planning behaviors. For many in McGrew’s (2000) study, these unwanted or feared possible selves were so contemptible they were not motivated to plan for them. Similarly, Pinquart and Sorenson (2002a) found that some older adults avoid preparing for potential care needs because of a concern that thinking about future dependency would somehow reduce present psychological well-being, making them depressed or anxious.

A final psychological factor concerns the related beliefs that one has the capacity to plan and that planning would make a difference in long-term care (McGrew, 2000). Individuals with an internal locus of control, “the belief that one determines one’s own fate rather than being
subject primarily to external control” (Pinquart, Sorenson, & Peak, 2004, p. 6), are more likely to think and talk about future care (Sorenson, 1998). Relying on the plans of significant others, such as doctors or adult children, keeps some individuals from making their own arrangements for long-term care (Pinquart & Sorenson, 2002a).

**Unrealistic Optimism**

A third theoretical perspective on planning for later life is the theory of unrealistic optimism. Developed by Weinstein (1980), unrealistic optimism asserts that individuals tend to underestimate their personal risk for negative events and overestimate the likelihood of positive future circumstances. At an individual level, it is difficult to determine whether optimism is realistic or unrealistic. However, when the vast majority of people in a group believe their chances of experiencing a negative event are less than average, this is clearly not just optimistic but unrealistic (McKenna, 1993; Weinstein, 1980).

Significant evidence supports the notion that people believe negative events are more likely to happen to their peers than to themselves and that positive events are more likely to happen to themselves than to their peers. Moreover, the tendency toward unrealistic optimism does not discriminate by age, gender, education or occupational group (Weinstein, 1987). For both positive and negative life events, an optimistic bias is present when two conditions are satisfied. First, when the event is perceived to be controllable and two, when people have some degree of commitment or emotional investment in the outcome (Weinstein, 1980). However, some research suggests that collectivist cultures are less likely to have self-enhancing biases than Western cultures which emphasize an independent construal of self and an internal locus of control (Heine, 1989; Markus & Kitayama, 1991).
When asked to assess the likelihood of a negative event such as being involved in a car accident (Robertson, 1977), developing cancer or having a heart attack (Perloff & Fetzer, 1986), or being the victim of a mugging (Weinstein, 1980), most people consider their chances as less than others. Dunning, Heath, and Suls (2005) reviewed empirical findings on the imperfect nature of people’s self-assessment and found that people “tend to be unrealistically optimistic about their health — as they are about other areas of life — perceiving themselves to be significantly less at risk than their peers for a wide range of physical diseases and negative health outcomes” (p. 79).

Unrealistic optimism tends to hold true more for predictions made about oneself than about others. Walz & Mitchell (2007) found that adult children had higher expectations for their parents needing care in the future than they or their parents had for their own future care needs. Weinstein (2003) suggests that unrealistic optimism comes from a need to defend one’s self-esteem against possible threats. Similarly, failure to plan for future care needs has been linked to protecting one’s present psychological well-being. McGrew (2000) and Pinquart and Sorenson (2002a) found that one reason people did not prepare for potential care needs was because thinking about future dependency was feared and people believed thinking about it would make them depressed or anxious. The underestimation or denial of needing care in old age prevents many individuals from securing the appropriate type and amount of care that may be needed in the future. Perceptions of invulnerability also have implications for immediate plans such as behavior changes to optimize one’s health behaviors (for example, quitting smoking or exercising regularly) or modification of one’s residence to allow aging in place (Walz & Mitchell, 2007).
In sum, there are several psychological barriers to planning for the possibility of future care needs. These include lack of a future orientation, the inability to envision a frail or dependent possible self, unrealistic optimism about the future, and an external locus on control. Also related to planning for one’s aging are contextual factors that encourage or inhibit planning for later life.

**Caregiving as a Factor in Planning for Later Life**

Caregiving is one contextual factor that has been given limited attention in the literature on planning for old age. The following section presents observations from authors and researchers on how caring for an aging parent might foster psychological growth and proactive planning for late life. Three theoretical approaches will also be used to argue how caregiving might influence women’s sense of self and aging.

**Previous research on the influence of caregiving.** Robinson and Moen (2000) examined expectations for future housing and moves for workers and retirees in late midlife. In their late midlife sample, they found that volunteers and women caregivers had higher expectations of purchasing long term care insurance. In addition, caregiving predicted higher expectations of moving into a retirement community. The authors suggest that both volunteering and caregiving experiences might “increase late-midlifers’ firsthand awareness of the frailties that often accompany aging, reinforcing their desire to take control over their own future housing and [long-term care] arrangements to optimize both care and independence” (Robinson & Moen, 2000, p. 525).

In their research on individual’s plans for late life, Roberto, Allen, and Bleiszner (2001) found that most older adults with formal plans were female. The authors suggest that because of women’s personal knowledge of family caregiving, “they may be more realistic and self-
sufficient in anticipating their own future care needs” (p. 119). Caregivers’ personal experiences might make them more aware of the need to plan for old age.

Cannon’s (1988) research suggests a connection between the health and functional status of aging parents and an adult daughter’s own preparation for aging. She examined what factors were most significant to middle aged women’s decision to plan for their own aging in terms of relevant demographic and socioeconomic characteristics of themselves and their aging mothers. Cannon (1988) found that mothers’ health and functional status were highly correlated with midlife women planning for old age. Women whose mothers were in poor health and had limited functional ability had more concrete plans for later life.

Other authors have noted the relationship between aging parents and adult children’s conceptions of their aging self. Based on his interviews of professionals between the ages of 50 and 60, Karp (2000) declares this to be the “decade of reminders” and remarks specifically on what he calls “generational reminders.” He observes that “respondents see their own aging reflected in the aging of their parents, children, and grandchildren” (Karp, 2000, p. 72). The interconnectedness of lives is reflected in how one participant speaks of her mother, “She’s slowing down in every which way…And I think when these things happen you’re finding out that you’re vulnerable” (Karp, 2000, p. 72). Similarly, Stephanie Marston (2001) states, “In every ache and pain, in our changing energy level, in our changing roles with our parents and children, we catch a glimpse of our own mortality” (p. 123). She speaks of women seeing frailty in their aging parents and realizing their parents can no longer protect them as they used to do. Adult children who are caregivers are now in the role of protector and caretaker; this role reversal can create a sense of vulnerability in the grown children (Marston, 2000).
Caregiving and identity processes. Whitbourne and Connolly (1999) note that research on how contextual experiences stimulate identity development is sparse and focuses not on identity but on variables related to personality and well-being. The authors suggest that significant experiences in adulthood related to identity development have to do with long-term relationships, parenting, work-related experiences, community activities, and socio-historical context. Although the relationship between adult children and aging parents is not mentioned as an experience stimulating identity development, caregiving for a parent certainly influences adult children in direct ways (impacting their physical and psychological functioning) and indirectly through the processes of identity assimilation and accommodation (Whitbourne and Connolly, 1999).

Caring for aging parents can be a salient experience in midlife that influences identity by stimulating both assimilation and accommodation. As Karp (2000) and Marston (2001) point out, caregivers see themselves in their aging parent and in the changing parent-child relationship. There is often a reversal of roles where adult children are now having to protect and assist their parents. Caregivers can respond to these experiences in several ways.

The frequent and close contact between a caregiver and care recipient is likely to affect both individuals, and specifically might make the caregiver more cognizant of her own aging. Identity assimilation occurs when adult children screen out this information, refusing to adjust their identities to incorporate age-related information and changes in relationships. The personal experience of caring for an older adult provides adult children with firsthand knowledge about the financial, environmental, and social factors that impede or assist in caregiving. Assimilative individuals will not see this information as relevant to them; however, an accommodative person might become overly obsessed with her own late life plans. An accommodative woman caring
for a blood relative may be concerned with genetic or lifestyle similarities that could make her susceptible to the same physical or cognitive impairment. Such awareness could lead to extreme anxiety or proactive behaviors concerning later life.

According to Whitbourne (1987), “Identity styles would represent the way that stable individual differences in coping strategies influence how health and social role changes in adulthood interact with the individual’s self-definition, particularly that component of it that falls along the dimension of age identity” (p. 200). There is no “right” way to adapt psychologically to growing older; assimilation, accommodation, and balanced identity styles have advantages and disadvantages with regard to the aging process (Whitbourne, 1987). Theoretically, however, optimal adjustment to aging would come from a balanced identity style. This would describe adult children who gradually integrate age-related information into a cohesive sense of self. Moreover, balanced individuals would take advantage of medical, social, or psychological interventions to plan for their own late life.

**Caregiving and possible selves.** The theory of possible selves can also inform how caregiving might change midlife women’s view of themselves. In their research, Hooker and Kraus (1994) found that possible selves related to health became predominant during midlife. The authors suggest three contextual influences associated with midlife that might explain why health is a more salient concern at this period in the life course. It is in midlife that individuals start to personally experience life-threatening health incidents (such as heart attacks or cancer diagnoses) or witness peers going through such events. Midlife is also a time when adult children are concerned about aging parents’ health problems. Lastly, a time orientation change from “time since birth” to “time left to live” (Neugarten, 1968) can be triggered by a realization of one’s own mortality (Hooker & Kraus, 1994).
According to Frazier, Johnson, Gonzalez, and Kafka (2002), possible selves are “dynamic and situationally responsive, and yet stable and contextually grounded visions of self” (p. 308). Caregiving is likely to be an experience, especially for women in late midlife, which influences both hoped-for and feared possible selves. An adult daughter’s view of herself as an older woman will largely be affected by her parent’s experiences in later life.

**Caregiving and the relational model of women’s development.** Many authors have noted that women often define themselves by their connection to others (Chodorow, 1978; Gilligan, 1982; Miller, 1996). The notion that women learn and develop in the context of their relationships has implications for how caregiving might change women (Hayes, 2001; Jordan et al., 1991; Miller, 1996). From this perspective, an understanding of how women develop in middle adulthood must be situated in the context of their significant relationships. Caregiving involves watching a loved one struggle with frailty or chronic disease, assisting with daily (sometimes intimate) tasks, and often providing round the clock care. This is likely to have an effect on a woman’s view of herself and her own aging. Barrett (2005) observes:

> Although they have received little attention, health-related events in the lives of significant others, including partners, children, parents, other relatives, or friends are likely to shape perceptions of one’s aging self. They may serve as reminders of age-related transitions that one eventually will experience, which may stimulate reflection on one’s own age and location in the life course. (p. 168)

Similarly, Rosenberg (1986) observes that a person’s social connections can be viewed as “ego extensions,” and the successes and failures of significant others may influence self perceptions.

In her research on how gender differences in midlife relate to age identity, Barrett (2005) found relationships to be significant to women’s perception of their aging self. Using data from
the National Survey of Midlife Development, Barrett found many women to have life circumstances that were associated with older identities. Such life situations included lower levels of perceived control over their marriages/partnerships, having an older partner, and having a parent in poor health (Barrett, 2005).

To summarize, numerous authors have observed an association between women’s role as caregivers for older adults and their planning for later life (Cannon, 1988; Roberto, Allen, & Bleiszner, 2001; Robinson & Moen, 2000). Women’s sense of self is largely connected to their relationships with others (Jordan, 1995; Jordan et al., 1991; Miller, 1996), so the experience of caring for an aging parent is likely to influence a woman’s view of herself and her own aging. Although others have observed this connection, no studies exist that specifically examine how caregiving influences women’s sense of self. This research will fill a gap in the literature by focusing on how caregivers in late midlife construct meaning from their caregiving role and how this shapes their perspectives and plans for later life.

**Chapter Summary**

This chapter presented theoretical perspectives on midlife development and planning for later life. Theories related to self-development in middle adulthood are relevant since participants in this study were in late midlife. Traditional views of midlife development were reviewed, including those of Jung, Erikson, and Levinson. The person-in-environment perspective characteristic of social work practice supports the notion that personal growth can come from significant life experiences and relationships with others. Therefore, alternative theories of adult development and old age were discussed; these include identity processes, possible selves, and the relational model of women’s development.
The second section of this chapter reviewed three theoretical perspectives on planning for later life. Proactive coping theory, possible selves, and unrealistic optimism have all been used in previous studies examining the extent to which people plan for the possibility of needing long-term care assistance. The final section discussed caregiving as a relevant life experience that might influence women’s sense of self and aging.

The culmination of this chapter is to acknowledge how caregiving might impact one’s decision making about aging. Other authors have suggested that caring for an aging parent might influence proactive planning for later life. However, previous research has not sampled caregivers specifically or examined how caregiving influences perceptions and planning for later life. This study helped fill this gap in the literature. Chapter 4 describes the methodology that was used to examine how women are affected by their role as caregivers.
CHAPTER 4

METHODOLOGY

Introduction

This chapter presents the strategies I used to explore how women were affected by their role as caregivers, particularly with regard to their own preferences and plans for late life. The following subsections detail the methodology that was utilized in this research: design of the study, sample selection, data collection, data analysis, ethical considerations, validity and reliability, and researcher bias and assumptions.

Study Design

Many authors maintain the importance of selecting a methodological approach based on its appropriateness with the purpose of the research (Chafetz, 2004; Patton, 2002). Much of the previous research on how individuals think about and prepare for aging has sampled older adults. Preferences and planning for future aging have been examined both quantitatively (Delgadillo, Sorenson, & Coster, 2004; Friedemann et al., 2004; Pinquart, Sorenson, & Davey, 2003; Pinquart & Sorenson, 2002c) and qualitatively (McGrew, 2000; Pinquart & Sorenson, 2002a; Roberto et al., 2001). Planning for late life is important not only for older adults, but also for adults in late midlife. Research suggests that individuals have more choices and control over their options in late life the earlier they plan (USDHHS, 2008c). Those who communicate their preferences and plans ahead of time are more likely to receive the type of care they prefer (Brechling & Schneider, 1993; Holden, McBride, & Peronzek, 1997). Planning for future care also results in less stress on family members by giving them time to prepare for the caregiving
role. It also relieves them of the burden of having to make decisions on behalf of the care recipient (Pinquart, Sorenson, & Peak, 2004; USDHHS, 2008b). Several authors note that preferences and plans for later life are influenced by contextual factors such as access to resources, a cultural emphasis on acute rather than chronic conditions, and quality of family relationships (Pinquart, Sorenson, & Peak, 2004, Roberto et al., 2001; San Antonio & Rubinstein, 2004). However, caregiving is one contextual factor that has been given limited attention in the literature on planning for old age.

Qualitative research is appropriate when “a complex, detailed understanding of the issue” (Creswell, 2007, p. 40, emphasis in original) is needed. Although caregiving is becoming a normative event for many women in midlife, the actual experience will be different for every woman and every caregiving dyad. Most of the research on caregiving outcomes focuses on negative consequences such as the physical and emotional burden of caregiving. Less attention has been given to caregiving gains such as personal growth and development in the caregiver (Chen & Greenberg, 2004; Kramer, 1997; Tarlow et al., 2006). Qualitative methods allowed me to explore how caregivers in late midlife construct meaning from their caregiving role, particularly in relation to their perspectives and preferences for their own aging.

Quantitative and qualitative approaches stem from different epistemological assumptions. Quantitative methods are often associated with positivism and the ideas that “knowledge gained through scientific and experimental research is objective and quantifiable” (Merriam, 1998, p. 4). Conversely, qualitative researchers emphasize the socially constructed nature of reality and seek to reduce the distance between the researcher and the phenomenon being studied (Denzin & Lincoln, 2000). Even more, qualitative researchers identify their personal biases in relation to the study, realizing “there is no value-free or bias-free design” (Janesick, 2000, p. 385).
Two key traditions in qualitative design that are concerned with meaning are interpretive work and phenomenology (Crotty, 1998; Merriam, 2002). The research method for this study was informed by both interpretive research and phenomenology because of the focus on participants’ meaning. According to Merriam, qualitative researchers conducting an interpretive study are interested in:

(1) how people interpret their experiences, (2) how they construct their worlds, and (3) what meaning they attribute to their experiences. The overall purpose is to understand how people make sense of their lives and their experiences. (p. 38, emphasis in original)

Although there are various types of qualitative research designs, several key characteristics underlie all qualitative research.

**Characteristics of Qualitative Designs**

Some features of qualitative inquiry are a focus on understanding meaning, researcher as instrument for data collection and analysis, inductive process, use of a conceptual framework, emergent research design, emic perspective, and richly descriptive findings.

A distinct feature of qualitative research is that it helps us understand how people make meaning of their lives (Bogdan & Biklen, 2007; Creswell, 2007; Merriam, 2002). The meaning of something consists of its personal and social significance. Jaffe and Miller (1994) assert that when researchers inquire about meaning, they ask, “How is it [the object, experience, idea or relationship being studied] used as a guide or justification for behavior or for thinking about something in a certain way?” (p. 52). Qualitative methods were most appropriate for this study because it sought to understand the personal significance of caregiving to adult daughters and how this guides or explains their attitudes and plans for later life.
A second characteristic of qualitative research is the researcher is the primary instrument for data collection and data analysis (Guba and Lincoln, 1981). The researcher is the human instrument through which “data are mediated…rather than through some inanimate inventory, questionnaire, or computer” (Merriam, 2002, p. 7). This unique position allows the researcher to consider the context of the phenomenon, adapt techniques according to the circumstances, attend to nonverbal behavior, clarify and ask questions to draw out relevant information, and process data immediately (Merriam, 2002). Although this allows flexibility during the research process, this feature of qualitative inquiry also “means the researcher must have the ability to observe behavior and must sharpen the skills necessary for observation and face-to-face interviews” (Janesick, 2000, p. 386). I believe my experience as a social worker, particularly my skills in interviewing, observation, and assessment, assisted me in this aspect of the research.

Thirdly, qualitative research utilizes induction, as opposed to deductive reasoning used in quantitative research. Quantitative methodology relies on hypothesis testing and pre-determined variables to apply general principles and theories to particular situations. In qualitative research however, the particular is given special attention. From specific cases, researchers “gather data to build concepts, hypotheses, or theories” (Merriam, 2002, p.5). The exploratory nature of inductive research best fits this study because little is known about how caring for aging parents shapes caregivers’ beliefs and desires about their own late-life needs.

Both quantitative and qualitative researchers bring assumptions to a study, just in different forms. Quantitative research assigns a priori hypotheses to a study while qualitative researchers begin with guiding questions and a theoretical lens (also called a conceptual framework) (Creswell, 2007; Rossman & Rallis, 1998). This study examined how providing assistance to older parents shapes female caregivers’ concept of themselves and their own aging.
Caregiving was viewed as a relevant, contextual experience influencing women’s perceptions of their aging self as well as their plans for aging. Rossman and Rallis (1998) note that the conceptual framework “can be — and most often is — changed, modified, and refined once in the field as other, perhaps more important, questions are discovered” (p. 9-10). This leads to the next feature of qualitative inquiry, the emergent research design.

Not only might theoretical assumptions be modified in the course of a study, but interview questions, settings, and participants might be reconfigured in order to understand the phenomenon from the perspective of the participants, rather than the perspective of the researcher (Creswell, 2007). This is referred to as the emic, or insider’s, perspective and is characteristic of qualitative inquiry (Merriam, 1998). For example, in the planning of this study, I intended to spend a full day observing a few participants to obtain “firsthand experience” and “personal knowledge” to inform subsequent data collection and analysis (Patton, 2002, p. 264). After consulting with my committee, I determined that observing only a few participants in their home would likely present a skewed view of the caregiving experience and may not necessarily represent the emic perspective of all study participants.

A final feature of qualitative research is findings that are richly descriptive (Merriam, 1998; 2002). Data are presented as words and pictures, rather than numbers (Bogdan & Biklen, 2003). In this study, the participants’ own words comprised most of the descriptive findings; all interviews were digitally recorded and transcribed verbatim. Data also included narration from field notes recorded during interviews. This type of data, either in quotes or excerpts, was most appropriate for answering the research questions, which center on the meaning participants ascribe to caregiving and how this affects their perspectives and plans for later life.
Sample Selection

Since qualitative research seeks to understand the meaning of a phenomenon from the perspectives of the participants, researchers typically select a sample from which the most can be learned. This is known as purposive, or criterion, sampling (Patton, 2002). This study employed purposeful sampling in order “to yield the most information” and select participants whose experiences are “information-rich” as related to the research questions (Merriam, 2002, p. 20).

Sampling Criteria

Eight criteria were used to obtain a sample for this study. Participants must a) be women, b) identify themselves as the primary caregiver to a parent or parent-in-law with a chronic illness and disability, c) have been a caregiver for at least 6 months, d) provide an average of seven hours of direct care per week (over the course of 6 months), e) be between the ages of 50 and 65, f) be willing and capable of participating in a 60 to 90 minute in-person interview and a follow up interview (or telephone call) if clarification is needed after reviewing the transcript, g) be willing to respond to preliminary findings, and h) live in Georgia.

The first two criteria were necessary as this study sought to illuminate how female caregivers were influenced by the caregiving experience. This study looked at adult daughters specifically, caregivers with a legal relationship to the care recipient (not fictive kin). I also included women who had been caregivers for at least six months and provide a minimum of one hour of direct care per day. These criteria suggest that a minimum amount of time has passed for women to have assumed the caregiving role and caregiving has thus had an impact on their daily lives. An average of seven or more hours of care per week suggests that the parent requires daily or weekly assistance.
Including participants between the ages of 50 and 65 years old is because I wished to focus on caregivers in late-midlife. Late midlife has been distinguished from early midlife as spanning from age 50 to 72 (Robinson & Moen, 2000) as well as characterizing individuals in their late 50s and early 60s (Vandewater & Stewart, 2006). Research shows that increased age is associated with planning for future care needs (Black, Reynolds, & Osman, 2008; Delgadillo et al., 2004) so I anticipated that younger caregivers would be less likely to think about their aging than women in their 50s and 60s. Although the typical caregiver in the United States is about 46 years old, approximately 30% of caregivers are between 50 and 65 years old (NAC & AARP, 2005).

The next two criteria were necessary since the primary source of data came from face-to-face interviews. Follow up interviews and phone calls did not last more than 30 minutes but were necessary to clarify information from some of the initial interviews. Through either email or telephone, I attempted to contact each participant so she could look at her individual profile (which is included in Chapter 5) to make sure her story is accurately presented. Finally, living in Georgia ensured geographic proximity that was a practical consideration because I traveled to the location of the participants.

Locating the Sample

Three approaches were used to find participants for this study: recruitment fliers, gatekeepers, and snowball sampling. Qualitative researchers typically have to “go to where the respondents are” to recruit participants for a study (Padgett, 1998, p. 51). First, I advertised for study participants using recruitment fliers (Appendix A). These fliers were distributed at locations such as assisted living and nursing homes, geriatric hospitals, and community centers.
Fliers were also sent through an Internet list serve to the Learning in Retirement group at the University of Georgia.

Second, because I am an outsider and not a caregiver myself, I employed the assistance of gatekeepers to help me locate women who met the criteria for participation. A gatekeeper “is a member of or has insider status….and leads the researcher to other participants” (Creswell, 2007, p. 125). Professionals at Area Agencies on Aging in the Atlanta and northeast Georgia areas were contacted for help in locating women who meet the criteria for participation. Through my volunteer experience, I developed a relationship with the director of the local Adult Day Health Center. The director agreed to send letters to several caregivers whom she thought might be interested in participating in the study. Approximately two weeks after the letters were sent out, I contacted these women by telephone to give them details of the study and determine if they were interested in participating. Existing professional contacts such as these assisted with locating participants. Caregivers previously interviewed for a qualitative class project as well as personal contacts also served as gatekeepers; individuals were contacted to assist in recruiting and referring other participants.

Finally, snowball sampling was used to locate participants (Patton, 2002). Snowball sampling takes place during the course of research when participants “are asked to provide the names of people they know or know about, who like themselves, have experienced some problem or…meet the necessary criteria for inclusion in the research study” (Yegidis & Weinbach, 2009, p. 209). Study participants were asked if they knew of other caregivers who might be interested in participating. As an outsider, I believe the use of gatekeepers (professionals, participants from class pilot, personal contacts) and new participants helped me establish rapport and trust with the women I interviewed.
Once potential participants were located, a screening guide (Appendix B) was used to determine if they were eligible for inclusion. A brief phone interview also allowed me to explain some details of the study. The screening interview provided an opportunity to clarify the purpose of the study, to describe the intended audience, and to discuss logistics such as arranging the time and place of the interview.

The criteria for participation indicate some choices I made regarding my sample, specifically with respect to gender and age. In addition, I decided to focus more generally on caregivers for aging parents, rather than caregivers for specific groups of older adults (such as caregivers of individuals with Alzheimer’s or caregivers of elders with a physically disability). The diagnosis of the care recipient influences the caregiving experience with regard to duration, type of assistance needed, and burden (NAC & AARP, 2005; Ory et al., 1999; Papastavrou et al., 2007). It was not known if care recipient diagnoses have different influences on caregivers’ decision making about late life. The exploratory nature of study warranted the inclusion of a wide variety of caregivers to older adults.

Not only did I strive for a diverse group of caregivers with regard to care recipient diagnosis, but special considerations were made to interview women from different socio-economic backgrounds and ethnicities. A varied sample also included diversity in marital status, employment, children, and relationship to the care recipient (e.g., biological, daughter-in-law). Social work values diverse populations; therefore, social work research should also seek inclusion of diverse caregivers (Amador, Travis, McAuley, Bernard, & McCutcheon, 2006). I believe a varied group of participants resulted in a more holistic understanding of how caregivers think about and plan for their late life.
Several strategies were used to obtain a diverse sample of caregivers. First, I made contact with a woman who belongs to several Hispanic women’s groups in the Athens community. This contact person assisted me in sending the recruitment flier to other group members. Second, when getting assistance from the director of the local Adult Day Health Center, I focused initially on contacting and recruiting women of color.

Sample Size

In qualitative research, there are no hard and fast rules regarding sample size. Lincoln and Guba (1985) recommend sampling until the researcher reaches a point of redundancy or saturation. They point out:

In purposeful sampling the size of the sample is determined by informal considerations. If the purpose is to maximize information, the sampling is terminated when no new information is forthcoming from new sampled units, thus redundancy is the primary criterion. (p. 202, emphasis in original).

There was no way to know how many participants would be needed for the data to become saturated. Guest, Bunce, and Johnson (2006) examined the issue of sample size in qualitative research empirically and found that data saturation occurred by the time they had analyzed twelve interviews. The final sample size for this study was 15 caregivers; information about these participants is provided in Chapter 5.

Data Collection

Data in qualitative research typically come from interviews, observations, and documents. This study used in-depth interviews as the primary data source. The following sections describe this data collection method, the strengths and weaknesses of the method, and how interviews were used in this study.
Individual interviews were the primary data collection method in this study. Interviews allow the researcher to get at “feelings, thoughts, and intentions” that cannot be directly observed or readily found in existing documents (Patton, 2002, p. 341). Qualitative interviewing can vary in the degree to which the interview is structured, ranging from structured or semi-structured, to open-ended interviews (Bogdan & Biklen, 2007). The interviews in this study were semi-structured, consisting of both structured and less structured questions.

Structured questions were used to elicit background information such as age, marital status, health, income, work histories, and descriptions of their caregiving experience. Semi-structured questions which followed an interview guide helped me gather information in the participants’ own words. This format helped ensure the research questions were the focus during the interview while also allowing the participants to guide the content of the interview by sharing information that was significant to them (Patton, 2002). The interview guide (Appendix C) consisted of questions to cover the following topics:

1) Participants’ histories of how they came to be caring for their parent
2) Caregivers’ perspectives and decision-making about their own aging
3) Practical plans the caregivers have made about their aging
4) Socio-demographic information

All interviews were digitally-taped and transcribed in their entirety. Field notes were also taken and used to inform study findings. Before the interviews started, each participant signed a consent form for participation (Appendix D).

Patton (2002) identifies several strengths and limitations to using an interview guide in qualitative research. The structure provided by the interview guide makes data collection somewhat systematic and keeps the interviewer focused on the predetermined research topic.
This format also allows for a conversational style as the researcher “remains free to build a conversation within a particular subject area [and] to word questions spontaneously” (p. 343).

However, there are some limitations to an interview guide approach. Topics that are important or salient to the respondents may be unintentionally omitted from the guide and therefore, not explored during the interview. Also, the flexibility allowed in wording and sequencing the questions might result in responses from various perspectives, thus reducing the comparability across transcripts (Patton, 2002). In addition to the particulars of an interview guide approach, qualitative in-depth interviews also have strengths and limitations regarding data collection with this population.

A strength of qualitative interviewing is that participants are not restricted by predetermined responses present in a survey instrument and can share their experiences in their own words. In their research on older adults’ preferences for future care, Roberto, Allen, and Blieszner (2001) point out, “When carefully planned and conducted, in-depth interviews are respectful to the life experiences of older adults and place them in the role of expert on their own lives” (p. 114). I believe the same was true for female caregivers in this study, especially since I approached this study as an outsider.

A limitation of qualitative interviewing is the possibility that some participants may filter their responses to provide a perspective they want the researcher to hear. The presence of the researcher, particularly an outsider, may influence the data that are collected (Padgett, 1998). As an outsider, some women may have felt uncomfortable talking with me about their thoughts and plans for their own aging. In addition, though I interviewed women who agreed to participate and discuss their experiences, some of the respondents may not have been “articulate, perceptive, or clear” (Creswell, 2008, p.226). This is discussed in the limitations section of Chapter 7.
When conducting research with family caregivers, unique challenges arose for which I had to be flexible. Research recruitment and retention issues that are particular to this population include constraints imposed by caregiver stress and burden and caregivers’ inability to participate due to not having backup help for care recipient (Amador et al., 2006). Each participant received a $25 Visa gift card to show appreciation for the time it took to participate in the study. Although I was amenable to times and days to schedule the interviews, I had several instances where interviews had to be rescheduled or cancelled. Although most of the interviews took place at participants’ homes, two interviews were conducted at public libraries, one at the home of a mutual acquaintance, and I met one participant in the break room at her place of employment. Several interviews had to be rescheduled due to unforeseen circumstances. For example, Joanie called the morning of our scheduled interview because she had noticed a possible infected wound on her mother’s foot and needed to take her to the doctor before going out of town the next day. Another caregiver was unable to be interviewed for this study because her mother passed away the night before our scheduled interview.

In sum, I used in-depth interviews to collect data about caregivers’ perspectives and plans related to aging. In these interviews I learned about participants’ caregiving experiences and the meanings they have made about those experiences (Seidman, 2006). Interviews ranged in length from 28 minutes to two hours and ten minutes although most interviews lasted about an hour and a half. I completed the interviews over a six month period, from May 3, 2009 to September 15, 2009. I used three professional transcription services to transcribe verbatim 10 of the 15 audio files. After receiving the transcripts back, I checked the documents against the audio files to ensure accurate transcripts. For unknown reasons, the audio for one interview, Jacqueline’s, was
impossible to hear. I discovered the mistake immediately after the interview and took detailed
notes from our meeting.

In addition to the structured and semi-structured questions on the interview guide, data
also came from two instruments that participants completed during the interview; these
instruments provided additional information about their caregiving situations. The Katz Basic
Activities of Daily Living (ADL) Scale (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) and the
Lawton-Brody Instrumental Activities of Daily Living (IADL) Scale (Lawton & Brody, 1969)
were used to elicit information about care recipients’ ability to perform ADLs and IADLs which
are often used as measures of individuals' functional health status (Morgan & Kunkel, 2007).
These instruments are located in Appendix C as part of the interview guide.

Data Analysis

Findings in basic interpretive studies are typically a combination of description and
analysis (Merriam, 1998). I adapted methods from grounded theory to analyze the data,
particularly the techniques of coding, constant comparison, and memo-writing. Analysis started
while I was still collecting my data, which is recommended by several authors (Bogdan &
Biklen, 2007; Ezzy, 2002; Kaufman, 1994).

During my initial reading of the transcripts, I employed open coding procedures, where
codes are created from what is present in the data. This “initial identification of topics” (Ezzy,
2002, p. 87) is intended to be inductive and exploratory as the researcher approaches the data
without themes and categories already in mind. Charmaz (2006) recommends, “Remain open,
stay close to the data, keep your codes simple and precise, construct short codes, preserve
actions, compare data with data, (and) move quickly through the data” (p. 49). As noted by
Ezzy, this process is similar to reading texts for school — taking notes in the margins and
highlighting significant passages. After identifying initial codes in the transcripts, I moved to focused coding. Focused coding “means using the most significant and/ or frequent earlier codes to sift through large amounts of data” (Charmaz, p. 57). This involved making decisions about what codes were most relevant to the research questions, discarding codes that were not relevant, and combining earlier codes that were similar. The grounded theory method of constant comparison was used to look for similarities and differences in categories across the transcripts (Charmaz, 2006). This process involved “continuously comparing one unit of data with another” (Merriam, 2002, p. 8) and took place throughout the analytic process.

Janesick (2000) points out that “simply observing and interviewing do not ensure that the research is qualitative” (p. 387). A distinguishing feature of qualitative inquiry is the interpretive process of analyzing qualitative data (Ezzy, 2002; Janesick, 2000). To move beyond simply identifying codes, I used memo-writing (Charmaz, 2006) to help me conceptualize and flesh out my thoughts after reading the transcripts. The memos allowed me to shift from categorizing and labeling the data to interpreting the data. Charmaz states that “memo-writing is the pivotal intermediate step between data collection and writing drafts of papers” (p. 72). Oftentimes, notes taken during the analytic process are used — either whole or in part — in initial drafts of a qualitative write-up.

In summary, I adapted techniques from grounded theory during the analytic phase of this research. Specifically, I used open and focused coding, constant comparison, and memo-writing to analyze transcripts and field notes individually and then collectively.

**Ethical Considerations**

Several ethical considerations pertain to this research study. Approval from the University of Georgia Institutional Review Board was obtained prior to beginning the study.
Confidentiality for the participants was addressed by assigning each caregiver a pseudonym in order to protect their identity. All participants were able to provide consent for participation in the study (located in Appendix D); they were over the age of 18 and cognitively intact. Each caregiver documented her agreement to participate by signing a consent form prior to the individual interview.

The consent form for participation also included a statement about my professional role as a social worker, including my duty as a mandated reporter. As a licensed social worker, I am required by law to notify adult protective services if I have reason to believe that a disabled adult or elder person is being abused, neglected, or exploited. Therefore, one risk for participants was that, if I obtained information from interviews that led me to suspect a care recipient was being mistreated, I was required to report this to adult protective services. In addition to having this information in the written consent form, I explained this verbally to each participant and answered any questions they had about this professional obligation.

**Validity and Reliability**

The notions of reliability and validity in qualitative research are approached differently than in traditional, positivist research (Kirk & Miller, 1986). Qualitative researchers put forth an alternative approach to rigor in methodology, primarily because the basic assumptions of qualitative research differ from its quantitative counterpart. Some authors further emphasize the distinctiveness of qualitative inquiry by referring to these concepts in different terms. Guba and Lincoln (1981) suggest using credibility, transferability, and dependability instead of internal validity, external validity, and reliability. Regardless of which terminology one employs, these concepts are equally as important in assessing the trustworthiness of qualitative research as they
are in evaluating quantitative research. Consideration of these issues in the present study is framed in the traditional language of validity and reliability.

**Internal Validity**

Internal validity in qualitative research is concerned with how well the research findings match reality (Merriam, 1995). However, “qualitative research assumes that reality is socially constructed, multi-dimensional, and ever-changing; there is no such thing as a single, immutable reality waiting to be observed and measured” (Merriam, 1995, p. 54). Since there are multiple interpretations of reality, internal validity really assesses how well the research findings match the participants’ reality. “Has the researcher accurately represented what the participants think, feel, and do?” (Bloomberg & Volpe, 2008, p. 77). Merriam (1998) describes six strategies for enhancing internal validity in qualitative inquiry: triangulation, member checks, long-term observation, peer examination, participatory or collaborative modes of research, and researcher biases. To address internal validity in the present study, I employed four strategies: triangulation, member checks, peer examination, and acknowledging my biases as a researcher.

Triangulation refers to using multiple sources of data, more than one researcher, or more than one method to collect and/or analyze data (Mathison, 1988). It “provides a rich and complex picture of some social phenomenon being studied” (Mathison, 1988, p. 15). I used triangulation of sources by interviewing a varied group of 15 participants who represented a variety of caregiving situations. This triangulation strategy provided holistic understanding of how female caregivers perceive their own late life needs.

Member checks and peer examination were also utilized to strengthen internal validity. I employed member checks in several ways. Initially, interviews provided an opportunity for me to check my understanding with participants. I did this by asking questions to clarify
information (as needed) and summarizing what I heard to verify the accuracy of my understanding. I also conducted final member checks on two levels. First, I checked individual stories by writing up a profile of each participant and sending it to them for feedback (via email and mail). I sent participant descriptions to participants and received several comments, all of which were positive. I changed a few details in the individual profiles based on the responses and clarifications I received from the participants. Secondly, after I developed preliminary interpretations of the data, I took this information back to few participants. I provided a summary of the findings and sent this information to five caregivers via email and received feedback from four participants. This provided an opportunity to check common themes across all the participants and see if my interpretation rang true to their experience. Peer examination also enhances internal validity. Two social work colleagues, familiar with qualitative research, acted as peer reviewers (Josiphine Chaumba and Jennifer Hadden). Based on member checks and peer review, I made adjustments to ensure my findings and interpretations were credible.

The final method I used for enhancing internal validity is expressing my biases as a researcher (Creswell, 2007; Merriam, 1995). This is particularly important because qualitative researchers act as the instrument for data collection and seek to minimize the distance between themselves and the phenomenon being studied. A statement of the researcher’s past experiences, assumptions, biases, and orientations “enables the reader to better understand how the data might have been interpreted in the manner in which they were” (Merriam, 1995, p. 55). My personal orientation in relation to this study is discussed at the end of this chapter.

External Validity

Qualitative research does not aim to produce results that are generalizable but to shed light on the particular. Thus, external validity in qualitative research is not generalizability in the
statistical sense, but refers to how well the findings of a study can be applied to other settings (Merriam, 1995; 2002; Patton, 2002). Conceptualized in this way, generalizability has commonly been thought of as “reader or user generalizability…. [when] readers themselves determine the extent to which the findings from a study can be applied to their context” (Merriam, 2002, p. 28-29). The burden is on the reader to consider how qualitative findings can apply to their particular setting, but it is the researcher’s responsibility “to provide detailed description of the study’s context to enable readers to compare the ‘fit’ with their situations” (Merriam, 1995, p. 211).

Two primary methods are discussed in the literature for enhancing external validity in qualitative research. These strategies are providing thick, rich description and maximum variation or multi-site designs (Merriam, 1995; 1998; 2002). The first strategy I used is providing specific and thorough descriptions of study participants, the research context, and findings. This was done so that readers have sufficient information to transfer findings to a broader group of caregivers. I also aimed to have variation in the sample, particularly regarding caregivers’ relationship to the care recipient, socio-economic background and ethnicity. The strategy of diversity in the sample is intended to encourage that “results can be applied to a greater range of situations by readers and consumers of the research” (Merriam, 2002, p. 29). A thorough description of study participants is provided in the next chapter.

**Reliability**

A final consideration when evaluating the trustworthiness of qualitative research is reliability. Reliability in quantitative research refers to consistency of findings or measurements over time (Punch, 1998). It “is based on the assumption that there is a single reality and that studying it repeatedly will yield the same results” (Merriam, 1995, p. 205). In the social sciences
particularly, the idea of replication can be challenging because human behavior is rarely static (Merriam, 2002).

Lincoln and Guba (1985, p. 288) offer the terms “consistency” and “dependability” as alternative conceptualizations of reliability. Thus, reliability in qualitative research is concerned with how consistent or dependable the results are with the data collected (Merriam, 1995). “Rather than insisting that others get the same results as the original researcher” (Merriam, 2002, p. 27), reliability begs the question — when compared with the data, do the findings make sense to readers? Four strategies are suggested in the literature to enhance reliability: triangulation, peer examination, researcher’s position, and the audit trail (Bloomberg & Volpe, 2008; Merriam, 1995; 1998; 2002). All four strategies were employed in this study to strengthen reliability.

Triangulation, specifically the use of multiple sources (participants), helped me get “data that are most congruent with reality as understood by the participants” (Merriam, 2002, p. 27). Peer examination from colleagues also provided feedback regarding how well the findings and interpretations correspond with the data collected. The process of checking the consistency of the findings with outsiders reduces possible bias of a single researcher collecting and analyzing the data (Bloomberg & Volpe, 2008). Expressing my subjectivity as a researcher also strengthened the credibility of research findings.

Lastly, an audit trail provided a detailed description of how data were collected, how categories and themes were derived, and how decisions were made throughout the entirety of the research process (Merriam, 2002). My audit trail is in the form of a researcher’s journal that I began keeping during the writing of my prospectus. It includes thoughts, ideas and hunches about the research process and data collected. I also journaled about my volunteer work at the
Council on Aging and my attendance at caregivers’ support group meetings as these experiences informed my research.

**Role of the Researcher**

The process of planning for a research study includes thinking about things like research questions, sampling criteria, and data collection techniques. However, another integral part of research preparation is acknowledging and reflecting on my own subjectivity in relation to my research. Bloomberg and Volpe (2008) maintain, “Integral to the notion of *self as instrument* is a capacity for reflection” (p. 4, emphasis in original). Being mindful of how my personal values, assumptions, and worldview affect my research is something that I needed to attend to throughout the entire research process.

My personal experience has certainly influenced my interest in the phenomenon of caregiving. My mother was the primary caregiver for her father, who moved from Tennessee to Georgia to be close to her. A few months before he died, he moved in to our home. She provided daily, hands-on care and received little help from her younger sister. I remember coming downstairs one day before school, and seeing my granddaddy’s bed empty and neatly made. I immediately knew that he was gone. He had passed away during the night and left in an ambulance as I slept upstairs, completely unaware of what was going on. My mother also provides care for my father, who has had Type I Diabetes since he was a teenager. From what my grandmother says, he never took care of himself until he met my mom at the age of 21. I believe my father has survived the heart attacks, minor strokes and seemingly never-ending foot wounds because of the persistent (sometimes pushy) care from my mother. When my husband and I discuss jobs and places we might live in the future, I frequently include my parents in the discussion, not wanting to leave my older sister with the entire responsibility of caring for them.
However, when my husband thinks about where he will be living in the future, my in-laws are often not a factor in his decision making.

I expect that the decision to provide unpaid care to a relative results largely from the fact that women’s morality (how they differentiate between what is right and wrong) is based largely in terms of caring and relationships (Gilligan, 1982). I anticipate that being a caregiver is something that requires much sacrifice. Not only does it involve giving time and energy to another person, but it typically involves watching a loved one go through illness, pain, and possibly death. It is an assumption of mine that this experience would change a person. Based on previous research (Karp; 2000; Marston, 2001) and my own personal theories, I think that women in midlife will see themselves in the person they are caring for, wondering what things will be like for them when they get older.

My goal is not to make assumptions about specific ways caregiving has changed the participants or what planning for future aging might look like. It is possible that the caregivers may not have concrete plans, but might have changed their thinking about late life. Qualitative methods will allow me to better understand this topic “from the perspectives of those who have lived it” (Padgett, 1998, p. 8).

I believe a lot can and should be learned from women providing care for aging parents. Family caregivers provide the majority of long-term care for older adults (NAC & AARP, 2009; Takamura & Williams, 2006); they are affected first hand by services and policies intended to help caregivers. Individual interviews provide a way for women to talk about what services have been a help and a hindrance to them and their aging parents. These women also represent the older women of tomorrow. Demographic changes such as smaller family sizes, more women in
the labor force, and higher divorce rates are going to impact these women as they enter late life. For instance, these trends will likely mean fewer caregivers available to help them as they age.

An assumption that I have made about interviewing female caregivers is that they will want to talk with me about their experiences. Feminist theory (Gilligan, 1993; McQuaide, 1998; Miller, 1996; Rossiter, 1999) informs my research as well as the desire to give voice to the women in my study. I also believe that seeking “to understand a woman’s experience through listening to her story with all its meaning for her,” (Van Voorhis, 2005, p. 356) has some therapeutic value. While the interview was not therapy, I hoped that participating in the interview benefited the women by allowing them to think about and acknowledge the ways that being a caregiver changed them. This assumption proved to be true as many participants commented on the therapeutic value of the interview; this is discussed further in Chapter 7.

I believe my professional experience as a social worker assisted me in this research endeavor. In the field of child welfare, I have been in the role of case manager, parent aide, and therapist. I have done countless interviews, often surrounding topics of a sensitive nature. I recognize the difference between social work interviews and research interviews, but I feel my ability to build rapport, ask open-ended questions, and listen actively and empathetically served me well in this study. Field notes collected from individual interviews were used as data. As a social worker, I am extremely competent in writing case notes and documentation from interviews and observations with my clients. My ability to write “detailed, non-judgmental concrete descriptions of what has been observed” (Marshall & Rossman, 2006, p. 98) helped me in data collection.

Another experience I drew from is a class pilot of this research which I conducted in three qualitative methods courses. The class projects gave me practice in data collection and
analysis; specifically, I developed an interview protocol, interviewed four caregivers, transcribed the interviews, and worked with the data to analyze them using inductive analysis, narrative analysis, and a poetic representation.

Peshkin (1988) notes that “untamed subjectivity mutes the emic voice” (p. 21). Therefore, being mindful of how my own biases and personal orientation “will shape what I see and what I make of what I see” was central to the research process (Peshkin, 1988, p. 21). I sought to maintain an awareness of my own subjectivity so that the participants’ reality remained the focus of this study.

Chapter Summary

This chapter presented the study’s design, sample selection, data collection methods, data analysis techniques, ethical considerations, validity and reliability concerns, and researcher subjectivity. The inductive nature of qualitative inquiry was appropriate for this study because it fills a gap in the literature by exploring how caregiving influences women’s perspectives and plans for aging. Qualitative methodology allowed the voices of female caregivers to remain central in the study as their words will informed my understanding of how caregiving has changed them.
CHAPTER 5

INDIVIDUAL PROFILES

Introduction

The purpose of this study was to understand how providing care for aging parents shapes informal female caregivers’ beliefs about and desires for their own aging. This chapter presents the individual profiles of study participants. These individual summaries are provided to a) allow for a more comprehensive, in-depth understanding of the participants and their experiences as caregivers and b) provide context for the experience. The profiles highlight the uniqueness of each caregiver and their respective situations. Thus, varying amounts of descriptive detail are offered regarding particular features of the caregiving dynamic (i.e., participants’ relationship with care recipient).

The Participants

The participants in this study consisted of 15 female caregivers, ranging in age from 50 to 64. Eleven members of the sample were White, three were African American, and one was Venezuelan American. Eight women were married, four were divorced, two had never been married, and one was widowed. Twelve participants had children and three did not. Regarding employment status, six participants worked full-time, six did not work (due to either unemployment or retirement), and three were employed part-time. Table 3 provides demographic information about these participants, including their pseudonyms, and follows the order in which they were interviewed.
# Table 3

**Participant Characteristics**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Race</th>
<th>Marital Status</th>
<th>Children</th>
<th>Siblings</th>
<th>Employment</th>
<th>Financial Status</th>
<th>Health Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kathleen</td>
<td>55</td>
<td>White</td>
<td>Divorced</td>
<td>Boy, 31</td>
<td>Sister, 63</td>
<td>Part-time</td>
<td>Has just enough</td>
<td>Asthma</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Boy, 28</td>
<td>Sister, 61</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Sister, 47</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Barbara</td>
<td>60</td>
<td>White</td>
<td>Married</td>
<td>Boy, 32</td>
<td>Sister, 65</td>
<td>Never worked outside the home</td>
<td>Has just enough</td>
<td>None</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Girl, 30</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mary</td>
<td>64</td>
<td>White</td>
<td>Widowed</td>
<td>Girl, 36</td>
<td>Sister, 62</td>
<td>Retired</td>
<td>Always has money left over</td>
<td>High blood pressure, high cholesterol Arthritis, high cholesterol</td>
</tr>
<tr>
<td>Eva</td>
<td>63</td>
<td>Hispanic</td>
<td>Married</td>
<td>Boy, 37</td>
<td>Brother, age 68</td>
<td>Retired</td>
<td>Always has money left over</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Boy, 35</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Janice</td>
<td>60</td>
<td>White</td>
<td>Married</td>
<td>Girl, 40</td>
<td>Sister, 57</td>
<td>Full-time</td>
<td>Has just enough</td>
<td>Back problems</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Boy, 39</td>
<td>Brother, 56</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Brother, 53</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maggie</td>
<td>50</td>
<td>White</td>
<td>Married</td>
<td>Boy, 18</td>
<td>Sister, 59</td>
<td>Full-time</td>
<td>Always has money left over</td>
<td>Heart Condition</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Brother, 66</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jody</td>
<td>64</td>
<td>White</td>
<td>Married</td>
<td>Boy, 42</td>
<td>Brother, 61</td>
<td>Retired</td>
<td>Always has money left over</td>
<td>High blood pressure, thyroid problems</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Girl, 38</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Karen</td>
<td>64</td>
<td>White</td>
<td>Divorced</td>
<td>Girl, 38</td>
<td>Brother, deceased</td>
<td>Part-time</td>
<td>Always has money left over</td>
<td>Diabetes, fibromyalgia</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Boy, 36</td>
<td>Brother, 50</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sandra</td>
<td>58</td>
<td>White</td>
<td>Divorced</td>
<td>None</td>
<td>None</td>
<td>Full-time</td>
<td>Cannot make ends meet</td>
<td>Diabetes, high cholesterol, bone spurs</td>
</tr>
<tr>
<td>Participant</td>
<td>Age</td>
<td>Race</td>
<td>Marital Status</td>
<td>Children</td>
<td>Siblings</td>
<td>Employment</td>
<td>Financial Status</td>
<td>Health Status</td>
</tr>
<tr>
<td>-------------</td>
<td>-----</td>
<td>-----------</td>
<td>----------------</td>
<td>-------------------</td>
<td>-----------------------------------------------</td>
<td>--------------</td>
<td>-----------------------------------</td>
<td>-----------------------</td>
</tr>
<tr>
<td>Jacqueline</td>
<td>54</td>
<td>African American</td>
<td>Married</td>
<td>Boy, 34</td>
<td>2 Brothers, deceased Brother, 57 Sister, 56 Sister, 52 Sister, 50 Sister, 49 Sister, 48</td>
<td>Part-time</td>
<td>Has enough with a little left over</td>
<td>None</td>
</tr>
<tr>
<td>Joanie</td>
<td>58</td>
<td>White</td>
<td>Married</td>
<td>Son, deceased Daughter, 35</td>
<td>None</td>
<td>Full-time</td>
<td>Has enough with a little left over</td>
<td>Arthritis</td>
</tr>
<tr>
<td>Evelyn</td>
<td>58</td>
<td>African American</td>
<td>Divorced</td>
<td>Daughter, 36 Son, 34 Daughter, 31</td>
<td>Brother, 55 Brother, 52 Sister, 50 Sister, 47 Sister, 46</td>
<td>Not working</td>
<td>Has just enough</td>
<td>Fibromyalgia, Muscle pain from stroke</td>
</tr>
<tr>
<td>Melanie</td>
<td>50</td>
<td>White</td>
<td>Never Married</td>
<td>No children</td>
<td>Brother, 61</td>
<td>Full-time</td>
<td>Has just enough</td>
<td>Muscle strains, back problems</td>
</tr>
<tr>
<td>Beverly</td>
<td>58</td>
<td>African American</td>
<td>Never Married</td>
<td>No children</td>
<td>Brother, 64, Sister, 60 Brother, deceased</td>
<td>Full-time</td>
<td>Always has money left over</td>
<td>None</td>
</tr>
<tr>
<td>Kay</td>
<td>52</td>
<td>White</td>
<td>Married</td>
<td>Daughter, 25 Daughter, 22</td>
<td>Sister, 56</td>
<td>Not working</td>
<td>Has just enough</td>
<td>None</td>
</tr>
</tbody>
</table>
Table 4  
Description of Caregiving Situation

<table>
<thead>
<tr>
<th>Participant</th>
<th>Care Recipient</th>
<th>Age of Care Recipient</th>
<th>Length of Time Caregiving</th>
<th>Illness/ Disability of Care Recipient</th>
<th>Living Situation of Care Recipient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kathleen</td>
<td>Mother</td>
<td>85</td>
<td>2 years</td>
<td>Alzheimer’s disease</td>
<td>Lives with Kathleen</td>
</tr>
<tr>
<td>Barbara</td>
<td>Mother</td>
<td>93</td>
<td>11 years</td>
<td>Dementia</td>
<td>Nursing home</td>
</tr>
<tr>
<td>Mary</td>
<td>Mother</td>
<td>91</td>
<td>8 years</td>
<td>Macula degeneration, arthritis, heart problems</td>
<td>Independent living facility</td>
</tr>
<tr>
<td>Eva</td>
<td>Mother</td>
<td>96</td>
<td>1 ½ years</td>
<td>Arthritis, back problems, poor eyesight</td>
<td>Lives with Eva</td>
</tr>
<tr>
<td>Janice</td>
<td>Mother</td>
<td>79</td>
<td>1 year</td>
<td>Frailty, complications from chemo.</td>
<td>Lives with Janice</td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>80</td>
<td>1 year</td>
<td>Heart problems</td>
<td>Lives with Janice</td>
</tr>
<tr>
<td>Maggie</td>
<td>Mother</td>
<td>80</td>
<td>6 years</td>
<td>On feeding tube</td>
<td>Nursing home</td>
</tr>
<tr>
<td>Jody</td>
<td>Father/Mother-in-law</td>
<td>86</td>
<td>8 years</td>
<td>Dementia, physical disability due to a stroke</td>
<td>Nursing home</td>
</tr>
<tr>
<td></td>
<td>Mother</td>
<td>86</td>
<td>7 ½ years</td>
<td>Macular degeneration, arthritis, failure to thrive</td>
<td>Lives with Sandra</td>
</tr>
<tr>
<td>Karen</td>
<td>Mother</td>
<td>86</td>
<td>2 ½ years</td>
<td>Parkinson’s Disease, diabetes, high blood pressure</td>
<td>Lives with Karen</td>
</tr>
<tr>
<td>Sandra</td>
<td>Mother</td>
<td>86</td>
<td>7 ½ years</td>
<td>Macular degeneration, arthritis, failure to thrive</td>
<td>Lives with Sandra</td>
</tr>
<tr>
<td>Jacqueline</td>
<td>Mother</td>
<td>80</td>
<td>8 years</td>
<td>Alzheimer’s disease</td>
<td>Lives with Jacqueline’s sister</td>
</tr>
<tr>
<td>Joanie</td>
<td>Mother</td>
<td>82</td>
<td>3 years</td>
<td>Dementia, complications from broken hip</td>
<td>Lives with Joanie</td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>88</td>
<td>3 years</td>
<td>Short term memory loss, heart problems, fractured hip</td>
<td>Lives with Joanie</td>
</tr>
<tr>
<td>Melanie</td>
<td>Mother</td>
<td>90</td>
<td>3 years</td>
<td>Arthritis, short-term memory loss</td>
<td>Independent living facility</td>
</tr>
<tr>
<td>Evelyn</td>
<td>Mother</td>
<td>76</td>
<td>10 years</td>
<td>Diabetes, high blood pressure, heart problems, kidney failure</td>
<td>Lives independently</td>
</tr>
<tr>
<td>Beverley</td>
<td>Mother</td>
<td>88</td>
<td>7 years</td>
<td>Hypertension, glaucoma</td>
<td>Lives with Beverley</td>
</tr>
<tr>
<td>Kay</td>
<td>Mother</td>
<td>77</td>
<td>7 years</td>
<td>Hypertension, Imbalance, Tachy Brady Syndrome</td>
<td>Lives with Kay</td>
</tr>
</tbody>
</table>
Care recipient diagnoses included Alzheimer’s disease and dementia, Parkinson’s disease, heart problems, eyesight problems, and arthritis. The length of time participants had been caring for a parent or parent-in-law ranged from 11 years to one year. At the time of the interview, two care recipients were under hospice care and thirteen were under the care of their ongoing medical provider. Since the time of the interviews, two care recipients (though not those on hospice) have died. Table 4 gives an overview of each caregiving situation and includes care recipients’ ages, diagnoses, and the length of time that participants had provided care up to the time of the interview.

When meeting with participants for their individual interviews, I asked each caregiver to complete two scales to provide further detail regarding the type of care they provided to their parent. The scales used were the Katz Basic Activities of Daily Living (ADL) Scale (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) and the Lawton-Brody Instrumental Activities of Daily Living (IADL) Scale (Lawton & Brody, 1969), which indicate the level of assistance needed in the primary ADLs (bathing, dressing, toileting, transferring, continence, and feeding) and IADLs (using telephone, shopping, food preparation, housekeeping, laundry, transportation, taking medications, and managing money).

Table 5 provides information obtained from the Katz ADL Scale, and Table 6 outlines information regarding IADLs from the Lawton-Brody IADL Scale. Care recipients’ ability to perform ADLs were categorized as No Assistance Needed, Minimal Assistance Needed, and Maximum Assistance Needed. Kay and Beverly’s mothers appeared to be the most able to perform these activities, as indicated by the information provided by their daughters. Care recipients’ abilities to perform IADLs were categorized as Independent, Able with Some
Table 5

*Care Recipients’ Ability to Perform Activities of Daily Living*

<table>
<thead>
<tr>
<th>Care Recipient</th>
<th>Bathing</th>
<th>Dressing</th>
<th>Toileting</th>
<th>Transferring</th>
<th>Continence</th>
<th>Feeding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kathleen’s mother</td>
<td>Maximum assistance needed</td>
<td>Maximum assistance needed</td>
<td>Minimal assistance needed</td>
<td>Minimal assistance needed</td>
<td>Maximum assistance needed</td>
<td>No assistance needed</td>
</tr>
<tr>
<td>Barbara’s mother</td>
<td>Maximum assistance needed</td>
<td>Maximum assistance needed</td>
<td>Maximum assistance needed</td>
<td>Maximum assistance needed</td>
<td>Maximum assistance needed</td>
<td>Maximum assistance needed</td>
</tr>
<tr>
<td>Mary’s mother</td>
<td>Maximum assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>Minimal assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
</tr>
<tr>
<td>Eva’s mother</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
</tr>
<tr>
<td>Janice’s mother</td>
<td>Maximum assistance needed</td>
<td>Maximum assistance needed</td>
<td>Minimal assistance needed</td>
<td>Maximum assistance needed</td>
<td>Minimal assistance needed</td>
<td>Minimal assistance needed</td>
</tr>
<tr>
<td>Janice’s father</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
</tr>
<tr>
<td>Maggie’s mother</td>
<td>Maximum assistance needed</td>
<td>Maximum assistance needed</td>
<td>Minimal assistance needed</td>
<td>Minimal assistance needed</td>
<td>Minimal assistance needed</td>
<td>Maximum assistance needed</td>
</tr>
<tr>
<td>Jody’s father</td>
<td>Maximum assistance needed</td>
<td>Maximum assistance needed</td>
<td>Maximum assistance needed</td>
<td>Maximum assistance needed</td>
<td>Maximum assistance needed</td>
<td>Minimal assistance needed</td>
</tr>
<tr>
<td>Jody’s mother-in-law</td>
<td>Minimal assistance needed</td>
<td>Minimal assistance needed</td>
<td>Minimal assistance needed</td>
<td>No assistance needed</td>
<td>Minimal assistance needed</td>
<td>No assistance needed</td>
</tr>
<tr>
<td>Care Recipient</td>
<td>Activities of Daily Living</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------------</td>
<td>-----------------------------</td>
<td>---</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bathing</td>
<td>Dressing</td>
<td>Toileting</td>
<td>Transferring</td>
<td>Continence</td>
<td>Feeding</td>
</tr>
<tr>
<td>Karen’s mother</td>
<td>Maximum assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>Minimal assistance needed</td>
<td>Minimal assistance needed</td>
</tr>
<tr>
<td>Sandra’s mother</td>
<td>Maximum assistance needed</td>
<td>Maximum assistance needed</td>
<td>Minimal assistance needed</td>
<td>Minimal assistance needed</td>
<td>Maximum assistance needed</td>
<td>Minimal assistance needed</td>
</tr>
<tr>
<td>Jacqueline’s mother</td>
<td>Minimal assistance needed</td>
<td>Minimal assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>Minimal assistance needed</td>
<td>No assistance needed</td>
</tr>
<tr>
<td>Joanie’s mother</td>
<td>Maximum assistance needed</td>
<td>Maximum assistance needed</td>
<td>Minimal assistance needed</td>
<td>Minimal assistance needed</td>
<td>Maximum assistance needed</td>
<td>No assistance needed</td>
</tr>
<tr>
<td>Joanie’s father</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>Minimal assistance needed</td>
<td>No assistance needed</td>
</tr>
<tr>
<td>Melanie’s mother</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
</tr>
<tr>
<td>Evelyn’s mother</td>
<td>Maximum assistance needed</td>
<td>Minimal assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>Minimal assistance needed</td>
<td>No assistance needed</td>
</tr>
<tr>
<td>Beverly’s mother</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
</tr>
<tr>
<td>Kay’s mother</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
<td>No assistance needed</td>
</tr>
</tbody>
</table>
Table 6

*Care Recipients’ Ability to Perform Independent Activities of Daily Living*

<table>
<thead>
<tr>
<th>Care Recipient</th>
<th>Instrumental Activities of Daily Living</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ability to Use the Telephone Shopping Food Preparation Housekeeping Laundry</td>
</tr>
<tr>
<td>Kathleen’s mother</td>
<td>Unable Able with some assistance Unable Unable Unable</td>
</tr>
<tr>
<td>Barbara’s mother</td>
<td>Unable Unable Unable Unable Unable</td>
</tr>
<tr>
<td>Mary’s mother</td>
<td>Able with some assistance Able with some assistance Able with some assistance Able with some assistance Able with some assistance</td>
</tr>
<tr>
<td>Eva’s mother</td>
<td>Able with some assistance Able with some assistance Unable Able with some assistance Able with some assistance</td>
</tr>
<tr>
<td>Janice’s mother</td>
<td>Able with some assistance Able with some assistance Able with some assistance Able with some assistance Able with some assistance</td>
</tr>
<tr>
<td>Janice’s father</td>
<td>Independent Independent Able with some assistance Able with some assistance Able with some assistance</td>
</tr>
<tr>
<td>Maggie’s mother</td>
<td>Able with some assistance Unable Unable Unable Unable</td>
</tr>
<tr>
<td>Jody’s father</td>
<td>Independent Unable Unable Unable Unable</td>
</tr>
<tr>
<td>Jody’s mother-in-law</td>
<td>Unable Unable Unable Unable Unable</td>
</tr>
<tr>
<td>Karen’s mother</td>
<td>Independent Unable Unable Unable Unable</td>
</tr>
<tr>
<td>Sandra’s mother</td>
<td>Able with some assistance Unable Unable Unable Unable</td>
</tr>
<tr>
<td>Care Recipient</td>
<td>Ability to Use the Telephone</td>
</tr>
<tr>
<td>----------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td>Jacqueline’s mother</td>
<td>Independent</td>
</tr>
<tr>
<td>Joanie’s mother</td>
<td>Able with some assistance</td>
</tr>
<tr>
<td>Joanie’s father</td>
<td>Able with some assistance</td>
</tr>
<tr>
<td>Melanie’s mother</td>
<td>Independent</td>
</tr>
<tr>
<td>Evelyn’s mother</td>
<td>Independent</td>
</tr>
<tr>
<td>Beverly’s mother</td>
<td>Independent</td>
</tr>
<tr>
<td>Kay’s mother</td>
<td>Independent</td>
</tr>
</tbody>
</table>
Assistance, or Unable. As with the ADLs, Kay and Beverly’s mothers had the most ability to perform these activities. Conversely, Jody’s mother-in-law and Barbara’s mother were unable to perform any of the IADLs, even with assistance. As in Tables 3 through 6, the individual descriptions follow the order in which I interviewed these individuals.

**Kathleen**

Kathleen, at 55 years of age, is a youthful-looking, articulate White woman who cares for her 85 year-old mother. Kathleen is the divorced mother of two sons, age 28 and 31, who live in a shared apartment nearby. She was recently laid off from a full-time job. As a result, she was forced to cash out her 401(k) plan to relieve the financial strain caused by the job loss. She continues to look for full-time employment while working a part-time job she has had for many years.

In 2007, Kathleen moved her mother into her home so she could care for her full-time. Her mother has Alzheimer’s disease, and one of her various ailments as a result is incontinence of urine. Feeling her home now “unfit for guests,” Kathleen chose to meet for the interview at a public library. Kathleen stated that while she has two older and one younger sister, she became her mother’s caregiver “by default” because “no one else wanted to do it.”

Kathleen commented that two issues are causing her significant stress as she grapples with the experience of living with an Alzheimer’s addled mother, and said that the issues have influenced her experience as a caregiver. First, is her mother’s various “toileting issues” which mean daily laundry and time-consuming clean up. Second, Kathleen’s mother “has always been very sarcastic and snide.” As long as Kathleen can remember, her mother has been prone to careless comments that are condescending and hurtful to others around her. She described a particularly bothersome event that occurred about three weeks earlier. Kathleen was pleading
with her mother to help with the incontinence situation by wearing a pad. Her mother, rather than cooperate, responded by saying, “Oh, you poor little martyr.” Nevertheless, and in spite of the great stress caused by these issues, Kathleen is choosing to focus on the positive aspects of the caregiving experience. She remains determined to continue caring for her mother in her home rather than place her in a nursing home.

**Barbara**

Barbara is a 60 year-old White woman who met me for her interview during a two week period when she was home, having taken a break from being a caregiver to her mother who lived in East Tennessee. Robert, Barbara’s husband referred his wife for the study after seeing the recruitment flier in the nursing home where his mother is a resident. Although he couldn’t be interviewed for the study, Robert nevertheless sat in during Barbara’s interview. Robert often interjected his own, unbidden, comments which led to the longest of all the interviews, at two hours and ten minutes.

Reflecting back on her life, Barbara feels her calling in life has been to care for other people. Her long caregiving career began as a stay at home mother to her two children, a now 32 year-old son and 30 year-old daughter. When her children were still young, Barbara also built a friendship with “Nana”, a neighbor who became an adopted grandmother. Barbara’s care of Nana began as a result of Nana’s inability to drive; they took her grocery shopping and to her medical appointments, particularly after Nana’s husband died. Over time, Nana required more intense care, which Barbara gladly provided, particularly since her children had then left home for college. She recognizes that, “I wasn’t really finished taking care of people.” In total, Nana’s relationship with the family lasted 25 years. Barbara’s husband encouraged her to write a book entitled, “Wednesdays with Nana”, to recount the tale of their regular lunch dates and
advances. Nana’s care eventually overlapped with the needs of Barbara’s mother until Nana died at age 94.

At 93 years of age, Barbara’s mother, “Honey” (as she was called by everyone) had survived four separate bouts of cancer, during the last of which, radiation treatment had led to dementia. Barbara’s routine for the last five years has been to travel to Tennessee for two weeks at a time, every month. At first, Barbara traded off responsibilities with a professional care provider. After her sister retired, she and Barbara began to share the responsibility for their mother’s care. When Honey suffered a broken hip, she was moved into a nursing home in the small town in which she had always lived. Although Barbara is pleased with the care her mother receives, she and her sister continue to travel long distances to supplement the professional care that she is getting in the nursing home. To take care of herself during this time, Barbara makes sure to “have a life here (in Atlanta) and then go up there (to Tennessee) and be totally dedicated to that life there.” To accomplish this, she nurtures relationships in both towns.

As she described it, Barbara’s relationship to her mother appeared to be especially close. During our interview, she got up to show me pictures of Honey, and she spoke of her mother’s kindness and quiet strength. Two and a half weeks after we met, Barbara’s husband emailed to let me know Honey had died. During the interview, Barbara shared that “there is not one little thing I will not miss about my mother.”

Mary

Mary, age 64, is a small-framed, soft-spoken White woman who provides assistance to her mother, age 91. She was referred for the study by Barbara and Robert, her friends and neighbors from across the street. Mary is the only participant who has been widowed. In 2008, Mary unexpectedly lost her husband, age 64 at the time, when he had a massive heart attack in
the middle of the night, dying instantly. She is the mother to one daughter, age 36, who lives nearby with her husband and three children.

About eight years ago, Mary, along with the help of her younger sister began providing assistance to their mother when she became unable to drive. Mary’s mother has vision problems due to macular degeneration. She also uses a walker because of back problems and arthritis. Although Mary’s mother lives independently in a retirement community, Mary visits her mother several times a week, spending most of the day with her. In addition to caring for her mother, Mary also helped her husband care for his mother (now deceased) who was disabled due to a stroke.

During the interview, Mary said that she did not know how to answer some of the questions. Her interview was one of the shortest; she often answered with few words and little elaboration. Mary frequently used the word “hard” to describe her experiences as a caregiver. What had been particularly difficult for her was the emotional strain of being a caregiver; Mary admitted to being surprised by how emotional she had become as she has cared for her mother.

Eva

Eva is a 63 year-old Hispanic woman who is a caregiver to her mother, age 96. Upon my arrival at her large, beautifully decorated home, Eva greeted me at the door in what appeared to be a traditional Venezuelan dress. Eva moved to the United States from Venezuela at age 17 to attend college; she stayed after marrying her husband of 41 years. Realizing she would be living in the United States permanently, Eva’s parents and brother moved to this country from Venezuela. Eva is a mother to two sons, age 37 and 35, who currently reside in California.

After retirement, Eva and her husband moved from southern California to Athens, Georgia. Eva was pleased with the move to Athens, enjoying both the slower-paced lifestyle and
sense of community in a smaller town. She and her husband are involved in numerous community groups, and Eva in particular is an active member of several Hispanic women’s groups. For Eva, a former ballerina, physical health and nutrition are important; she is committed to daily exercise.

Eva’s father died in 1982 and at this time, Eva’s mother came to live with her and her husband. At 96 years of age, Eva’s mother is in fairly good health. However, due to arthritis and back problems, she cannot stand for long periods and relies on a walker to ambulate. She has poor eyesight as well. For many years, Eva’s mother has made yearly trips to Venezuela, staying for six months at a time with family members. Although her mother was scheduled to return home from Venezuela the week following our interview, Eva wondered if this would be the last year her mother would be physically able to travel this long distance.

Eva described caring for her mother as a “spiritual experience” because now that she is retired, she has time not only to learn more about her mother, but also to reflect on her own life. She spoke of her mother’s devotion to family, saying, “Literally, she lived for me.” During the interview, Eva praised her mother’s internal strength and was particularly impressed by how her mother did not complain or focus on her physical pain. Eva tearfully expressed her desire to make her mother’s last few years “as bright as possible.” At the time of the interview, she was in the process of forming a social group of Abeulitas (grandmothers) to help her mother connect with other Hispanic older women. Over the years, Eva had learned that mother needs “her food, her language, her music, and her Catholic church.”

**Janice**

Janice, age 60, is a White woman who provides assistance to her mother and father, ages 79 and 80. She is tall and wore her long blond hair loosely pulled back. Janice is mother to a
daughter, age 40, and a son, age 39, from a previous marriage, as well as to her husband’s two sons, ages 21 and 16, who live in California. She and her husband are part owners in a real estate company.

In 2008, Janice moved her parents into the downstairs apartment in her home. She decided to bring her parents to live with her after her mother had a series of falls and her father was unable to lift her up, due to a heart condition. Janice is the oldest of four siblings, and although her two brothers and one sister live nearby, Janice does not receive any help from them in caring for her parents.

Despite efforts to encourage her siblings to visit and help out with their parents, Janice admitted that her siblings will likely not assume any responsibility in caring for their parents. She felt lucky, though, to be helping her parents and said her siblings “don’t know what they’re missing.” Janice admires her parents’ kindness and the way they “reach out to people who [are] not as bad off as they are.”

Janice is a great-grandmother and also has living in the home her 22 year-old granddaughter who is pregnant, her granddaughter’s 24 year-old husband, and their 2 year-old daughter. In spite of the myriad demands on her attention during the interview (i.e., frequent phone calls, people coming in and out of the room), Janice nevertheless maintained a calm demeanor.

Janice’s deep love for her family is evident in the way she opened her home to her parents and granddaughter’s family. Even more, at the time of the interview, she was preparing to host a wedding in her backyard for another granddaughter. Although Janice has a seemingly chaotic living environment, her home felt inviting and warm. I found myself reluctant to leave after the interview.
Maggie

Maggie is a 50 year-old White woman who spoke quickly and energetically during our interview, with a pronounced southern accent. Even though she is one of the youngest participants in the study, Maggie has been a caregiver off and on for 18 years. In fact, her 5400 square foot home was designed with this in mind. The spacious home includes a mother-in-law suite and basement apartment for extended family. When she was ten years old, Maggie said she knew she would be caring for her parents in their old age. While dating her husband, Maggie told him, “If you marry me, you have to understand you’re going to be taking care of my parents.” Over the years, Maggie has cared for family members suffering from throat, lung, and prostate cancers, as well as heart conditions. Maggie herself had a heart attack at only 31 and has since undergone five heart surgeries.

Maggie and her husband have a son, age 18, who is academically gifted. He was accepted to 15 universities including MIT, Yale, Harvard, and Johns Hopkins with scholarships to all. She and her son are particularly close and she described him as her “soul mate.” Over the years as Maggie provided care to her in-laws and parents, she also juggled a hectic schedule of taking her son to out of town science fairs and supporting his educational development. Maggie is well-educated herself; she lacks only a dissertation for a doctorate in chemistry and is also a trained music therapist.

In 2002, Maggie’s father passed away from small cell lung cancer. During his illness, she made daily trips to Emory Hospital in Atlanta, from her home in Athens in order to spend the day with him. For two years following her husband’s death, Maggie’s mother remained at their home in south Georgia. Maggie recalls days when she would drive ten hours round-trip to visit
her mother in Brunswick, Georgia. Eventually, Maggie decided to bring her mother to live in Athens.

Maggie’s 80 year-old mother has been residing in a local nursing home since 2007. She is now on a feeding tube. Maggie spends several hours a day with her mother and also talks with her numerous times throughout the day. Speaking of her mother, Maggie described her as “very, very resilient…very tolerant…[and] very smart.” In the caregiving of their mother, Maggie does not receive any help from her siblings, a sister age 59 and brother age 66. In fact, they are angry and resentful that Maggie is acting as her mother’s proxy for all medical and financial decisions. As well, they believe they are owed part of their mother’s estate even as she is still alive.

Of all the women interviewed for this study, Maggie was particularly knowledgeable about the medical and financial aspects of family caregiving. She repeatedly said that she had “learned a lot” through her experiences as a caregiver. She has immediate plans to start a blog to share with other women what she had learned about issues such as accessing services, protecting one’s assets, avoiding billing fraud, managing financial matters, and advocating to medical staff.

**Jody**

An attractive 64 year-old White woman, Jody is a caregiver to both her father and her mother-in-law. She was casually dressed for our interview and appeared to be at ease with the situation. Jody is married with two children, a son age 42 and a daughter age 38. Recently retired, she and her husband enjoy spending their time playing golf. For Jody, since many of her friends also have aging parents, talking to her friends during a golf game is “as good as a support group.”

Jody and her husband brought her parents and his mother to Athens, Georgia in 2000. Within a few weeks of each other, Jody’s parents and her mother-in-law moved to a local
assisted living facility. Prompting the move to Athens was the increasingly difficult time Jody’s mother was having in caring for her husband, who was in the early stages of dementia. Soon after arriving, Jody’s father suffered a stroke and has since been in nursing homes. Not needing to be in a nursing home herself, Jody’s mother moved to an apartment near Jody and her husband. Until the last year of her life, she lived fairly independently. Jody tearfully shared about her mother’s death in 2008, as a result of pulmonary fibrosis. Towards the end of her illness, she required a significant amount of help from Jody.

At present, Jody travels several days a week to visit both her father and mother-in-law who are in facilities out of town. At 91 years-old, Jody’s mother-in-law has Alzheimer’s and lives in the memory care unit of a nursing home approximately 45 minutes away. She describes her mother-in-law as “just delightful…a character.” Jody also travels an hour one way to visit her father in a nursing home. As a result of a stroke several years earlier, Jody’s father lost the use of his left leg and left arm. He has dementia as well. Traveling in between nursing homes to visit family admittedly caused Jody significant emotion strain. Jody stated, “As much as you love your parents…my dad is a difficult person.” Jody did not appear to have a particularly close relationship with her father and this appeared to aggravate an already stressful caregiving situation.

Jody surmises that she and her husband assumed caregiving responsibilities because they are both the oldest siblings. Jody’s younger brother lives in Detroit and her sister-in-law is in Oregon. Although they do not provide practical assistance with caring, Jody feels supported by them. She and her husband can call their siblings to “just rant and rave, or bounce things off of [them], or tell funny stories.”
Karen

At age 64, Karen is a full-bodied White woman with brown hair, cut in a short bob. Karen and I met for the interview at the home she shares with her 86 year-old mother. The walkway up to the front door was decorated with a small Canadian flag. Referring to herself as “half-Canadian,” Karen explained that her mother is originally from Ontario and her father is from Texas. She is the divorced mother of two children, a 36 year-old son who lives nearby and a daughter, aged 38, who lives in Arizona.

When her stepfather became ill in 2006, Karen traveled to Canada to help her mother in caring for him. She stayed with them for about six months, until her stepfather died. At this time, Karen gave her mother the choice to either move to Georgia with her or stay with Karen’s 50 year-old brother in Colorado. Her mother decided to go with Karen, and the two relocated to Athens, Georgia which Karen described as the “best move we ever made.” The two have become very involved in a church and have made several good friends where they live. While Karen and I were talking, her mother sat with us in the room, quietly reading a book. A frail-looking woman, Karen’s mother suffers from Parkinson’s disease, with which she was diagnosed in 1997. Karen deferred to her mother several times during the interview to ask her opinion or verify information she was sharing with me.

In addition to caring for her mother, Karen recounted caregiving for her son after he was paralyzed in a car accident overseas. She traveled to Spain, staying with him for a month as he recovered in the hospital. Her care for him continued for several months after he came back to the United States.
Karen was laid off from a full-time job several years ago, but is now in the process of starting her own business in sales. She states that a primary motivation for starting this business is to have the resources to set aside money for her later life.

When Karen was contacted for the member checking phase of this study, she informed me that her mother had passed away in early October. After her mother was unable to get out of bed and was hallucinating, staying awake for seven days and nights, Karen called in hospice, which helped them for three weeks before she died.

Sandra

Sandra, a 58 year-old White woman, provides care to her 86 year-old mother who lives in her home. She met me for the interview during her lunch break at work, a local social service agency serving older adults and their families. Sandra is divorced and has no children. She spoke quickly in a distinctly raspy tone. In her interview, Sandra presented a frank, and at times a harsh, view of the aging process. Her insight might be the result of a long caregiving career as well as her work at a local aging resource center.

Sandra’s caregiving of her parents began in the late 1990s when they were living in New Jersey and she in Georgia. Her father was experiencing health problems including diabetes, a heart condition, and stroke. From August to November 2001, Sandra traveled regularly to New Jersey attending to both their medical and financial needs. She eventually had to assume power of attorney in order to manage their finances. As her parents’ medical needs increased, it became more and more difficult to attend to them from a distance. With no siblings to share the responsibility, eventually Sandra brought her parents to Athens, moving them into an assisted living facility.
After one year of staying in assisted living while also paying the mortgage on a house in New Jersey that had yet to sell, Sandra’s parents were no longer able to afford to live in the facility. In late 2002, Sandra moved her parents into her home, and for the next five years, her caregiving centered primarily on her father who was on hospice until his death in September 2006.

According to Sandra, her father’s death exacerbated the family’s already insecure finances since they were no longer eligible for his pension benefits, which comprised half their income. At this time, Sandra went back to work full-time. Unfortunately, her job has provided little financial relief since she now has to also pay a home health aide to stay with her mother during the day.

Just recently, Sandra’s mother was put on hospice due to significant weight loss and a diagnosis of failure to thrive. According to Sandra, the weight loss and deterioration was the result of health complications from a broken leg and the poor treatment her mother received while in a hospital and rehabilitation facility. Her mother also suffers from macular degeneration.

Sandra spoke about several difficulties as she cared for her parents. In order to keep her mother and father in her home, Sandra has had to hire home health aides. She has had numerous incidents of workers stealing things from her; one care provider would even shower at her home and wear Sandra’s clothes out of the house. Additionally, she experienced abandonment from friends and acquaintances as her parents’ care needs increased.

**Jacqueline**

Jacqueline is a married, 54 year-old African American woman who works part time as a hair dresser; her husband is an owner in a family-operated funeral home. Jacqueline is a petite
woman with medium complexion, shoulder-length hair, and glasses. Jacqueline comes from the largest family of all the women interviewed; her mother had nine children — six girls and three boys. Two of Jacqueline’s brothers are deceased. Along with several of her siblings, Jacqueline helps care for her 80 year-old mother who was diagnosed with Alzheimer’s disease in 2001.

Although Jacqueline is a middle child and not one of the oldest siblings, she has a leadership role among her brother and sisters with regard to her mother’s care. When it became evident that their mother needed more hands-on assistance, Jacqueline called a family meeting to discuss a plan for her mother’s care. Jacqueline’s younger sister has their mother living with her full time and each sibling relieves her on the weekends. Jacqueline insists that if a sibling is unable to care for the mother on an assigned weekend, he or she must reimburse the sister financially for the weekend.

When Jacqueline’s mother realized that she was becoming ill, she gave power of attorney to Jacqueline to take charge of her finances. About 20 years earlier, however, long before she got sick, Jacqueline’s mother had decided to put her house in Jacqueline’s name. Rather than become the sole owner of the family’s home, Jacqueline arranged for the home to be co-owned with her younger sister. Jacqueline explained this decision by saying she worried that putting the home in her name only might give her too much control in the family; also if she died, the home would now still belong to her sibling.

Religion is very important to Jacqueline, and she prays not to develop Alzheimer’s like her mother. She acknowledges that, since both her mother and grandparents had the disease, there may be a high risk that at least one of the nine children might get Alzheimer’s. However, Jacqueline prays that none of her siblings will get the disease.
Melanie

Melanie is a 50 year-old White woman who works full time as a musician and music teacher. She was dressed casually for the interview, wearing a one-piece bathing suit and khaki shorts. Melanie has never been married and has no children but she considers herself the proud mother of four dogs. She describes her lifestyle as bohemian.

When Melanie noticed her mother’s social network was dwindling, she asked her mother to leave her home in Florida and move to Georgia. Her mother was persuaded to relocate to Georgia after Melanie found her a part-time job. While she was able to do this for a short time, her mother eventually could no longer work due to severe arthritis and other health problems. After living in a mother-in-law suite in Melanie’s home, Melanie’s mother transitioned to a nearby independent living facility.

Melanie has no family close by. Her only sibling, a brother age 61, lives in Chicago with his wife and children; the rest of the family lives in the northern United States. Consequently, Melanie is the sole caregiver of her 90 year-old mother. Although she has received some help from Jewish Social Services, Melanie said that she “is only one person” which makes it challenging to be the sole individual attending to her mother. Although she tries to consult with her brother about their mother’s care, “he tends to not want to make major decisions” so Melanie is the primary decision maker with regard to her mother’s care.

During the interview, Melanie related two issues that were causing her some stress as she cared for her mother. First, as a self-proclaimed “late bloomer,” Melanie feels torn between spending time with her mother while wanting to spend time and energy on building her career and her life. A second source of stress is Melanie’s worry that her mother will outlive her money. And although Melanie does not particularly enjoy being a caregiver, she said what an
honor it was for her to be able to care for her mother; she stated that she “wouldn’t want anyone else to do it.”

**Joanie**

Joanie is a 58 year-old White woman who provides care to her father, age 88, and mother, age 81. After having to cancel and reschedule our interview two previous times due to her mother’s health, Joanie and I were finally about to meet one afternoon after she got off work. Upon meeting, Joanie revealed that she almost cancelled the interview a third time because her mother had become ill the night before and was taken to the emergency room.

During the day, while Joanie is at her job as a middle school paraprofessional, a paid care professional stays with her mother and father. Joanie’s husband is retired and assists in the instrumental tasks related to caregiving. She and her husband have one daughter, age 35, who lives in Florida with her husband and child. They had another child, a son, who died at age 25.

Previously, Joanie and her husband had moved in with her parents after their home sold more quickly than they had expected. Although this was supposed to have been a temporary move, three years later, Joanie and her husband are still residing with her parents, but now in a home that Joanie and her husband purchased with her parents in mind.

Joanie commented about a vacation the family took to Florida in the summer of 2009, when her mother fell and broke her hip. For two months, her mother had to remain in Florida to recover; she was moved between a hospital and rehabilitation nursing facility. With tears, Joanie explained that during this time her mother almost died due to a bleeding ulcer and extreme weight loss. Currently, her mother is confined to a wheelchair and has early onset dementia. Joanie describes her father as relatively healthy although he does have a fracture in one of his hips and as well as short term memory loss.
Joanie’s interview was full of both tears and laughter; she would often cry and laugh simultaneously as she talked about living with her parents. Her mother’s personality has changed since having dementia; her mother often lashes out at her husband as well as Joanie. In addition, her mother also is very demanding of her time and Joanie often feels guilty, thinking she is not doing enough for her mother. With no siblings or family members to share the caregiving responsibilities, Joanie also discussed the immense strain she is under as she works full time while also caring for her parents. Recently, however, a co-worker has offered to stay with her mother and father every other Saturday. Joanie is looking forward to this respite every other week and hopes it will alleviate some stress.

**Beverly**

Beverly is a 58 year-old African American woman who helps care for her mother, age 88. She met me for her interview at a public library near her home. Although she had the day off from her full-time job at a local social service agency, Beverly looked polished and professional in slacks and a blouse. She has never married and does not have any children.

In 2002, Beverly returned to her home town of Athens, Georgia and moved in with her mother. While Beverly’s mother suffers from glaucoma and hypertension, she seems to have the least impairment of all the care recipients in this study. It was an adjustment for Beverly to begin sharing a house with her mother, but overall both are very pleased and comfortable with the living arrangement.

Beverly is the youngest of four children, with a brother, age 64 and sister, age 60 who live nearby. Her other brother died in 2009 after battling a long and difficult illness. With some help from her siblings, Beverly’s primary caregiving responsibilities include taking her mother to doctor appointments, helping her manage her medication, and assisting her with shopping.
Beverly spoke about a close group of female friends whom she has known since childhood; she describes their children as her godchildren. These women provide much support and companionship to Beverly, as does the aerobics ministry she is involved with at her church. She revealed that, when she and her friends get together, they often talk about growing older. Beverly notices, however, that because she has neither a husband nor children, her priorities and thought-processing about later life are much different than her friends who are married with children.

**Evelyn**

At 56 years of age, Evelyn is an attractive, well-educated African American woman who provides assistance to her 76 year-old mother. She wore glasses and had her long hair pulled back in a ponytail. Evelyn is the divorced mother of two daughters, ages 31 and 36 and one son, age 34. Evelyn is the eldest daughter, with two brothers and three sisters. When asked how long she had been caring for her mother, Evelyn indicated that her mother had always been sickly and, since childhood, Evelyn has been the “mother hen” of her family. As a young girl, she cooked meals, did housework, and helped raise her younger siblings.

Evelyn’s mother has diabetes, high blood pressure, heart problems, and kidney failure. Yet, as Evelyn described it, her mother is physically able to do much more than she actually does which makes caring for her particularly daunting. About this, Evelyn said, “I don’t mind doing it, because she’s my mom, and she needs me to do it. But if she doesn’t need me to do [for her], then why should we have to do it?” Evelyn admits that her mother has always been lazy and more inclined to have others do for her things she is able to do for herself.

Evelyn does receive help from one brother, age 55, and sister, age 46, who live nearby. For example, each of them takes their mother to one of her three weekly appointments at the
dialysis clinic. On the day each of them takes their mother to dialysis, as well as one other day during the week, the three siblings also clean and do household chores, such as laundry and cooking. One sister, age 47, who lives in Augusta helps out minimally due to living out of town, and the family is rarely able to see the other brother, age 52, who lives in Germany. Also living with their mother is Evelyn’s 50 year-old sister who needs a significant amount of help due to cognitive and physical injuries from a stroke.

An additional stressor for Evelyn is her own health problems. A stroke in 2003 left her with damaged nerves on the right side of her body. She suffers from muscle pain and spasms, which are severe at times, as well as fibromyalgia.

Despite the occasional frustration she feels with her mother, Evelyn believes she was born to be a caretaker to not only her mother and sister, but also others in her family. She clearly has a leadership role in her family and delights in helping others.

Kay

Kay, a 52 year-old White woman, cares for her mother, age 77, who lives in the home Kay shares with her husband. She is also mother to two daughters, ages 22 and 25. On the day I arrived at Kay’s home to interview her, she had forgotten about me coming over and hurried to get dressed while I waited downstairs. She laughed about her mistake and said, “Well you wanted to learn about what it’s like to be a caregiver and this is part of it! We have so much going on that we forget things a lot!” She was dressed casually in jeans and a black button down; she wore her brown hair in a shoulder-length style.

In 2002, Kay and her husband moved from their home in California to Georgia, where Kay had lived as a child. What precipitated the move back to the city where she grew up was Kay’s father being diagnosed with pancreatic cancer. From the time she and her husband moved
back to Georgia in 2002, Kay’s parents lived with them in their basement. Kay helped her mother care for her father until his death in 2004.

Kay explained that at age 69, her mother had been a caregiver to Kay’s grandmother. Two months after the grandmother died, Kay’s father was diagnosed with pancreatic cancer. Only after her father’s death did Kay realize her mother’s health was not good. She suffers from Tachy Brady Syndrome — a form of atrial arrhythmia (Flammang, Loteanu, Hamani, Lambiez, & Flammang-Dorie, 2005), hypertension, and walking imbalance.

Kay has one older sister, age 56, who lives in Alabama. When asked about her sister’s role in caring for their parents, Kay explained that, while she herself was living in California, her sister was close enough to visit and look after their parents. During this time, Kay’s father had two heart bypass surgeries and her mother had breast cancer and a mastectomy. Kay laughed as she commented, “I sort of felt like it was my turn [to take care of mom and dad] although, after seven years, I’m feeling like, can you take a turn?”

Chapter Summary

The participants in this study represent the variety of caregiving situations experienced by women in late midlife. Significant features of the caregiving experience that were mentioned by participants concern relationship quality with their parent and competing demands on their time and energy.

A commonality among participants was that relationship quality between the adult daughter and her parent or parent-in-law influenced the caregiving experience. By itself, caregiving was often stressful and difficult, but when participants had strained relationships with their parent, the task of caregiving was doubly challenging. Both Kathleen and Jody mentioned past difficulties with their parent, primarily because of their parent’s harsh personality. Joanie
often felt pressured by her mother to do more and to be more available, despite the already limited amount of time she had for herself. Sandra spoke of not only losing privacy as she shared her home with her parents (and their home health aides), but also having less independence as her mother and father often monitored her coming and going, as they did when she was a child.

Although some participants mentioned challenges in getting along with their parent, some caregivers had a particularly close bond with their parent. Janice felt grateful to have the opportunity to spend time with her parents, whom she respected very much. Barbara used words like “sweet” and “cute” as she talked about her mother. Likewise, Eva’s description of the caregiving experience as “spiritual” was primarily because of the chance to learn from her mother, whom she greatly admired.

Despite attention given to the “sandwich generation,” no participants in this study had children living in the home for whom they were providing care (Brody, 2004). But this is not to say that participants did not have other responsibilities vying for their time and energy. Janice had her granddaughter’s family living with her, including a toddler and another child due to be born soon. Nine of the participants were working; six were employed full time. Both Barbara and Jody traveled out of town to provide care to their parents. Although Barbara went the longer distance, to east Tennessee, Jody traveled to two different locations to visit her father and mother-in-law. Driving long-distances to visit their parents meant they were not spending this time with their spouse or engaging in leisure activities that often occur during retirement (Harvard Center for Health Communication, 2004; Nimrod, 2007; Robinson & Godbey, 1997).

Despite the strain that caregiving might put on free time, many participants, including Barbara and Jody, made a conscious effort to engage in pleasurable activities: Jody was an avid golfer,
Eva participated in numerous social clubs, and Beverly and others maintained a strong friendship network.

In addition to features of the caregiving experience that distinguished these women, the interviews with study participants were also similar and different. Most of the interviews took place in the homes of participants. Two participants, Kathleen and Beverly, opted to meet at a public library. I interviewed Sandra in a public place as well — the lunch room at her place of work. Joanie and I met at the home of a mutual acquaintance who had referred her for the study. Both Karen and Barbara opted to have another person present during the interview: Karen, her mother and Barbara, her husband.

Interviews also differed with respect to the quantity and quality of data provided by the participants. Probably because her husband interjected his own comments, Barbara’s interview lasted over two hours. Other interviews were much shorter — Melanie’s interview lasted only 28 minutes and Beverly’s, 32 minutes. The length of the interview sometimes, but not always corresponded to the degree participants were reflective in their interviews. During some of the longer interviews, participants spent time talking about challenges they faced as caregivers, which was not directly related to the purpose of this research.

While this chapter focused on the individual profiles of study participants, Chapter 6 discusses the aggregate findings as they relate to the three research questions.
CHAPTER 6

FINDINGS

Introduction

This chapter details the findings which are presented as they relate to the three research questions outlined on page 10. The findings are reported below in three sections which correspond to the research questions. The chapter ends with a summary of the findings.

Overview of Findings

The purpose of this study was to understand how providing care for aging parents shapes informal female caregivers’ beliefs about and desires for their own aging. Findings in the first section relate to how the participants came to be caring for their ill and disabled parent. In the section that now follows, “emergent” and “deliberate” were identified as themes concerning participants’ path to caregiving, yet both follow one or more triggering events. The second section describes findings related to how caregiving influenced participants’ perspectives and plans for their own aging. Analysis revealed that caregivers were affected by the caregiving experience in five ways: gaining awareness, provoking fears, providing a comparison for current functioning, providing firsthand knowledge about aging, and providing an example of how to age. Finally, the third section outlines the desires and plans participants had for their own aging. For those with plans for later life, these projections centered on finances, living arrangements, health, and social networks. Caregivers also expressed preferences for long-term care if such needs came about as they got older. Three themes were identified: caregivers had desires for where they would want to receive care, whom they would want to provide care, and what personal
Table 7  
*Categories and Properties*

<table>
<thead>
<tr>
<th>Research Questions</th>
<th>Categories</th>
<th>Properties</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Becoming a Caregiver</strong></td>
<td>Triggering Events</td>
<td>· <em>Deteriorating Health</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>· <em>Financial Problems</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>· <em>Social Network</em></td>
</tr>
<tr>
<td><strong>Influence of Caregiving on Participants</strong></td>
<td>Emergent or Deliberate</td>
<td></td>
</tr>
<tr>
<td><strong>Influence of Caregiving on Participants</strong></td>
<td>Gaining Awareness</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Provoking Fears</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Providing a Comparison</td>
<td></td>
</tr>
<tr>
<td><strong>Caregivers’ Plans for Later Life</strong></td>
<td>Providing Firsthand Knowledge</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Providing an Example for Daughters</td>
<td>· <em>Positive Example</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>· <em>Negative Example</em></td>
</tr>
<tr>
<td><strong>Caregivers’ Plans for Later Life</strong></td>
<td>Steps Taken to Plan</td>
<td>· <em>Finances</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>· <em>Living Arrangements</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>· <em>Health</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>· <em>Social Network</em></td>
</tr>
<tr>
<td><strong>Caregivers’ Plans for Later Life</strong></td>
<td>Limited Planning Efforts</td>
<td>· <em>Limited Resources</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>· <em>Limitations of Planning</em></td>
</tr>
<tr>
<td><strong>Caregivers’ Plans for Later Life</strong></td>
<td>Attitudes about Long-Term Care</td>
<td>· <em>Preferred Location</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>· <em>Preferred Care Provider</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>· <em>Preferred Characteristics of Care Provider</em></td>
</tr>
</tbody>
</table>

characteristics were desirable in a caregiver. Table 7 highlights the categories and properties for the three research questions guiding the study (see questions on page 10).

**How Participants Became Caregivers**

A first step in understanding how caring for a parent influences adult daughters’ perceptions about their own aging was to examine how participants in this study became
caregivers. Two themes were identified concerning how women became caregivers for their parent or parent-in-law. First, before daughters began providing help to their relative, an event or events triggered the daughter’s awareness that assistance was needed. These “triggering events” most often had to do with deteriorating health, financial problems, and loss of social ties. Second, after circumstances prompted parents’ need for assistance with daily activities, adult daughters in this sample became caregivers in either an “emergent” or “deliberate” fashion.

**Triggering events.** The transition to the caregiving role began when parent’s physical or cognitive health deteriorated to a point where they were unable to manage on a daily basis. At this time, family often stepped in to help. One triggering event typically created a domino effect where one crisis led quickly to another more serious crisis. For example, Maggie, an energetic 50 year-old who spoke with a strong Southern accent, recalled her mother coming down with bronchitis and being prescribed an antibiotic to which she was allergic. Her mother developed numerous internal ulcers because of the allergic reaction; she then had adverse effects from the narcotics she was prescribed for the ulcers. These medical complications resulted in significant weight loss and Maggie’s mother having to be put on a feeding tube, which she was still using almost two years later.

Daughters in this study discussed particular events related to health, finances, and social network alerting them of their parents’ need for more assistance. Parents’ health problems often resulted in an inability to manage daily tasks and personal care. Cognitive decline sometimes led to poor judgment and decision making, which manifested itself in financial troubles. A few caregivers also mentioned life circumstances that damaged their parent’s social network, prompting daughters to step in and support parents’ social ties.
Many participants discussed the onset of health problems which made them aware of their parents’ need for assistance. Janice, a married 60 year-old who had both parents living in her home, recalled first approaching her parents about their care needs in 2007, after her mother underwent chemotherapy for colon cancer. After a second bout with cancer and a series of falls, Janice became increasingly concerned and spoke with her parents numerous times about moving in with her to receive more help.

Similarly, Jody, age 64, moved her mother-in-law from North Carolina to Georgia when she became concerned about her safety. She described the events leading up to the decision in this way:

Mike’s mother, she’s always been a bit of a flake, just kind of an off-the-wall kind of person….but she just became stranger and stranger. She was using her little car in Detroit sort of like dodger cars, bumper cars ((Laughs)). There was one little bump after another. And then finally she totaled it….Talking to her on the phone we realized that we better get up there and find out what was going on….But we got there and she wasn’t eating—rotten food in her refrigerator. She wasn’t eating properly. She looked gray. She just was not healthy. Things were not right and she wasn’t right. We thought, no, this has got to end. We need hands-on here with her.

For Jody, “hindsight is terrific in figuring out people’s problems,” as she now realizes her mother-in-law’s inability to manage was due to dementia, which has since developed into Alzheimer’s disease.

The assistance that 60 year-old Barbara provided to her mother was episodic for many years, as her mother battled various cancers from age 82 to age 88. Barbara commented about her mother’s first bout with cancer:
She was 82 when she had her first lung surgery and [now] she’s 93 years….From 82 to 84 I had to be there for like 3 months when she had her lung surgery, and then after that she did pretty well so I would just come back and forth and visit and help.

It was not until she developed dementia after radiation treatment during her fourth cancer, that Barbara’s caregiving became consistent. At the time of the interview, when her mother was still living, Barbara traveled from Georgia to east Tennessee each month, spending two week periods with her mother, alternating with her sister who traveled from North Carolina. For Maggie, age 50, her mother’s deteriorating health was also the trigger that alerted her to the fact that her mother needed more hands on assistance; she moved her mother from south Georgia to a hospital nearby where she could better manage her medical care.

**Financial problems.** A second circumstance that triggered participants’ awareness of their parents’ needs for assistance was financial problems. Sandra, a 58 year-old caregiver who presented a frank view of aging, began long-distance caregiving when her parents were residing in New Jersey and she in Georgia. First, she began managing their finances and later assumed power of attorney. Although her parents hid their financial troubles from Sandra for some time, she eventually noticed they were not paying their bills. Sandra explained that her mother “owed something like $3 on a Sear’s credit card and just wasn’t paying it, so they’d add like $29 onto it every month. She had this big bill and hadn't bought anything in 15 years.” After several years of managing their finances from afar, Sandra moved her parents to Georgia because of her father’s health-related crisis. She said, “In August of 2001, he drove himself to the hospital and then that was it. He really was not able to care for himself really after that.”
It became apparent to Kathleen, the articulate and attractive 55 year-old, that her mother was no longer able to manage on her own when she was exploited financially. She spoke about an incident when a man “took advantage of her [mother’s] fragile mental state”:

She had a large sum of money and she moved it from one vehicle to another. And I had gone down to visit and she handed me a business card and she said, “This man came up to me somewhere and he knew I had money.” And, my heard just sank. And, thankfully it was a legitimate thing. However, it was an unscrupulous broker because they reaped a big benefit of her moving this money and she incurred a huge penalty.

After this, Kathleen and her three sisters became concerned and took turns caring for their mother for extended periods of time. Eventually, Kathleen assumed care for her mother full-time.

Similarly, Mary, the small-framed and soft-spoken 64 year-old, remarked about her mother’s involvement in a fraudulent scheme which had financial consequences. Mary said, “She did have some extra money and then she got into a fraud and she lost all that money. It wasn’t a lot of money but she lost what she worked so hard for.”

**Social network.** A loss in parents’ social networks is a third circumstance that triggered participants’ awareness of their parents’ need for help. Melanie, an unmarried musician, age 50, initially became worried about her mother after “she casually mentioned to me that she was running out of her money.” What prompted her to relocate her mother from Florida, however, were other circumstances:

It got to the point where most of her friends were leaving to go into assisted living or move closer to their children so her social life was dwindling and her ability to manage as well as seemed to be dwindling so I said, “Okay, it’s time to bring her here.”
Eva, the 63 year-old married woman from Venezuela, talked about a similar situation with her mother. When Eva’s father passed away in 1982, she and her mother discussed whether she would go back to Venezuela, or move in with Eva and her family. Eva explained, “[These were] the only two choices. She’s never lived alone. She comes from a family of about eleven kids, so she always had people around her.” When Eva’s mother first moved in, she was 69 years old and helped with household management and the care of Eva’s two sons. “She made it…possible for us to retire early in life because she took care of the house.” Now 27 years later, Eva’s mother, aged 96, continues to live with her not only for social support, but also due to health problems like short-term memory loss and arthritis.

After circumstances triggered adult daughters’ awareness of parents’ need for assistance, participants moved into their role as caregiver. Participants described their path to caregiving as either emergent or deliberate; these two themes are discussed in the following sections.

**Emergent path to caregiving.** Many participants described their transition to caregiving as arising casually and unexpectedly over a period of time. As they reflected on how they became caregivers, these daughters could not recall a time when they considered the options and decided on taking responsibility for their parents. Becoming a caregiver was done automatically and spontaneously as the need arose.

Kay, who moved from California to her childhood home of Georgia, describes her response when learning about her father’s cancer diagnosis, “We wanted to leave California. We were already planning on moving back here, and then we found out dad had pancreatic cancer, so that sort of sealed the deal.” She never envisioned caring for her parents until they needed assistance, “I don’t know that I’d ever thought about it until my dad got sick. But when he did,
that’s just what we did.” After her father’s death, she also did not anticipate having to be a caregiver to her 77 year-old mother.

And…when we moved in here with my dad and my mom, I can’t remember the thought going through my head, “And what are we going to do with mom when dad dies?” …. I had no plan. This [caring for mother] was not in my head….I thought my dad’s dying; I’m going to take care of my dad. And then he died and then I went, “Hhmmm, I’ve still got mom.”...All I know is that I never thought about it but when it happened, there wasn’t anything to consider.

Similarly, Barbara did not expect to be caregiving for her mother, but stepped into this role when her mother needed such care. When asked how she came to be caring for her mother, she expressed, “I just wouldn’t do it any other way.” Barbara went on to elaborate, “I mean, how could I not? That was sort of my feeling but my mother is just precious. I mean she’s just adorable. So, it’s kind of like — your mother needs you so that’s what you do.”

Some participants ended up as caregivers in an emergent fashion, but were not as internally motivated as Kay and Barbara. These women became caregivers somewhat reluctantly when family circumstances compelled them to assume responsibility for their parents’ care. When asked how she became a caregiver, Kathleen, the attractive and articulate divorcé, stated, “By default ((Laughs)). No one else wanted to do it.” When her mother developed incontinence issues and became unable to bathe herself, Kathleen’s sister was no longer willing to care for her.

My younger sister….made the comment to me and it still is true that, “I’ve never seen my mother naked and I don’t want to.” So, that was that. She’s been with me ever
since….She was with me visiting and then she just didn’t go anywhere else. It just kind of happened. Like I said, it was by default. It wasn’t a decision.

**Deliberate path to caregiving.** Compared with women whose path to caregiving was emergent and unplanned, others could recount a specific conversation or conscious decision that began their caregiving career. Most times, the transition to caregiving began when either the parent explicitly asked the daughter to assume this role, or when the daughter initiated the caregiving role. In these situations, the decision to ask for care or assume a caregiving role involved some forethought and planning.

When Jacqueline, the 54 year-old caregiver with nine siblings, realized her mother had dementia, she called a family meeting. At this meeting, she and her siblings discussed how caregiving responsibilities would be divided and shared among the siblings. The siblings agreed that Jacqueline’s mother would live full time with one of her daughters during the week but the siblings agreed to relieve their sister each weekend. If one of them was unable to keep their mother on their assigned weekend, he or she has to reimburse the younger sister $150 for the weekend.

For several of the participants, parents’ declining health pushed them to approach the parent about their increasing care needs. Janice had several conversations with her mother and father about moving into her home to get help, yet her parents would always change the subject; “they just didn’t want to hear it.” Upon returning home from a vacation with her parents, Janice decided to stop giving them the option:

My mother had fallen once that week [and] hit her head….It had been worrying me to death. So, I got up that Friday morning and I called and said, “Mom…you need to get dressed. The movers are on their way.”…I just decided as long as we kept giving them a
choice, they would never give it up. I just called them and said, “I’ve hired movers. They’re on their way. You need to get dressed.” We just packed them up in one day and moved them here with all the household belongings.

It was not always the daughters who initiated the caregiving relationship; some parents made a conscious decision to arrange for their own care needs. A 64 year-old Canadian transplant named Karen told about her mother explicitly asking for help. Karen also mentioned life circumstances which made her more available to provide such assistance. For Karen, being unemployed meant that she was free to travel to Canada to assist her mother in caring for an ailing husband. “She called me because her husband was in the hospital, and I had lost my job. And that's just the way things work out sometimes. I was available to go and went up there.” After her husband died, Karen’s mother moved with her daughter to Georgia. About this Karen said, “It was all her decision.”

In summary, transitioning to the role of caregiver for an aging parent began with a triggering event that made participants aware of their parents’ need for assistance. These circumstances most commonly involved health problems, financial concerns, or a diminishing social network. Following a triggering event, participants in this study became caregivers in either an emergent or deliberate fashion. The path to caregiving involved forethought and planning for those who approached it deliberately. Others did not anticipate providing help to their parent until the need emerged and they assumed responsibility, although sometimes reluctantly.

The Influence of Caregiving on Participants

Providing care to an aging parent brought about many reactions from participants regarding their own later life. Analysis revealed that parents’ experiences with illness and
disability affected participants’ perspectives on their own aging in five ways: gaining awareness, provocating fears, providing a comparison for current functioning, providing first-hand knowledge about aging, and providing an example of how to age. These five themes are discussed in the following sections.

**Gaining awareness.** Prior to assuming care for a parent, most caregivers did not think about their own aging and were living life focused on the here and now. When asked how much she thought about aging before taking care of her parents, Jody, the 64 year-old golfer, replied, “I didn’t. I didn’t. I was just kind of rolling along….I thought more about my grandkids and my kids and what they were doing. I was thinking more about the excitement of their careers and their lives.” Soft-spoken Mary also said, “I don’t think I thought about it that much. You know, things are just kind of going along okay. But then when you start taking care of somebody you realize that, this is not easy.” Kathleen, the attractive and articulate divorcé, remarked, “For the first time I am having to think very realistically about aging which I suppose I never did before.”

As a result of caring for a parent, participants became aware of many aspects of aging. Beverly, the professionally dressed single woman, said, “It’s like that you start looking at your own mortality, well not your own mortality, but your disability.” Joanie, the 58 year-old middle school paraprofessional, became aware of her own lack of planning for later life. When asked what she had learned about herself through caregiving for her parents, Joanie tearfully replied, “I don't want to even think about that one. What I learned is... that I don't know what kind of arrangements to make for me.” She went on to say, “I realized that I don't know what will happen to me if I live to be 82 and I'm in that shape.” Kathleen said it this way:

You hear about new drugs and treatments for diseases everyday, but unless you or someone in your family *has* that disease, you don’t think about it. You think, “Oh well
that’s good.” A new treatment for cancer or screening for breast cancer…I’m sure there are women who have breast cancer in their family who feel the same way about that as I do about Alzheimer’s. They want to know about the treatments and about the research. And when I hear about it I go, “Oh well that’s good” but I don’t look until it. Until recently I hadn’t had a mammogram in five or six years. And I don’t ever think it will happen to me because it’s not in my family. It’s not something I think about….No one in my family has ever had it and so I don’t [think about it]. I think when you’re personally affected, you take it to heart and you’re forced to relate it to your own experience. “Is this going to happen to me?”

Not only did participants become more conscious of disability and particular illnesses, but they also became more realistic about aging in general. Eva, the 63 year-old Venezuelan, said simply, “Well, we all have to get older. Nobody gets younger. It’s part of life.” Barbara, who traveled to Tennessee to care for her mother, believed that caregiving made her more realistic about aging, especially compared with women who had never cared for an older person. She expressed it this way:

I think [women who have been caregivers] are a little more realistic that this is the process of life. Like my friend Joanne, her mother’s been dead a number of years, and she was the one who said she was uncomfortable helping her [mother take a bath]. I think she just kind of doesn’t see it as an issue….She never wants to talk about it as one day, it’ll be our issue.

In speaking of her sister, Janice echoed a similar sentiment,

I think a lot of people who haven’t been presented with the challenges probably don’t know that it will ever be a problem. If [my sister’s husband] was gone and all of a
sudden she had to have a hip replacement or fell and got hurt, or got sick, or any of that stuff, I don’t think it’s ever even occurred to her what would happen to her.

Participants spoke of grandparents and other aging family members who had experienced illness and disability. Yet, compared with their parents’ aging, participants were more detached from these events. The disconnect that caregivers had to family members’ illness might be from a lack of closeness with these family members, or might indicate a denial of age-related health problems. These events might also not have been relevant due to participants’ young age and life stage. Nonetheless, these experiences with aging had little impact on them. Jody, the avid golfer, recalled her grandmother having cancer, undergoing numerous treatments, and experiencing a “prolonged death.” However, she did not experience it firsthand; “She was away…80 miles from us, and so I didn’t see her daily….I didn’t watch it. And you’re in junior high or whatever, what do you know?” For Joanie, the 58 year-old who worked in a middle school, her recollection of other family members consisted of short-lived illness and sudden death rather than a chronic illness. She said:

My granddaddy on my daddy's side, I don't really remember him real well. He died when I was fairly young. And my grandmother on his side, I always just thought she was old. I never knew her to be a young woman. She just always was old. And she died when I was 13, but she was still old. And so I just thought when you get old, you just die. You're not prolonged.

In addition to caring for a parent, birthdays were another life event causing participants to be more conscious of aging. Without asking about birthdays, several caregivers spontaneously discussed the importance of having reached their 60th birthday. Barbara said:
I don’t think I really ever thought too much about [aging] until probably until I turned 60….Now, when you go through your grandmother and you still got your mother, but when it’s your mother, you think, “Okay, I’m next on the list.”

Like Barbara, Janice also recalled the significance of her 60th birthday:

When I hit 60 it was harder on me than any of the other birthdays. But, I’m no different than my mom. I get out here on this deck and watch [my grandbaby] run and play out here, and life is good….life is good.

**Provoking fears.** A second way that caregiving influenced daughters’ perspectives on aging was by provoking fears about various aspects of aging such as illness, disability, and extreme old age. Participants expressed similar sentiments regarding late life. Kay commented, “I don’t think it’s very fun to get old.” According to Barbara, “It’s tough — this aging process” and aging “is not pretty.” Jody said it this way, “It can be ugly. [It’s] not pretty after 80.” Joanie now knows, “[aging] is more difficult that I thought.”

For some caregivers, fears related to getting the same illness their parent was suffering from. In taking care of her mother, Kathleen was particularly irritated by her mother’s incontinence which meant extra laundry and clean up, as well as making her feel her home was “unfit for guests.” Moreover, she worried about having these problems herself as an older woman: “The incontinence issues…*that* is a frequent problem for millions of women…. It’s scary! I never want to be there, but sometimes it’s all I can do to make it to the bathroom.”

Similarly Karen, the Canadian who cared for her mother with Parkinson’s disease, said, “I just pray I don't get Parkinson's. That's a debilitating disease. It's scary.” Jody’s mother died from pulmonary fibrosis which involves scarring of the lung, gradually causing an irreversible loss of the lung’s ability to transfer oxygen into the bloodstream (Pulmonary Fibrosis Foundation,
This illness has a genetic component which prompted fears that she too would develop the disease:

I hope I’m not in line for pulmonary fibrosis, but in our family there’s a lot of it. I’m just — I’m the next oldest ((Laughs but is tearful)). It doesn’t usually show up until their 70s. My mother’s sister is 72, and she was diagnosed about three, three and a half years ago. She has it. We’re going up there next month to spend some more time with her. I don’t think she’ll see another summer. And she knows it. She knows.

Caring for a parent also prompted caregivers to be concerned about their own disability and care needs in later life. Mary worried about who would care for her in old age, “Just by taking care of them you think, ‘Oh my goodness, one day I’m going to be here’. And my daughter is going to have to, or somebody’s going to have to take care of me.” Karen also commented about being impaired in later life, “I’ve…never cared about what age I am. [It’s] no big deal to tell somebody how old I am. That doesn’t bother me — being incapacitated does.” Evelyn, the “mother hen” who helped raise her younger siblings, went even further to discuss how dependency would influence her sense of self; “It won’t be me, because, although I have health problems, I’m a vibrant person. And when I stop being vibrant and stop thinking the way I think now, I won’t be me.”

Increased life expectancy was also a concern for many participants. The prospect of extreme old age was not an attractive thought for the caregivers, but something that many of them dreaded. Mary, the small-framed widow, stated simply, “I just don’t want to get too old.” About longevity, Barbara said, “I’m not thrilled about that aspect of life. I watch that in the nursing home all the time. Let’s improve this or that so you can live to be ancient? Well, ancient is not pretty.” Sandra offered a poignant story about her father.
You all think you want to live to be pretty old, but you don't want to live to be old and have that diminished capacity and suffer. I mean, my dad wanted me to kill him…. he was like, “Put me out of my misery.”

Kay said simply, “I don’t want to live longer. I would like to live more independently and more healthy, in better health. And die ((pause)) young.” Jody believed her father-in-law was fortunate to have a quick death:

We can’t all be — I was going to say lucky — but Mike’s father died at 64. Massive heart attack [when] he was fixing a shingle on the sun roof. [He] died up there. I mean, he just was [snaps fingers] gone. That’s not a pretty way to go, either. But at least he didn’t linger.

Related to fears of living to extreme old age, diminished quality of life as an older person prompted anxiety among these women. Sandra put it frankly:

My dad suffered for so long. And my mother said to me just night before last, last night, I can't remember, they all kind of blend together, something like, “When is this going to be over?” And I'm like, “What?” She's like, “This crap.” She didn't say, “Crap.” She's a little more genteel than I am. Well, considerably more genteel than I am. ((Laughs))

Sandra went on to discuss older people sometimes losing the ability to see, hear, smell, taste, and move around. Mary believed that “people are just living too long now.” She talked about things she observed in her mother’s life:

You can’t do as much as you would like to….Not being able to see. She likes to read and she can’t do that anymore. It’s very hard. That’s the hardest part, like magazines and books. She can see T.V. but she has to sit right close — as close as you can get to it to see. And I don’t know how much longer that’s going to work for her.
A last aspect of later life that participants became fearful of as they provided care to their parents was a diminished social network. Eva observed her mother’s need for people which prompted her yearly visits to Venezuela to see family and Eva’s motivation to start an “Abuelitas” group for other older Latinas. She said:

I can see that I’m going to live for a long time, but that has also provoked some fear, especially that I know that I have the longevity and my husband doesn’t. And my sons don’t live here. So, it provokes some insecurity, there. I also see [my mother’s] need for people, and my family doesn’t live here, so that’s fearful.

Providing a comparison. A third way that caregiving influenced women’s perspectives and plans for their own later life was that parents served as a comparison for participants’ future aging. Parents reflected to daughters where they might someday be as they progressed into later life. As they watched their parents face illness and disability, daughters saw themselves reflected in their parents’ experiences. The experience of caregiving served an evaluative function whereby participants compared themselves to their parents to assess their current functioning and estimate how they might age. Sandra put it this way:

You look at your parents, and I’ve found that that’s very disturbing because you want your parents to not be this sick because you go, “Oh, if you get better, or whatever, then this horrible thing isn’t necessarily in my future.” Because you see that what your future is going to be is somehow going to mirror what you’re seeing in them. There’s some of that where, “You’ve got to get better. You’re not going to die, because I don’t want to.”

Karen, who cared for her mother with Parkinson’s disease, compared her current functioning to that of her mother at age 64, “It scares me to death to think that she wasn’t like this at all. At 64, she was still playing golf. And what am I going to be like at her age?” Eva, the former ballerina
committed to diet and exercise, said she still felt “extremely young” at age 63 with her mother being 96 and her grandmother living to be 103. Looking ahead she reflected, “If I age as good as my mother, I realize it’s going to be a nice, long life.” Barbara put it this way:

Now, when you go through your grandmother and you still got your mother, but when it’s your mother, you think, “Okay, I’m next on the list.” You do start to think that way.

“How many good years do I have left?” And you’re basing it on your mother.

In explaining that she did not want her children to care for her as she aged, Kathleen discussed her mother:

Even though I know that I’m a much nicer person than she is. I’m not snide and mean and sarcastic, and she’s always has been that way. But still I wouldn’t want them to have to deal with what I’ve had to deal with.

As she compared herself to her mother, Kathleen acknowledged how different they were, yet was still concerned her sons would have an experience similar to hers if they became her caregivers.

Providing firsthand knowledge. A fourth way participants were influenced by caregiving is that caring for a parent provided first-hand knowledge about aging, particularly what is involved in assisting an older person with illness and disability. Daughters identified what they had learned about the physical and cognitive aspects of aging. As well, participants became more familiar with medical care and expenses involved in caring for an older person.

Barbara, who traveled to Tennessee to care for her mother, learned about the practical aspects of aging through caring for her mother as well as her neighbor, Nana. This knowledge helped her as she planned for her own aging.

I think what has really helped me to plan is when I’ve taken care of these people. We’ve actually gone from stage to stage — through all the stages. Now I think it would be
harder for me to see the entire picture had Mother just had a massive stroke and that’s where we were [and] we didn’t gradually move into any of this stuff.

Participants also became more familiar with the physical and cognitive aspects of aging through caregiving. Barbara said definitively,

At some point, either your mind goes and your body may be intact or your body goes and your mind is intact, [it’s] one or the other. Something goes — either your body or your mind. And, if you live long enough, like my mother, then they both pretty well go.

Jody, the 64 year-old who enjoys spending time on the golf course, made a comparable comment as she spoke of what she has observed in her mother-in-law.

The longer you live, like my mother-in-law, your body might continue …. There is nothing physically…Chemically, there’s nothing the matter with her. It’s her brain that’s going. I don’t know which is worse, to not know where you are and still be going or, like my mother, her brain was fine. Two days before she died, we were having logical conversations …. She was fine, but her body just wouldn’t go. So, one way or the other, it’s going to happen.

Adult daughters in this sample discussed mistakes they had made while caregiving. Yet, these mistakes provided indispensable knowledge. Joanie told how she learned that obtaining power of attorney was necessary to manage her parents’ finances:

Power of attorney happened last summer…. [Health care professionals] would say, “Do you have power of attorney?” Well, I was ignorant, totally. And I said, “Yeah! I do.” Because I always signed everything. And nobody had ever asked me….Mother had [just] given me permission verbally. I just thought, “Well, yeah, I do. I have it.” But then
when we got home and we started trying to move some of their money around into another bank, I realized, “Um, I don't have it.” So I got it.

Maggie, one of the youngest participants at 50 years old, hired an elder-care coordinator to help in making arrangements for her mother. Of all the women interviewed, Maggie appeared the most knowledgeable about the financial and medical aspects of caring for an older person. Most of what she learned, however, was experiential and came from actually being with her mother as her illnesses progressed. She stated, “I’ve learned all this by default from going through the process.” In hindsight, Maggie would have done several things differently with regard to her parents’ care, such as selling her parents’ home sooner or putting the home in her name in order for her mother to qualify for Medicaid. Maggie spoke of the gap between what she needed to know and the information given to her by the elder care professional.

[The elder care coordinator] did a fantastic job of making a match [to] what Mom’s needs were at the time, but we needed to go one more step; one more step; one more step.

What happens as you go downhill? Or, what happens as your assets decline?

Many participants received assistance from professional caregivers in taking care of their parents. Nursing homes were frequently mentioned as a type of long-term care service they had learned about through their caregiving experiences. Sandra described some challenges to living in a nursing home:

I think that was one of the most devastating things to my mother to be in the nursing care [facility], is that you have no privacy. People are coming in on you constantly, even throughout the night. You never have absolute darkness or quiet. To some people that lack of privacy is devastating. To me, that’s one reason why you want to stay in your
home. You want your things, your place. You want them to be where you know they are and not have somebody just putting it wherever they want to.

Although Sandra talked here to the lack of privacy faced by nursing home residents, both she and others spoke to a similar concept, being a “prisoner in your own home” which related to how some participants felt who shared a residence with their loved one.

Some caregivers, particularly those residing with their parent, expressed feeling confined in their home, experiencing less privacy in their home, and feeling like their home was no longer their own. Kathleen’s home had undergone irreversible damage due to her mother’s incontinence issues:

My carpet is ruined. When she’s gone…it’s got to all be ripped up. There’s no redemption. The mattress that she sleeps on is ruined….when she’s gone it will all just have to be disposed of and changed….You clean up what you can when you can. The rest of it, you leave it.

Kathleen no longer had visitors in her home, even relatives, “My house is unfit for guests. I don’t even have my family over for holidays.” Likewise Sandra said her residence no longer felt like home. When her parents moved in, Sandra’s house was “turned upside down” as her furniture was moved to the shed to make room for her parents furniture and belongings. Her dad even said, “You know this your mother's house now, don't you?” In addition to feeling trapped by her parents’ presence in her home, Sandra also reported a feeling of “being held hostage” by her parents’ home health aides. She was dependent on the help of paid caregivers because she worked full time and needed help during the day, yet felt it also was “an invasion of [her] privacy” having people come into her home. The realities of caring for a parent, particularly in
one’s home, may have contributed to the fact that many participants did not want their children to be caregivers for them, which will be discussed later on in this chapter.

The experience of caring for an ill and disabled parent provided participants with first-hand knowledge about what was involved in caring for an older person. While this sometimes brought about concerns for their own later life, it also offered practical lessons about the aging process.

**Providing an example for daughters.** A final way that caring for aging parents affected adult daughters’ perspectives and plans for later life was by offering an example either of what to do in later life or what not to do. When women reflected on how they wanted to be in old age, they often discussed whether or not they would approach aging as their parents did. If daughters perceived their parents to be having positive experiences with aging and long-term care, they identified what parents might be doing to bring this about, and daughters desired to emulate these behaviors as they aged. Conversely, when daughters observed their parent to be having difficulty in later life because of things parents did or did not do, daughters expressed a desire to approach their later life differently.

**Positive examples of aging.** As participants discussed their parents, they talked about how their parents approached aging and planning for their later years. Maggie, the 50 year-old with a pronounced Southern accent, described her father as having “insight” as she discussed his tremendous organization in preparing personal documents, putting Maggie’s name on financial accounts, and giving her access to the safety deposit box. Maggie’s father prepared her for the caregiving role, telling her, “Before you die, this will be the hardest thing you’ve ever done.” Caregivers also mentioned parents’ behaviors that they admired and wanted to emulate which were primarily in the areas of finances, living arrangements, and lifestyle (e.g., diet, exercise,
Karen, the 64 year-old Canadian transplant, had already taken financial steps toward her own aging based on her mother’s positive example. She said,

I did go get some life insurance. [It’s a] first step. Second step is I’m going to look into pre-needs [insurance]. [Mom] has got all this, and it makes me realize how I need to do this for my children.

Similarly, Kay observed, “My mom has long term care insurance….I think if Tom and I ever get to a place where we have — I would like to have that.”

Along with finances, parents’ approaches to housing and living arrangements influenced what adult daughters’ wanted for their own later lives. Barbara expressed satisfaction with the care her mother received in a small-town nursing facility in east Tennessee. Long before she needed an intense level of care, Barbara’s mother had intentions to relocate to this facility:

My mother always said… “Well, if my house burns down I’ll just go to the nursing home.” ((Laughs)) I used to get so tickled. She was on this nursing home wait list for years because her sister didn’t want to be on it unless she was on it too. And mother was in much better health than her sister. So they both got on it…. So every few months they’d call her and mother would say, “Oh, I can’t come now. I’m in too good of shape.”

But, she knew where she was going.

Based on her mother’s positive experience in this particular facility, Barbara desired to also be placed in this nursing home if she lost the inability to care for herself. She was especially attracted to the small-town atmosphere and intimate care her mother received.

It’s just such a simpler way of life. And I’ve always heard, and I’ve read this in the AARP magazine, that when you start to look for a nursing home, make sure you’re looking in small towns because it’s your neighbor taking care of you. And you’ll run into
them in the grocery store…. they tend to be a little more conscientious if they know your family and all of those things.

Parents also served as a positive example for children with regard to lifestyle behaviors, such as diet, exercise, and friendship networks. Eva admired her mother’s attitude and her level of activity.

[She] doesn’t focus on pain. Doesn’t like to complain and doesn’t like to hear complaining. She likes to feel useful. She says her mother taught her not to ever sit down and be idle. So, Mother is sitting down and she’s knitting. She’s crocheting. She cannot see that well, so she makes holes and she takes it all apart. And she’s always busy. She’s always doing something.

Eva had already begun imitating these behaviors she respected so much in her mother. She said, “I am that way. I am very, very productive” and “I exercise. I’m as proactive as my mother is.”

Although not necessarily in the areas of finances, housing, and lifestyle behaviors, analysis revealed the theme of “being easy” which related to how parents responded to being cared for by their children. Being easy meant being flexible and not struggling against help provided by family members. Based on her experience working at a social service agency for older adults and their families, Sandra talked about this concept:

[People] say, “I don’t want to be a burden on my children. I don’t want them to have to do anything for me.” The way they present it…they’re so wonderful and so altruistic. “We don’t want to burden our children.” But in effect, they’re actually being selfish, because they don’t want to relinquish any of their care….and they’re actually most of the time hurting their kids….Most people want to help their parents and when parents refuse
to allow them to do that, it’s very stressful. It makes things ultimately worse in the long run.

Barbara also described her mother as “easy” to take care for, especially compared with her mother-in-law who was extremely independent. The difficult role reversal that is inherent in parent-child caregiving was only exacerbated for participants whose parents resisted their assistance. While some parents modeled positive behavior with regard to aging, others offered a negative example of how to age.

**Negative examples of aging.** Not all participants wanted to emulate their parents’ approach to later life. Sandra, the 58 year-old who worked for a social service agency serving older adults and their families, was frustrated by her parents’ lack of planning.

I tried to get them to make some plans, because I could see them deteriorating and I wanted them to address these issues.... I tried getting them to talk about what their last wishes were. They were like, “I ain’t going to worry about it. I’m just going to die, and then I won’t need to worry about it, because I’ll be dead and it’ll be your problem.” But they really wouldn’t address the issue. And I really think that they both just kind of thought that, “Well, I’ll just die. I’ll just tra-la-la-la along, and then I’ll die.” And unfortunately that is not at all what happened. They became incapacitated.

Despite Sandra’s annoyance at her parents’ failure to plan, she said this about making plans for herself:

You just take it one day at a time and do what you can do that day. Some things you can plan, like when am I going to go to the store, what am I going to buy for dinner for next week. But beyond that, you can’t.
Melanie, the single musician and music teacher, also spoke of her mother’s shortsighted view of her own aging:

[My mother] didn’t budget or anything and when she set up her annuity way back however many years ago, the person who was guiding her through that process asked her, “Do you want the life option which would give you $150 less a month or a little bit more per month up to a certain age?” She figured, “Who’s going to live past 85?” So she took the other option which is the big… with one little flick of a pen…. There’s not forward thinking. She deals with exactly what is in front of her at that moment.

Some parents set negative examples in the area of housing and living arrangements.

Joanie, the 58 year-old paraprofessional, felt burdened as the only child caring for her mother with dementia and father with physical disabilities. Her mother had made no plans for housing in later life, but only told Joanie to never place her in a facility.

I'd never want to say to my daughter, “I'm never going to a home. Don't ever put me in a home” ….At this point Mother doesn't realize what she's done to me…. We've had to put our life on hold.

Yet, like Sandra, this negative example had not yet moved Joanie to make her own plans for where she might reside. She also made contradictory statements about what she experienced as a caregiver and what she wanted for herself. When asked what advice she would offer women her age about planning, Joanie replied,

This may sound really ugly, but I would tell [them] not to ask [their] children to put their lives on hold. Make arrangements. And here I am, I’ve made no arrangements. I haven’t really put a lot of thought into it.

She went on to say,
The other day [my daughter] said, “Do ya’ll have any kind of insurance that will help pay for a place, mother?” I said, “No. No we don’t.”…. I said, “Nope. Ya’ll are just going to be looking after us. That’s all I know.”

Last, some participants were shaped by their parents’ negative behaviors in the areas of diet, exercise, and friendship networks. Kay, who moved during her 40s back to Georgia from California, commented about her mother’s lack of friendships.

My mom and dad growing up, they had a lot of friends, very social, very active. And as they got older, for a variety of reasons, they sort of just kept to themselves….They didn’t do a lot of things socially….My father became my mother’s whole life….There’s a really good side to that. They loved each other deeply and I think it was a very good role model for me and what a marriage should be like. The flip side of that is — I love Tom, adore him, but I don’t want my whole life to be him. Because something could happen to him before something happens to me, and I’ve got to have other things in my life, besides my children and my husband.

For Kay, nurturing her female friendships was important in supporting not only her current well-being, but also related to her life satisfaction in the coming years.

Jody spoke of her commitment to exercise that came about partially through witnessing her own father’s lack of mobility:

I want to walk when I’m 80. I just want to be upright and mobile. I want to be as strong as I can be. I guess that’s been a conscious decision. Where my parents didn’t do that. Daddy wouldn’t exercise, didn’t even want to walk the dog. That, I think, contributes to some of his decline after his stroke. He was so unfit and then wouldn’t do the therapy.
She and her husband golf on a regularly basis and lift weights at a gym in order to maintain a healthy physical body.

**Caregivers’ Plans for Later Life**

Given how caregiving influenced adult daughters’ perspectives about their own aging, participants’ opinions about planning for later life are relevant. While some caregivers believed planning was worthwhile and had taken steps to plan, others believed planning was futile or acknowledged the limitations of planning. Yet regardless of whether or not caregivers had planned for their aging, all of the participants had preferences for long-term care, including where they would prefer to receive care, who they would want to give care, and the traits of the care provider.

**Steps taken to plan.** Planning for future aging was regarded as important by several participants in this study. These caregivers asserted that thinking ahead about preferences for later life was beneficial not only to them, by giving them more control, but also to family members because it alleviated the stress of making decisions on their behalf. About planning, Maggie affirmed, “I think it’s important to talk about it very early on. I think that you need to, no matter how young or old you are. So many families don’t have a clue.” She went on, “Be sure [of] what you want. Write it down. Take care of it legally, especially if you have more than one child.” Mary, the soft-spoken widow, also discussed the importance of planning:

We need to try to save what we can and…I don’t think that people think about it until…until it’s too late. You don’t think about planning for this kind of a thing…..You need to plan — to do something. And I’m glad we did. I’m glad we did that.
About planning for living arrangements in later life, Barbara said this: “I think it is definitely something you really have to consider. It’s really no different than where you’re going to live in your younger years or raise a family or your occupation.”

Some children of participants had approached their parents to inquire about their desires for care in later life. Barbara said:

My advice would be to make those decisions as far ahead as you can and have it written down. My son is already saying to me, “Make sure you write that down and tell me exactly how you want this done. [Tell me] where it’s located….where you want to be buried…all those things. What your first preference is and that’s what we’ll try to do and if we can’t then you got to go with Plan B.” And he’s already told me he will go by my request if at all possible. So you have to give him some thought.

Maggie’s son has also asked her, “What do you want?” to which she replied, “It’s on top of the refrigerator. Don’t worry about it now. Everything’s taken care of. It tells you exactly what to do [and] who to contact.” The areas of planning most frequently mentioned by participants were plans that related to finances, living arrangements, health, and social networks.

**Finances.** Many of the caregivers in this study were making financial plans for their later life. These plans included saving money for retirement or care needs and purchasing long-term care or life insurance. Mary, the small framed 64 year-old, said this about her decision to buy long-term care insurance:

I have the long term care insurance, which should help if I have to go [to a facility]…I don’t want my children to have to — they’re going to have enough on their own. We’ve had it for a while, maybe five, six years….So that they wouldn’t take everything that we do have saved.
Barbara, Mary’s friend and across the street neighbor, had also purchased long-term care insurance. Karen was of the opinion that, “There is a certain amount of money no matter how little you make, there’s an amount of money you can put aside.” Jody contrasted her view of financial planning with what her parents had done: “Unlike my parents, financially I’m hoping that what we can do is go some place where, eventually, we can provide for ourselves.”

**Living arrangements.** In addition to financial planning, making preparations for housing accommodations was frequently mentioned as an important consideration in planning for later life. Some caregivers planned to relocate when they needed assistance from professionals or family members. Eva viewed her relocation from California to Athens as a significant step toward preparing for her aging. After learning about Athens, Georgia from an article in *Fortune Magazine* about the best places to retire, she said, “[My husband and I] moved here. We retired here.” Yet Eva was not convinced this was a permanent move for her: “The chances that I do live longer than my husband are probably in the 90 percent, if my sons don’t move here, I am already thinking that I will probably move back to California….I will not be a victim.” Like Eva, Jody also anticipated relocating and had researched facilities near family:

> Our daughter is in Lebanon, Ohio. We’ve already — we haven’t gone in, but I’ve gone by, I know there’s a lot of nice places not too far from her that we could go and have a decent place to live and be close to someone in the family who has eyes on and at least can report and say, “Hey, Mom and Dad are okay.”

Jody had spoken to her daughter about moving to Ohio as well. “She is in full agreement ….She’s never offered to take me into her home, and I wouldn’t accept that either.” Barbara had plans to move locations. She wished to relocate to the small east Tennessee town where her
mother lived. Barbara also wanted to be easy and flexible in later life, compared with her mother-in-law:

These are the plans. At some point we’re going to move back to Knoxville which is a smaller place. If something happened to [my husband] before me, I would move back on my own. I would really like to live as independently as I can until I needed…now I don’t want to wait until the bitter end like [my husband’s] mother has, I’d like to go into an assisted living if I needed that assistance.

Caregivers’ housing plans also included more alternative arrangements like intentional communities and co-housing with other female friends. Melanie, the single woman who worked as a musician, said:

I’m thinking about ways to maintain my version of community and hopefully get into a situation where there will be many people around including others my age that would be considered….So I’m actually looking into some intentional community concepts, which is something I’ve always wanted to do, but now I have a different reason for it.

Kay and her girlfriends had discussed living together in later life. “Carolyn and I have talked about it. My best friend, Betsy, and I have talked about it. Now, Betsy says she’s never leaving her house, so we’ll have to come live over there in her house.” She went on to say, “…A bunch of widows living together….I could see myself enjoying that…. We could just take care of each other.”

One participant, Beverly, mentioned housing modifications that would enable her to stay in her own home:

I’m planning to do things to modify the house….Probably doing the handicap ramps and making sure the bathrooms have the handles in the tub and the shower. Making sure the
doorways are open enough so that if anybody ends up in a wheelchair…making sure that there’s enough space so that, if need be, a caregiver could come in as opposed to me having to move some place.

Since she had neither a partner nor children, Beverly, believed one of her only options was to make arrangements ahead of time that would allow her to remain in her own home.

**Health.** A third area of planning frequently mentioned by participants relates to cognitive and physical health. Caregivers spoke about several ways of attending to their health needs including diet, exercise, and accessing health-related information. Evelyn, the 56 year-old who helped care for her mother and sister, shared her outlook on health:

- Take care of yourself mentally. Take care of yourself physically. Take care of yourself.
- Eat the right foods. Take exercise. Take occasional trips. You may not be able to afford it, but you sit down and you look at your budget and you squeeze it out….Be good to yourself. If you are good to yourself, then the years will be good to you.

Regarding her health plans, Jody said, “My husband and I play golf. We’re trying to keep ourselves active enough and mentally doing things.” Like Jody, Eva spoke about the role of exercise in her health-related planning:

- I’m 63, but I was a ballet dancer when I was young, so I’m very strong physically. I love going to the gym, so I’m physically active. I take silk painting classes, so I’m proactive.
- I’m very proactive and I’ll probably always be.

Karen, the 64 year-old from Canada, did not have a fitness routine at the time of the interview, but planned to lose weight using Wii Sport and Wii Fit gaming systems, “I think I'll do this….I think that's something that I can stay with. It's being recommended by doctors now.”
Kathleen, the articulate and attractive 55 year-old, mentioned another area of health-related planning — information seeking. “The biggest decision I’ve made is that I want to stay informed about Alzheimer’s and research and know about any breakthroughs. Even after Mom’s gone I want to keep up with that for my own good.” Karen also revealed that she had “found a good doctor,” which for her was an important aspect of thinking ahead to age-related health needs.

Melanie, the artistic 50 year-old, offered a more holistic view of attending to her health. “I would say if you’re not exercising, you’ve got to find something that you like to do physically. Just find a way to relieve your stress and be creative and keep healthy and positive people around you.”

**Social networks.** In addition to plans pertaining to finances, living arrangements, and health, many participants stressed the importance of planning ahead in order to maintain relationships. Eva, the Venezuelan woman who cared for her 96 year-old mother, had already taking action in order to strengthen her social network.

We belong to three organizations now…Learning in Retirement, it’s a wonderful organization…. And then we have another organization where we belong that is where we meet on Monday nights….It was founded by some Americans who kept taking Spanish classes, but they realized they needed to converse, so they started inviting the Spanish teachers at UGA. So now it’s a pretty large group, about 40 people….. The third one is the Hispanic group that was founded by [a literature professor from Barcelona]…. We have a very active life. I [also] belong to an opera group.

Melanie, who planned to live in a co-housing community, stated, “I would like for there to be multi-generational people around me, not just old people around me.” Likewise, Karen’s desire
to be social influenced her preferences for where she might live in her later years. “I like to be around a lot of people. I think, maybe, a retirement-assisted living thing would the ideal thing for me, and be around people, being able to play cards, or games, and stuff like that.”

As with finances, housing, and health, participants’ plans concerning their social networks were often influenced by their parents’ experiences with social networks. Barbara reflected on her mother’s situation in the nursing home as she commented about wanting people around her:

I’ll go in, and she’ll just be in there by herself. Now I’m sure, even in her diminished state, she probably likes some time by herself. And I really do believe that. But for a good bit of the day I’d like to have some company.

Kay’s mother had socially isolated herself after her husband passed away. This influenced Kay’s perspective on relationships in later life:

I [want to] have friends that I keep up with….As I get older, to not let those friendships diminish. If something were to happen to Tom, I would think, I mean I’ve said to Mom, “Maybe you could have somebody move in with you.” No, she doesn’t [want that], but I could see myself doing that hopefully. And that doesn’t diminish my love for [my husband] or how much I would miss him.

Although some caregivers believed planning was valuable and had planned for their finances, living arrangements, health, and social networks, other caregivers remarked on the futility and limitations of planning. The views of these participants are discussed in the following section.

**Limited planning efforts.** Some caregivers had taken few or no steps towards planning for their later life. Two themes emerged as reasons why participants did not plan for aging. First,
for many women planning was not feasible due to limited resources to plan. Second, even with the ability to plan, participants acknowledged limitations to preparing for one’s later life.

**Limited resources.** First, several caregivers commented about a lack of resources, particularly financial resources, that inhibited their ability to plan for later life. Sandra believed her income prevented her from making plans: “It doesn’t matter what you would like to do or how you would like to plan for it, you’re still limited by what your resources are.” Kathleen, who cared for her mother with Alzheimer’s and incontinence issues, maintained the importance of educating herself about current research related to Alzheimer’s as well as learning about investment strategies. Yet, she had recently lost her full-time job and had to cash out a 401(k) to help pay her living expenses. Kathleen spoke of her financial constraints in planning for later life, particularly related to long-term care:

> I’m making no plans financially for my own care. My home will be paid for, but [my mother’s] home is paid for…. She still can’t afford it. And she’s got more money in the bank than I ever thought about having and she still couldn’t afford a nursing home.

Karen, a caregiver to her mother with Parkinson’s, was unable to save for retirement due to unemployment, and she also had to use one of her 401(k)s to pay her bills. She recently started pursuing a business in sales, for which her “number one goal” was to save money “for a retirement home, assisted living, the kind [of facility] that progresses….I want to be able to travel, but more than that I want to have the future planned as well as possible for old age for me.”

**Limitations of planning.** A second theme related to taking few steps toward planning for aging was limitations to planning. Even women who had made some plans acknowledged that preparing for later life was not a panacea and believed that aging-related challenges are
inevitable, despite well-intentioned planning. There was a paradox between recognizing the benefits to preparing for later life, yet knowing that even the best planning efforts can fail when life circumstances change drastically and unexpectedly. Kay commented on this as she mentioned the recent death of a friend’s son, “You can have all these great plans, but... life just takes a turn. A kid could die of cancer at 29 years old. You just do the best you can.”

Finances were frequently mentioned as being out of one’s control. Karen, who cared for her mother with Parkinson’s, commented on the recent economic downturn which has had a bearing on financial planning efforts. “I was crying the blues over not having a good 401(k) built up. Well, nobody does now. So now, I don't feel bad, because ... a lot of people are in that position, if they even have a job.” Beverly made a similar comment: “I think having enough money [is important]. And I don’t know if you can ever have enough money because anything can happen.” Evelyn also said, “Like this economy has gone down, your money can be gone in a minute, if you have any.” According to Kay, “We talk about [planning] in the financial sense. But you know, a lot of that is out of your control.”

Health was mentioned as another area of uncertainty for some participants. Joanie commented about length of life being uncontrollable:

Do I really want to be 88 years old and have to have somebody to feed me [or] to change my pants? I don’t know that I want [that]. But of course it’s not up to us. It’s not our decision.

Melanie felt powerless with regard to her cognitive health, “I think the part that I don’t feel as in control of is this memory loss stuff.”

Participants described strategies they used to cope with an inability to plan and the uncertainties of the future. Although Melanie was concerned about her cognitive health, she
expected to see advances in medicine and research, “I’m really hoping they will make some serious breakthroughs in the next few years. And I’m pretty sure they will.” In contrast to Melanie’s faith in medical breakthroughs surrounding dementia, other caregivers coped with their lack of planning or limited planning by trusting in a higher power, mainly God. Janice, who cared for both her parents in her home, commented about this:

I’ve always been a firm believer that our destiny was cast by God the day we were born. Who knows? I may end up going before my parents do. They’re tough stock. They really are. You just have to live every day and not worry about the future too much. It’ll take care of itself.

Evelyn was also comforted by her faith in God. “I know that whatever happens as I get older, the Lord is going to take care of me…. Things are going to be what they’re going to be. He’s going to take care of me.” Beverly, who lived with her mother, brought up the importance of chance in old age:

I see people — and I’m always amazed — they’ve never worked in their lives, they’ve never purchased insurance, they don’t have any plans, and they seem to be fine…. I see those persons who are extravagant and they’ve never planned and they seem to…they do just fine!

In addition to faith, rather than making concrete plans for later life, some caregivers relied on reciprocity among family and friends. Janice talked about her own approach to planning:

I don’t know that you can do much. You either have to be very business-like about it and plan on doing everything yourself or you have to be loving and open enough with people that if that time should come that would not be a consideration.
Janice believed she was the “open and loving” type of person. At the time of the interview, along with her parents, Janice and her husband had living in the home her 22 year-old granddaughter who is pregnant, the granddaughter’s 24 year-old husband, and their 2 year-old daughter. Jacqueline, the caregiver with nine siblings shared a similar sentiment. She believed that, because she helped her mother and other family members, someone would be available to help her in her old age.

In response to not being able to plan for later life, some caregivers focused on the present-day rather than looking to the future. Evelyn, who cared for her mother and sister, had this attitude:

Live your life like there’s no tomorrow. Live in the here and now. Unless you are financially able to plan for that with finances, if you’re not, then you just live your life like there’s no tomorrow, and do what feels good.

Sandra made a similar comment:

You just take it one day at a time and do what you can do that day. Some things you can plan, like when am I going to go to the store, what am I going to buy for dinner for next week. But beyond that, you can’t.

It is important to note that the distinction between planners and non-planners was not clear cut. Although some participants had made no plans for aging, others had planned in a few areas. For instance, even though Kathleen believed she was unable to plan financially, she had learned the importance of educating herself about Alzheimer’s disease and available resources. Other women made contradictory statements about planning. Joanie, who cared for her mother and father in her home, thought it best to “make arrangements” for one’s own aging, and yet said, “And here I am, I’ve made no arrangements. I haven’t really put a lot of thought into it.”
When asked why she had not made plans, Joanie surmised, “Because I don’t think I’m old. I don’t…. But yet, I’ve got arthritis [and] I’ve got aches and pains.”

**Attitudes about long-term care.** Participants in this study were asked about their preferences for long-term care if such needs arose in their lives. All of the women expressed definite opinions about the kind of assistance they wanted as an older person. These preferences for long-term care are discussed in the following sections and include caregivers’ attitudes about where they would prefer to receive care, who they would want to give care, and the desired traits of the care provider.

**Preferred locations for care.** Some caregivers in this study preferred to be placed in a facility if they needed such care with daily activities. Maggie, the 50 year-old who was planning to start a blog to help other caregivers, said this about living in a facility, “I have no reservations at all. There are a lot of good facilities. I think in the next ten years there’s going to be facilities that are more reasonable.” Barbara believed her mother was alive due to the care she was receiving in the nursing home, “If we had her at home, she would definitely not be with us because….you don’t know exactly what you’re looking for like the staff does. So we do the little things. They do the major things.” Although she would not mind being in a facility, Barbara said, “If I’m in a nursing home I would rather be in a demented state than [be] very aware everything.”

Other women, however, revealed negative opinions about long-term care facilities, particularly nursing homes. Mary, the small-framed, soft spoken caregiver, based her opinion of nursing homes on the care her mother-in-law received: “The nursing homes are just awful because [my husband’s] mom was in a nursing home…. We had to go down there and it’s not a
pretty picture….It wasn’t pleasant at all.” Kay, who moved from California to help care for her father with pancreatic cancer, said this:

I hate nursing homes. I despise them. I think they’re just the saddest places on the planet….a lot of people in those homes have relatives that come and visit them, but a lot of people don’t…. that’s just the saddest, old people are just discarded or just forgotten.

Not cared for, not loved.

Yet, even as nursing homes may not be the preferred care location for Kay, she also acknowledged that at times, those facilities are helpful and sometimes necessary.

Caregivers spoke about quality of care issues in nursing facilities. Despite Barbara’s positive opinion about her mother’s convalescent center, she discussed some limitations to the care she received:

Even in a nursing home we keep somebody with mother all the time….The girls [at the nursing home] are wonderful, but at night they have four people they have to feed. Well, I mean the patient’s got to get with it! And mother doesn’t get with it. I mean, her mind’s bad, she doesn’t know to open her mouth [and] you have to coax her. Well, she’d probably get three bites and that’d be it….It makes us feel like that her care is complete when we’re helping.

According to Sandra, her mother’s poor health was in part due to inadequate care she received in a nursing facility:

[When mom broke her leg] she went in for the rehab at [Woodland Terrace], and she really deteriorated. She lost so much weight; she just deteriorated so bad. I took her out - what was it - March 9th. She's only just now starting to get back to where she was.
The atmosphere of a facility was important to several caregivers. Some participants acknowledged qualitative differences between facilities. Kay said this: “I’ve been to some good nursing homes. Well, I’ve been to some that were better than others.” Joanie, the middle school paraprofessional who cared for both her parents, expressed her opinion this way:

If I needed care, I would be okay going into a nursing home as long as it’s one close to my daughter and a nice one. Because the ones I’ve seen over the last couple of years, especially up in Gainesville, I would just as soon not be here as to have to live that way. As her mother’s caregiver, Joanie had experiences with several long-term care and rehabilitation facilities. She described the stark differences between two facilities in particular and spoke to the importance of atmosphere:

The atmosphere, the first impression that you get when you walk into a place. Little things like the desk where the receptionist was, I remember this so well…because I thought I was in the wrong place, had a big thing of lemonade sitting there for people to get….And it had this big table out in the foyer and this big arrangement of flowers and it had the gold trim stuff and I’m thinking, “How much does this place cost? Can we do this?”….And then when you walked into the [Laurel Park West], it was like, “I wouldn’t even want to spend the night here much less put my mom here”…. So, just comparing the two, it was like walking into a homeless shelter and walking into the Ritz Carlton.

Joanie went on to comment about friendly staff and a nicely decorated dining room and “feeling very comfortable right off the bat.”

Living in their own homes was preferred by many women. Mary said, “I’d like to be at home if I can”, yet she also envisioned relocating if need be: “I might go to another house or to a condo or something smaller.” Beverly, a single woman with no children, desired to receive care
in her home rather than in a facility, “I would prefer to be in my house and I would prefer to have someone come in and live with me.” She went on to say, “Ideally I would see it as somebody moving in. And then in that way, part of their expenses would be paid through living there.” Sandra, who also had no children, made a similar comment: “What I would want would be to stay in my own home. As I needed it more and more and more, have people come in.” She spoke of having more power to manage her own care if she were in her own home:

I would like to have more control to where somebody’s coming into my home. I could say, “No. I don’t want to wear that today. I want to wear this.” Where in a nursing home, you wear whatever they put on you a lot of times. That choice, some sort of choice... I have some control over my life.

Preferred care providers. Caregivers in this study had clear views on their children caring for them in later life. The vast majority expressed a desire for their children to not be caregivers for them. Evelyn, the “mother hen” of her family, said this about her children helping her in old age:

I don’t want [my children taking care of me] because I feel like this: I’ve lived my life. And I don’t want them to be burdened down with having to take care of me...my daughters, they having demanding jobs, my son has a demanding job, and then he’s looking for another demanding job to go with the one he already has, so I want to them to live a full life like I have.

In speaking of her only son, Maggie said, “I don’t want him to feel responsible for me as I age in this process.” Kathleen, who was troubled by her mother’s mean-spirited personality and incontinence, shared these strong words about having her children care for her:
Suppose that I became ill and still had my mental faculties, and my kids were saying, “Oh move in with us.” I’d say, “You don’t know what you’re getting yourself into.” It’s terrible. It’s horrible. I don’t want you to…no! ((Laughs)) No! It’s nothing I would ever wish on my worst enemy….As much as you would want them around you because you love them and everything, what it requires is not something you want to put them through. It’s just not…. I love them too much to want them to have to deal with what I deal with that.

When Jody considered whether she wanted her daughter caring for her, she reflected on her own situation and her mother-in-law who has Alzheimer’s: “[She] has never offered to take me into her home and I wouldn’t accept that either. I admire people who can do that. I can’t imagine having my mother-in-law running around here. No. They don’t need that. They don’t.”

A few women did want their children to be caregivers for them in later life. Mary, the small-framed widow, said this: “I will stay in the area if my daughter is here. Yeah. She’s going to take care of me.” Similarly, Karen had preferences to move in with her son and daughter-in-law who lived nearby. “I told my son to make sure he buys a big enough house that has a mother-in-law suite in it. And he laughed. And I said, ‘Hey, I'm not really kidding.’” Kay pointed out the contradiction that many caregivers feel about their children being responsible for their care needs:

It goes back to, what is it? A juxtaposition? It’s like, I don’t want to live with my kids. I don’t want to be a burden to my kids. I hate nursing homes, I’m going to get long term care insurance. If they don’t put me in their house, I’m gonna kill’em. ((smiling))

**Preferred characteristics of care provider.** Based on their own experiences as caregivers, participants in this study had developed clear ideas about what type of care they
would prefer as care recipients. An important aspect of quality elder care included personal characteristics of the care provider. The initial step of choosing a caregiver was a decision to be taken seriously. Barbara, who traveled to Tennessee to care for her mother, said this about selecting a caregiver: “What I’ve really learned is that you need to be screened and re-screened and be very particular about who you get to care for your loved ones if you are hiring to have it done.” Speaking of her good friend Joanne, Barbara told this story:

As good a person as Joanne is, I know her mother was having problems with her leg and she kept complaining about having to walk to get her meals. She said, “I just can’t walk good.” And her mind was still good and she was told, “Oh you can Mom, just walk.” So they made her walk but it wasn’t long after that that the doctor said she had a problem….a little while later they had to amputate her leg. Now, you know it was hurting her. So, you have to have some sensitivity to elder care.

Maggie, the 50 year-old music therapist and chemist, believed that even with trained care providers, people needed to be careful when it came to arranging care for a loved one:

People need to understand it’s not safe no matter where you have a parent, whether it’s the hospital or it’s a facility….You are not protected anywhere. You need to have family with you, or a sitter. [But] even with a sitter, unless you know that sitter, it’s an issue.

It was important for participants to have a caregiver who was knowledgeable about caring for an older person. Kathleen said, “I would hope that I could afford an assisted living facility or just paid professionals — people who are educated in knowing how to deal with that and who get paid for it.” She went on, “I would want it to be just professional nurses, people who are educated in what it takes to care for an elderly or infirm person.” Beverly also
expressed a preference for professionally trained care providers: “I would want them to be trained.”

Women also identified personality characteristics they desired in a potential caregiver — qualities such as kindness, empathy, and gentleness. Soft-spoken Mary said, “I want somebody that’s going to be nice to me…and give me good care.” Karen, who cared for her mother with Parkinson’s said, “You'd want it to be a caring situation.” Barbara desired “a soft-spirited, gentle person.” Beverly reported, “I would want them to be empathetic.” Karen and Sandra spoke to the importance of respecting the older person for whom people are providing care. According to Karen, “Just try from the start to realize that dignity starts to become involved, or, loss of….It's hard to have somebody give you a bath….Try to keep dignity intact.” Sandra’s negative experience with professional care providers for her parents gave her this perspective: “Respect my privacy and my dignity. Don’t go through my things. Treat me like a human being. Involve me.”

Chapter Summary

The manner in which participants became caregivers to their parents is best described as either emergent or deliberate. The emergent path to caregiving was characterized by little to no discussion or forethought prior to assuming care of a parent. Participants became caregivers unexpectedly, with no planning. In contrast, participants who deliberately assumed care of a parent could recall a conversation or decision that marked the start of their caregiving career. For these women, assuming a caregiving role or parents asking for care involved some forethought and planning. Alike in all participants was that the assistance they provided to their parent was triggered by a circumstance related to parent’s health, finances or social network.
The experience of caring for a parent or parent-in-law was significant for the participants in this study, particularly related to their perspectives and plans for their own aging. Caregiving influenced daughters in five ways: a) making them aware of aging, b) provoking fears, c) providing a comparison to how they might age, d) providing knowledge about aging, and e) providing an example of how to age. Participants in this study discussed plans for their later life that centered on the areas of finances, living arrangements, health, and social network. Such plans included purchasing long-term care insurance, researching assisted living facilities near children, beginning an exercise routine, and participating in social organizations.

Lastly, findings of this study reveal female caregivers’ preferences, should they need care in later life. In general, participants did not want their children to provide care for them; many of them viewed caring for aging parents as a burden they did not want to impose on their children. Participants preferred to be cared for in their own home yet some planned on being in a facility. Adult daughters in this study also wanted their caregivers to be knowledgeable about elder care and compassionate.
CHAPTER 7
CONCLUSION AND DISCUSSION, IMPLICATIONS AND RECOMMENDATIONS

Introduction

The purpose of this study was to understand how providing care for aging parents shapes informal female caregivers’ beliefs about and desires for their own aging. There were three research questions guiding this study: (a) how did the participants come to be caregivers? (b) how does being a caregiver affect their perspectives and subsequent decision making about their own late life? and (c) what desires and plans have caregivers made for their own aging?

This qualitative study consisted of in-depth interviews with 15 women between the ages of 50 and 65 who are primary caregivers to a parent with an illness and disability. The interviews took place in 2009 over the course of five months, from May to September. Participants were recruited from the Atlanta and Athens areas via gatekeepers, recruitment flyers, and snowball sampling methods. Interviews were transcribed verbatim either by the researcher or by a professional transcription service. Participants engaged in interviews lasting ranging from 28 minutes to two hours and ten minutes. In this chapter I provide an outline of the findings, the conclusions and a discussion based on the findings, implications for practice and policy, recommendations for future research, and a brief summary.

Summary of the Findings

The findings revealed that following one or more triggering events, participants became caregivers in either an emergent or a deliberate fashion. Events triggering daughters’ awareness of their parents’ need for assistance were in the areas of health, finances, and social network.
Although differences existed in each participant’s situation, five themes emerged related to how participants’ perspectives on aging were influenced by the caregiving experience. These five ways are that caregiving a) increased participants’ awareness of various aspects of aging, b) provoked fears related to illness, disability, and extreme old age, c) provided a comparison for how participants might age, d) offered firsthand knowledge about aging, and e) provided an example of how to age. Given the ways that caregiving affected their views on aging, many participants valued planning for their later years and had taken steps toward planning. Others however, conferred less importance to preparing for aging and discussed the limitations of planning. Yet, whether caregivers had planned for their aging or not, all of the participants had preferences about long term care, if this became a need in later life. Caregivers had preferences related to where they would receive care, who would provide the care, and characteristics of the care provider.

This chapter presents conclusions of the study based on the aforementioned findings. This presentation includes a discussion of the findings based on available and extant literature. Finally, implications for practice and policy, as well as recommendations for future research are highlighted.

**Conclusions and Discussion**

There were four conclusions based on the findings of this study: (a) assuming care of an ill and disabled parent can occur without planning; (b) caregiving influences perspectives and plans for aging in five ways; (c) caregivers’ plans for aging center on finances, living arrangements, health, and social network; and (d) caregivers state that they prefer to have non-family caregivers in later life.
Assuming Care of an Ill and Disabled Parent Can Occur without Planning

The first conclusion of this study is that when adult daughters assume care of an ill and disabled parent, this can occur without planning. In this study, some participants described an explicit conversation with parents about care arrangements, yet others became caregivers spontaneously with little forethought or planning. Consistent across participants was that one or more events triggered awareness of their parent’s need for assistance. These events concerned parents’ health, finances, or social network. Hanson and colleagues (1990) found similar patterns, specifically that adult children are stimulated to think about issues concerning their parents’ health needs when faced with health crises and disruptions in the parent’s status and relationship network (Hansson, Nelson, Carver, NeeSmith, Dowling, Fletcher, & Suhr, 1990).

Approximately half of the participants in this study assumed care of their parent unexpectedly over a period of time (i.e., emergent). These caregivers used phrases such as “it just happened” (Kathleen) and “I had no plan” (Kay) and responded automatically as their parents’ needs became evident. This is similar to the implicit negotiation type of family decision-making described by Radina (2007). Implicit negotiation describes a lack of open discussion when making family decisions. Families with implicit communication patterns often “rely on other methods for communicating individual and family responsibilities” and adult children become caregivers because of familial expectations and to fulfill social roles (Radina, 2007, p. 146).

This implicit communication was conveyed by Joanie, a 58 year-old participant in this study, when she described the unspoken assumption that she would care for her parents. “There was not really ever a sit-down conversation where they said, ‘Well, we're going to move in with you.’” Joanie’s mother made no plans for her own care, yet told Joanie (an only child), “Don’t
ever put me in a nursing home unless I’m totally crazy and I don’t know where I’m at.” Although Joanie was frustrated by the lack of open dialogue preparing her to assume care, she appeared to be repeating the pattern with her own daughter, also an only child. When her daughter inquired if she had financial plans for her own care, Joanie replied, “No. No we don’t….Nope. Ya’ll are just going to be looking after us. That’s all I know.” As Whitlach (2008) points out, “The well-being of both caregiver and care recipient depends on finding a balance between the recipient’s needs and desires and the caregiver’s ability to fulfill them” (p. 92). Caregivers who feel they have to assume the role of caregiver, rather than become a caregiver by choice, are more likely to experience negative consequences such as stress and strain (NAC & AARP, 2005).

Compared with women who became caregivers in an emergent fashion, other participants described a deliberate start to the caregiving role. These adult daughters were involved in discussions and planning prior to assuming care for a parent. This is similar to the explicit negotiation type of family decision-making. The family meeting that Jacqueline initiated illustrates the conscious, collective problem-solving method that is discussed in literature on how some families make decisions about care needs of elder family members (e.g., Finch & Mason, 1993; Radina, 2007; Sillars & Kalbfleisch, 1989). However, Radina (2007) suggests that implicit and explicit communication patterns should be viewed on a continuum. While Jacqueline and her siblings shared in the decision making process about their mother, other participants in this study who had explicit conversations with their parent about caregiving did so alone and without involvement of other siblings or family members. Explicitly acknowledging the need to make a decision does not mean a decision will be made using open communication strategies (i.e., with the involvement of several family members, conference-style).
Among the participants who became caregivers deliberately, many of them took charge during the decision-making process. Eva said that after her father’s death, her “mother had to choose whether to go back to Venezuela or stay with [Eva] in [her] my house….[and] she chose to stay with [Eva].” Previous studies have found that, in a majority of caregiving dyads, adult children dominate the decision-making process (Cicirelli, 2006; Pecchioni & Nussbaum, 2000). This leadership manifests itself in children “doing more talking, proposing more alternatives, and having his or her alternatives selected as the final decision more often” (Cicirelli, 2006, p. 118).

Several participants reported getting little to no support from siblings in meeting the needs of their parent. Kathleen’s perception that she became the caregiver “by default….[because] no one else wanted to do it” is not unlike de facto selection posited by Merrill (1997) and the default theme found by Radina (2007). In her study of European American families, Merrill identified de facto selection as the situation in which adult children enter the role of caregiver because other family members are either unwilling or unavailable to take on parent care. Likewise, in her study of Mexican-American families, Radina found many participants believed they entered the role of caregiver by default, because no other family members would assume responsibility.

Pillemer and Suitor (2006) describe several factors influencing whether a child will become a caregiver to his or her parent; these include parent-child similarities (e.g., gender, values), emotional closeness, past history of exchange, and children’s availability. Karen, the 64 year-old participant from Canada, illustrates the influence of children’s availability on assuming parent care. Karen believed part of the reason her mother reached out to her in a time of need was because she was out of work and thus available to help. Similarly, Pillemer and Suitor found that children’s availability most often centers around proximity and employment.
Understanding how adult daughters become caregivers has implications for caregivers and the family members for whom they provide care. Children who know in advance they will be giving assistance to an aging parent have more opportunity to develop proactive coping strategies (Aspinwall & Taylor, 1997) (e.g., accumulating resources) and problem solving skills which might contribute to positive adjustment to the caring role. When adult children talk to their parents about the possibility of future caregiving and have a sense of control in assuming the caregiving role, they are less likely to experience subjective stress and burden (Elliott & Shewchuk, 1998; NAC & AARP, 2005). Joanie expressed frustration at how she “evolved” into the role of caregiver for her parents, a responsibility she felt her parents assumed she would take on. The way she entered the caregiving role clearly affected her experience as a caregiver. She cried throughout most of the interview saying, “at this point Mother doesn't realize what she's done to me….we've had to put our life on hold.” Preparation for the caregiving role also improves the quality of life for care receivers (Berg, Strough, Calderone, Meegan, & Sanson, 1997; Hammond, 1990).

Caregiving Influences Perspectives and Plans for Aging in Five Ways

The second conclusion of this study is that caregiving influences adult daughters’ perspectives and plans for their aging in five ways. Female caregivers in this study were affected in that: 1) they gained more awareness of various aspects of aging, 2) caregiving provoked fears in the participants, 3) parents provided a comparison for participants’ current and future functioning, 4) caregiving provided firsthand knowledge about aging, and 5) parents provided an example of how or how not to age.

Increased awareness. Participants in this study used phrases like “just going along” and “rolling along” to describe their life before becoming aware of their own aging and potential care
needs in later life. They spoke of caregiving as a turning point in their lives, making them more conscious that they too were getting older. Before this increased awareness, participants were focused on things such as work and children. Many of the women had not given much thought to aging prior to being a caregiver. Kathleen said, “I never thought of these things. I never considered them. I just went about my business.” Likewise, Jody commented, “I didn’t really think about it. I didn’t think about it until they got sick. It hit home.” For women in this study, the caregiving experience was a significant event that brought about a revised understanding of themselves and their relation to the surrounding world (Ogle & Damhorst, 2005). This finding differs from the view that individuals in America tend to be assimilative (Whitbourne, 1987) in nature, just as individualism and independence are thought to be American traits. Antonio and Rubenstein (2004) suggest that “the American self is often described as individualistic, inviolate, and unchanging” (p. 39, emphasis added). As well, Troll (1995) believes that as Americans age, they do not believe that they are different; they have a “perceived continuity of self” (Troll, p. 77).

Without my asking about birthdays, several participants spontaneously mentioned birthdays as another life event causing participants to be more conscious of aging. This finding parallels Karp’s (2000) work which revealed the significance of 50th and 60th birthdays for many individuals in midlife. Decade birthdays are often a sign of age benchmarks and raise awareness of one’s own aging. One of Karp’s participants spoke this way about his fiftieth birthday, “When I turned 50...people asked me how I felt...I just became more conscious of the fact that I had made it to half a century” (p. 71).

Provoked fears. In this study, the caregiving experience provoked aging-related fears in many participants. This finding complements other qualitative studies which explore the salience of personal experience of illness in the family for perceptions of vulnerability to that illness (Erblich, Bovbjerg, & Valdimarsdottir, 2000; Rees, Fry, & Cull, 2001; Walters, Emery,
Braithwaite, & Marteau, 2004). For example, women with a family history of breast cancer whose mothers had died of breast cancer had significantly higher breast cancer-related distress than either women with a family history of breast cancer whose mothers had not died of breast cancer or women with no family history (Erblich et al., 2000). Likewise, Lindenmeyer and colleagues (2010) found that midlife women who had a personal experience with an ill relative integrate this new information into their sense of self, a process similar to identity accommodation (Whitbourne, 1987). When a woman expressed fear of becoming like the relative, it “almost always entailed some kind of loss of self, either through a perceived loss of mobility or changed appearance (arthritis, osteoporosis) or loss of memory (stroke, dementia)” (Lindenmeyer, Griffiths, Green, Thompson, & Tsouroufli, 2010, p. 289).

Earlier research on feared possible selves shows that possible selves related to health become predominant during midlife (Hooker & Kraus, 1994). One study found that when older adults were asked what they fear most, 26% reported loss of independence and 13% ranked placement in a nursing home highest, while only 3% ranked death highest (Clarity, 2007). Similarly, participants in this study were not concerned about death, but were afraid of prolonged life at the expense of independence and quality of life. Eva also feared loneliness as an older person, “I have absolutely no fear about death. Where I do have fear, it’s to be left alone. To be 90-something years old and be alone, that I would not like.” Indeed, older adults who outlive family members and friends and live alone are more likely to experience loneliness and isolation (British Columbia Ministry of Health, 2004; Victor, Scrambler, Bond, & Bowling, 2000). Sandra’s fears centered on losing her quality of life with extreme old age, “Basically what I’d like to do [is] fall dead out in the yard or something. None of this lingering in nursing home, where every day in the same. I’m not the type — I wouldn’t do well in that setting.” Sandra’s
concern is a reality for the increasing numbers of elders living with a chronic, life-threatening disease that requires ongoing care (Hooyman & Kiyak, 2005). Moreover, as individuals live longer, risk for chronic illness and disability increase (National Center for Health Statistics, 2002; Morgan & Kunkel, 2007).

**Provided a comparison.** A third way participants were affected by caregiving is that parents offered a point of comparison for women with regard to their current functioning as well as their future aging. Karen, age 64, judged her physical health against her mother’s health at the same age; “It scares me to death to think that she wasn't like this at all. At 64, she was still playing golf. And what am I going to be like at her age?” In their research on how family health narratives influence midlife women’s perceived vulnerability to illness, Lindenmeyer and colleagues (2010) also found that women oftentimes compared themselves to other relatives. Some participants “visualized their possible future selves by looking for signs of turning into (or ‘becoming like’) their [aging] relatives” (Lindenmeyer et al., 2010, p. 283).

The way participants situate themselves in relation to their parent illustrates the notion that women define themselves by their connection to others — a central concept of the self-in-relation theory (Jordan, 1995; Jordan et al., 1991; Miller, 1996). Through caregiving for her parents, Janice had learned, “When you’re growing up you always see yourself as a totally different individual” but she now sees, “I’m more like my mother than I ever thought I was.” Despite her mother’s many ailments, she continues to find joy in family relationships. Janice observed she was like her mother in this way, “I’m no different than my mom. I get out here on this deck and watch this baby run and play out here, and life is good.” For women, social ties are often viewed as extensions of self, and women’s identity is often influenced by significant others (Barrett, 2005). Similarly, Eva did not identify as old or aging as compared with close female
relatives, “I feel with my mother 96 and my grandmother 103, I feel extremely young at 63. I feel extremely young.”

Provided firsthand knowledge. Caring for an ill and disabled parent presented participants with experiential knowledge about the medical and financial aspects of elder care. Jody talked about people whose parents died at a young age, “They don’t have a clue about what it’s like to care for aging parents.” Robinson and Moen (2000) make a similar observation when they suggest that caregiving experiences may increase midlife women’s firsthand knowledge of “the frailties that often accompany aging, reinforcing desires to take control over their own future and [long-term care] arrangements to optimize both care and independence” (p. 525). As well, Roberto and colleagues (2001) observed that more women than men had formal plans for their future care and surmise this is because women “know the realities of family caregiving firsthand” they might be more pragmatic and proactive in anticipating their own future care needs (p. 119).

Professional caregivers were used by some participants to supplement their parents’ care. Although only one type of paid long-term care service, participants mentioned learning a considerable amount about nursing homes. Barbara, whose mother lived in a nursing facility full time, spoke about the financial considerations of long-term care, “It’s expensive to be in a nursing home but it’s twice that to be at home! I mean, it’s really unbelievable.” A few caregivers also mentioned challenges of having to care for family members at home, such as a loss of the privacy and freedom.

Provided an example. The fifth way that caregiving affected adult daughters’ perspectives and plans for later life is that parents provided an example of how to age. Parents modeled either what to do in later life or what not to do. Reflecting on how they wanted to age,
participants discussed whether or not they would approach aging as their parents did. Daughters who perceived their parents to be having positive experiences with aging and long-term care identified what parents might be doing to bring this about. These women then wanted to imitate these behaviors and attitudes in their own life. In contrast, other parents set a negative example for their adult daughters. These daughters expressed a desire to approach aging differently.

Many parents modeled planning behaviors for their children, especially in the areas of finances. Karen’s mother had life insurance and pre-needs insurance; Kay’s mother had purchased long-term care insurance. In the area of housing, Barbara’s mother had plans to relocate to a long-term care facility in her town whereas Sandra’s parents refused to make plans for their care. Evelyn’s mother modeled an apathetic attitude through having others do for her things she could physically do herself. Conversely, Eva described her mother as “extremely happy being active” and said she herself was “as proactive as [her] mother.”

The positive example set by some parents can be viewed as vicarious experiences that might have supported participants’ confidence in modeling similar behavior (Bandura, 1997). Maggie’s father was proactive in his approach to aging and care needs. He organized his personal finances and the necessary paperwork Maggie would need to assist him and his wife if their health deteriorated. Maggie, like her father, was extremely systematic in her planning behaviors. Not only had she communicated her desires verbally to her son, but she had her plans in writing and made arrangements with an attorney. Kay, age 52, observed her mother’s forethought in purchasing long-term care (LTC) insurance, yet was making no effort to purchase it for herself or her husband. Although experts do not recommend purchasing coverage before age 50, annual premiums for LTC coverage are much higher if individuals wait until their 60s or later to purchase a policy (Pond, 2009).
The concept of “being easy” emerged as an important part of the caregiver-care recipient dynamic. The role reversal in parent-child relationships is naturally challenging but when parents resisted help, it exacerbated this, already tenuous, dynamic. Melanie, Kathleen, and others commented on how their parent makes it hard for them to provide care. About her mother, Melanie said, “She fights it every step of the way.” This idea of being easy influenced how participants wanted to be in their later years. Speaking of her plans to situate herself close to her children so they can check on her when she needs help, Jody said, “I’m going to try to make it as easy as I can.” She went on to say,

I’m not going to do like a friend of mine here whose parents are still digging their heels in and staying in Florida. They decided that was it….She just got back. She went down and spent ten days with them, but they are needing more and more care and they will not budge.

Like Jody, many participants wanted to be flexible and easygoing in later life. Melanie said, “I want it to be more like how my uncle’s situation was, where I don’t fight it, where I’m grateful and easygoing.” Similarly, Kay described her mother-in-law as set in her ways and hoped that she would not “be rigid like that.”

**Caregivers’ Plans for Aging are in the Areas of Finances, Living Arrangements, Health and Social Network**

The third conclusion of this study is that participants had made plans for later life in the areas of finances, living arrangements, health, and social network. This is comparable to areas of planning discussed in the literature. In her work on long-term care planning, McGrew (2000) articulates three planning areas:
Financial (e.g., long term care insurance, self-insurance, estate planning),
social/environmental (e.g., legal agreements such as living wills and durable power of
attorney for health care, clear discussions and agreements with family members, shoring
up informal support systems including moves to be nearer family, and moves or
adaptations in housing to prolong livability), or comprehensive (a combination of
financial and social/environmental).

Likewise, Friedemann and colleagues (2004) describe three domains of planning: financial,
health-functional ability, and social-environmental.

Previous research on proactive planning shows that among middle-aged and older adults,
individuals with a future temporal orientation are more likely to exhibit proactive coping
behaviors in all situations (Ouwehand, de Ridder, & Bensing, 2007). In other words, people who
tend to be planners and to be concerned about their future make more effort to prevent stressful
changes in personal finances, health and social network. In this study, participants who had
prepared for their aging also appeared to have a propensity for planning in other areas of life.
Eva spoke of her tendency to plan, “We’re planners. [My husband] and I are planners. So we
planned even when we’re going to have children, how many, when we’re going to retire. Not
everything worked exactly, but we had a plan.” Similarly, Barbara believed it was important to
think about living arrangements in later life, “It is definitely something you really have to
consider. It’s really no different than where you’re going to live in your younger years or raise a
family or your occupation.” Conversely, Janice represents a different approach to planning,
“Who knows? I’ve always been a firm believer that our destiny was cast by God the day we were
born….You just have to live every day and not worry about the future too much. It’ll take care
of itself.”
Participants in this study were at various stages of planning for future care needs, which is a process that has been conceptualized into four steps: becoming aware of future care needs, gathering information, developing preferences, and concrete planning (Sorenson & Pinquart, 2000; 2001). Becoming aware involves paying attention to one’s vulnerability and is akin to the recognition and monitoring of potential stressors stage in Aspinwall and Taylor’s (1997) proactive coping model. Joanie, who admitted to having no plans for her later life, said she had not planned because she did not think she was old. When asked what would make it easier to plan, Joanie replied, “Being able to actually admit that you’re going to get old and that you’re going to need help.” The second step in preparing for one’s future care needs is gathering information about available resources. The steps Jody had taken to research facilities near her daughter in Ohio reflect this phase in the planning process. Next, deciding on one’s preferences includes evaluating different options and selecting which is the best fit. Melanie’s desire to “maintain [her] version of community and…get into a situation where there will be many people around including others [her] age” led her to consider relocating to an intentional housing community, rather than pursuing other housing options. The fourth and final step in preparing for future care needs is concrete activities that contribute to the implementation of plans. In this study, such actions included purchasing long-term care insurance and making arrangements with an attorney to solidify preferences for long-term care.

The benefits of planning ahead for future care needs in later life are well-documented. Ekerdt (2004) advocates that financial and social aspects of retirement planning should begin as early as possible in adulthood. Older adults who have prepared for long-term care needs ahead of time have more control over decisions related to their care compared with elders who have not planned (Pinquart, Sorenson, & Peak, 2004). Barbara, spoke to this advantage of planning, “You
just have to plan….Especially when you think you won’t have your mind. You still want to feel like you have had input into your care whether you are going to know it or not.” A second benefit of planning for later life is that it may relieve an older person’s relatives of the burden of making decisions (Pinquart et al., 2004). In this study, Maggie had her son in mind when she made plans. She did not want her son to have to make difficult decisions on her behalf, which Maggie felt would burden him. She said, “I don’t want feeding tubes. [My son] knows that. I’ve already gotten all that taken care of…. everything is on top of my refrigerator if something happens to me. And then he knows what attorney to call.”

The plans that study participants had made plans in the areas of health, finances, living arrangements, and social network are discussed in the following subsections.

**Finances.** In thinking ahead to later life, finances were a significant concern for caregivers in this study. According to Mary, “It’s important to have enough money.” Kathleen said, “The root of everything is financial, that you have enough money so that you can pay somebody to care for you so you don’t have to force yourself on your kids.” Janice also stated, “Even if you had to go live with your children, I think it’s important that financially you have some ability to care for yourself.” Compared with other areas of planning, financial plans made by participants are most consistent with the “concrete planning” phase of the planning process (Sorenson & Pinquart, 2000; 2001). Barbara and Mary had purchased long-term care insurance while Jody, Eva, and Maggie had saved for retirement, as well as future care needs, if needed.

With respect to financial planning, financial literacy is also important as defined contribution plans become the norm and responsibility for retirement funding shifts from employers to individuals. People who are financially literate are more likely to plan for retirement (Gaberlavage, 2009). Kathleen spoke to this: “Knowledge about financial planning
and investments is something that would benefit me and probably a lot of people like me.”

Evelyn also said, “Make sure you put your money in the right places. So that it will be there for
you, and you won’t find yourself in a situation where you don’t have any money, and you might
own your home but you don’t have the money for the taxes or whatever.”

Although Beverly felt it was important to “have enough money”, she said, “I don’t know
if you can ever have enough money because anything can happen.” Certainly it is difficult for
individuals to predict if or how much care they will need, whether they will have family or
friends to assist in some or all of the care, and how much care may cost them (U.S. Department
of Health and Human Service [USDHHS], 2008c). Individuals can, however, learn about what
services cost, what public programs they are eligible for and what they cover, what private
financing options are available, and which ones are the most appropriate for them (USDHHS,
2008c). A 2006 report by the AARP revealed that adults are extremely uninformed about
eldercare costs. Less than 10% knew monthly nursing home costs, and many incorrectly
believed that Medicare and Medicaid covered such expenses (AARP, 2006).

Financial planning was often viewed by participants as the first step in preparing for later
life. Indeed, financial resources contribute to a person’s ability to pay for health care costs and
long-term care costs. Research suggests that out-of-pocket health care spending will increase
much more rapidly than does income. Between 2010 and 2040, average annual out-of-pocket
costs for Americans age 65 and older will more than double (“in constant 2008 dollars”), from
about $3,300 to about $7,800 (Johnson & Mommaerts, 2010, p. 11).

Participants who were unable to prepare financially felt unable to plan for other areas of
later life. Evelyn equated planning for later life with planning financially, “Live in the here and
now. Unless you are financially able to plan for that with finances, if you’re not, then you just
live your life like there’s no tomorrow, and do what feels good.” Participants in this study claimed that having more financial resources would facilitate the planning process. Janice said that money would make it easier for her to plan for her own aging, “If you had a lot of money, then you could be independent on your own terms. Or, be enough of a help that people would gladly do it.”

**Living arrangements.** A second area of planning relates to where participants might live in later life. Caregivers in this study were mixed in their opinions about residing in a facility. Although some could picture living in an assisted living facility or retirement community, most participants grouped all facilities under the label of “nursing homes.” A lack of knowledge about housing options leads many elders to classify all formal housing options as nursing homes, a choice negatively perceived by most older adults, as well as women in this study (Gibler, Lumpkin, & Moschis, 1997). In spite of industry growth and media attention, most elders are also not familiar with alternative housing options such as congregate care or continuing care retirement facilities (Gibler et al., 1997). Melanie was the only participant who indicated knowledge and interest in intentional, co-housing communities.

Intentional communities are planned residential areas, typically founded on shared spiritual, social, or political beliefs or other similar values or goals. Residents often share resources and responsibilities, although the degree differs significantly among different community models (Thomas & Blanchard, 2009). Growth of these types of alternative living arrangements is important when considering the shortage in family caregivers (Koerin & Harrigan, 2002; Marks, 1996) and preference for nursing home alternatives (Glass, 2009).

Most older adults prefer to age in place and stay in their own homes (AARP, 2000) or at least continue to reside in the community for as long as possible (Burr, Mutchler, & Warren,
Although many participants expressed a desire to remain in their homes, only Beverly intended to make home modifications that would likely be necessary for her to stay in her home safely. If care needs arise, elders often prefer to remain in their own home and receive assistance from paid helpers or relatives (McAuley & Blieszner, 1995). Similarly, Sandra, who was unmarried with no children, said, “I thought maybe I can fix the mobile home up and bring some people in, and then maybe at some point in time, that will be someone to help me as I get older, where they get free rent.”

**Health.** For women in this study, health was an important consideration in planning for later life. Many participants believed that actions taken now towards healthy living, such as diet and exercise, would contribute to a good quality of life in old age. In fact, lifestyle factors such as exercise and eating habits, as well as health and family history, have been shown to affect risk of long-term care usage among older adults (USDHHS, 2008a). Information seeking was also a part of health-related planning. Kathleen had some expectation for dementia in later life because her mother had Alzheimer’s. For this reason, Kathleen said, “I think the biggest decision that I’ve made is that I want to stay informed about Alzheimer’s and research and know about any breakthroughs. Even after Mom’s gone I want to keep up with that for my own good.”

Participants’ hoped-for selves included activity and independence. Beverly said, “At 85, I’m hoping that I’ll be as independent and as well as [my mother] is.” High life satisfaction in older adults has been associated with a lifestyle based on high-activity along with proactive, but attainable life goals (Holahan & Chapman, 2002). Jody’s motivation to exercise regularly reflects this proactive, but realistic attitude. About her health behaviors, she said, “I’m not doing this to be a raving beauty. I’m just doing this to so my size 12s fit better…I don’t need to be a
size 8. That’s not my goal.” Jody did speak of her real motivation for staying physically active, “I want to walk when I’m 80. I just want to be upright and mobile.”

**Social network.** The final area of planning for later life related to participants’ social networks. Caregivers in this study took part in social clubs, continuing education classes, exercise programs, volunteering, and church activities. Goldberg and Beitz (2006) assert that planning for later life should include activities that can continue into older age, anticipating multiple losses that often occur in later years. Such losses might include the loss of personal health, deterioration in spouse’s health, and the death of the spouse. Several participants acknowledged that, with advanced age, such deficits are likely to occur. Kay and Eva both expected to outlive their spouses, and they took this into consideration in planning for the future. Kay nurtured her friendships to ensure strong relationships if her husband died before her, and Eva anticipated moving back to California in order to be closer to her family.

Since women tend to outlive partners and other potential family resources, alternative housing options are a practical option for women to help them stay connected to others. Glass (2009) found mutual support to be a significant reason for older adults to relocate to an intentional community. Communal or group living is not often thought of by women since families, rather than friendships, are the most important aspect of their personal relationships (Cruikshank, 2003). Barbara and others give attention to their peer relationships. Barbara, who traveled regularly to Tennessee to care for her mother, said, “You do have to form a [social] network….I think the social network is really important….You have to be really aware of what you need [and] I’m a pretty social person.”

**Limited planning efforts.** Despite the tremendous benefits of thinking ahead and planning for one’s aging, numerous barriers exist to doing so. Participants in this study who had
not made plans concerning their aging might be described as avoiders or ruminators according to Steele and colleagues’ (2003) four styles of preparation for future care needs. Avoiders try not to think about future care issues and have low levels of both awareness of potential future care needs and planning ahead. Ruminators (or “thinkers”) are highly aware of future care needs, yet make no concrete plans.

Caregivers in this study acknowledged many barriers that made it difficult for them to plan for their aging, including a lack of knowledge, financial constraints, limited social resources, and an inability to envision a dependent or impaired future self. First, a lack of knowledge about services and accessing resources prevents many individuals from preparing for late life and future care needs (Delgadillo, Sorenson, & Coster, 2004; Pinquart & Sorenson, 2002a; Pinquart, Sorenson, & Davey, 2003). Maggie, one of the youngest participants, recognized that many women her age lack knowledge about aging-related issues. She had plans to start a blog to share what she had learned about aging and caring for an older person.

Medical care these days is very difficult, whether it’s hospital stays, home care, home health care, home services. I have learned so much….There’s so much out there that I’ve learned, and I want people to know, which is why I’m really gung-ho about blogging. Interestingly, Sandra, who said she could not plan for her old age, other than make arrangements for her burial, worked at a social service agency serving older adults and their families. Although she was particularly knowledgeable about resources in the community and how to access services, she had made no plans for later life, despite strong opinions about what she would want.

Another barrier to planning for later life is limited access to financial resources (Pinquart, Sorenson, & Davey, 2003; Pinquart, Sorenson, & Peak, 2004). Particularly for single women in
this study, their ability to plan was limited by their financial constraints which were often the 
cumulative result of life circumstances. For example, when her children were still young, Karen 
divorced her husband; she subsequently had to work up to three jobs at a time in order to support 
support her children because her ex-husband did not contribute financially. According to Sandra, “You 
cannot step outside your financial constraints.” She had little “discretionary income” which 
meant she was unable to “pay for a nursing or long-term care facility.”

A third obstacle to planning is a lack of social resources, which includes not having 
family members available as potential helpers (Pinquart, Sorenson, & Peak, 2004). Older adults 
who have more frequent contact with adult children are more likely to have concrete plans for 
how to obtain personal care or assistance in the future (Sorenson & Pinquart, 2000, as cited in 
Pinquart, Sorenson, & Peak, 2004). Caregivers in this study who had no partners or children 
were sensitive to the fact that their options for care in later life would be limited by their family 
situation. Sandra said, “For me, and as a single person, maybe there are more options when you 
have a multiple income family base, where you have a husband and wife can pool their incomes 
or whatever, but I don’t have that.” Likewise, Beverly had developed alternative ways to acquire 
assistance if she needed care in later life. Beverly had considered living with some of her female 
friends or paying a professional caregiver to come and live with her. She intended that a portion 
of the care provider’s salary would include living expenses since the care provider would be 
living rent-free in her home.

A final barrier to planning was mentioned by only one participant, Joanie, but is certainly 
relevant to several caregivers in this study. When I asked Joanie why she had not made plans for 
later life, she replied, “Because I don’t think I’m old. I don’t.” Her attitude fits Weinstein’s 
(1980) concept of unrealistic optimism in that she acknowledged on the one hand her current
health problems (e.g., arthritis), yet on the other asserted that she feels too young to start planning. For some participants, their obstacle to preparing for aging was an inaccurate view of themselves and an inability to envision a dependent or disabled future self. According to McGrew (2000), in order to plan for future care needs a person must have “realistic beliefs about personal capacity (self-efficacy) to control the risk of dependency, to cope with its effects, and to plan for its possibility” (p. 6). Like Joanie, Evelyn also had minimal plans for her later life. Despite her fibromyalgia and complications from a stroke, Evelyn told her children, “I’m going to take care of myself till the day I die. I don’t want anybody taking care of me.”

**Caregivers Prefer to have Non-Family Caregivers in Later Life**

The fourth and final conclusion of this study is that caregivers stated they preferred to not have family caring for them if they needed assistance in later life. Deciding on and articulating preferences for long-term care is another important area of planning for one’s aging. Eckert and colleagues (2004) organized preferences along two interconnected dimensions: care location (home/community versus institution) and provider (kin versus professional/para-professional care). Likewise, when participants in this study were asked about their preferences for care, they repeatedly mentioned whom they would want to provide care and where they would want this care to take place. In addition, participants described qualities they desired in their care provider.

Along with preferring to live in their own homes, caregivers did not want family members, children in particular, caring for them if they became ill or disabled. Likewise Roberto, Allen, and Blieszner (2001) found many older people prefer formal caregiving while Eckert, Morgan, and Swamy (2004) and Pinquart and Sorenson (2002c) report that elders prefer a combination of both formal and informal caregiving. This preference for formal support differs from older studies which show that among older adults in the United States (U.S.) who
had articulated their preferences, 55% to 80% of them favored informal support (Brody, Johnson, & Fulcomer, 1984; Stoller, 1982).

The primary reason that participants did not want children to care for them was because they did not want to be a burden. Barbara expressed a sentiment that was common for many of the women in this study:

Even if my kids wanted me, I’d hate to do that to them. Because the care of another person is hard on...it’s hard to move into somebody’s house. That changes their life.

And you don’t want them to feel burdened by all that.

Likewise, Evelyn said, “I don’t want [my children] to be burdened down with having to take care of me.” The responsibility of caring for aging parents caused tremendous stress and strain for many of the women in this study. It is possible that participants who did not want their children to care for them felt this way so as not to be hypocritical, since caring for their parents often proved to be a burden.

The societal norm of adult children providing care to aging parents might also be changing. According to one participant, Maggie, the assumption that extended family moves in with their children in late life is an “old school” way of thinking. Although she built her home with enough room for her parents to live with her, after many years of caregiving Maggie was “exhausted” and no longer able to care for her mother in her home. “This was one time that I just had to do something different because I’m….very tired. This has been a long journey.”

Likewise, Jody believed baby boomers thought about family care differently than other generations. There was no longer the assumption that children bring older parents into their home. Jody attributed some of this to selfishness as well as the fact that there were now more housing and long-term care options for older persons.
The fact that participants in this study were considering non-family options for long-term care might be a positive thing considering future demographic trends affecting the availability of caregivers. Women’s participation in the workforce continually grows, family size is decreasing, and more marriages are ending in divorce which affects the availability of family caregivers (U.S. Census, 2008). Not only do spouses and children aged 65 to 74 make up a large group of primary caregivers, but there is also an increase in the proportion of caregivers who are aged 75 and older, nearly one-quarter of all primary caregivers in 1994 (636,000 persons), up from 18% in 1984 (Spillman & Pezzin, 2000). Thus, family caregivers who are themselves aging might be facing their own age-related health problems.

Many participants had strong opinions about not wanting children to care for them in later life, yet they often did not have plans or arrangements made for professional long-term care. Kathleen said,

I hope that my children never have to care for me. But right now…financially, there’s not a darn thing I can do about it because I just cashed out my 401(k) to live on…. One of them…I still have one other from a former job. I’m making no plans financially for my own care. My home will be paid for but [my mom’s] home is paid for.

According to Williams and Gilovich (2008), people are more likely to view themselves as “an evolving construction and [other] people as finished products” (p. 1042). Many participants in this study envisioned themselves relocating to an assisted living community or bringing in paid providers into their home. Yet not all these participants had taken action to ensure they would have the financial resources to pay for these housing plans. At times, caregivers in this study described their future in a way that was inconsistent with their current financial or social resources. Williams and Gilovich point out that the tendency to see the self as situated primarily
in the future might contribute to the preservation of bad habits and leisurely efforts to improve
the self. In the same way, caregivers who had intentions to receive formal care in later life, might
delay making arrangements to secure this preferred type of care.

**Limitations of the Study**

The findings of this study reflect how adult daughters caring for an aging parent think
about and plan for later life. The findings are limited to a non-random, small sample size,
approximately 15 women, although I strived to interview a varied group of female caregivers.
Because of the small sample size and nonrandom sampling, the study findings are limited in
generalizability. In other words, the ways that participants became caregivers and the ways they
were influenced by caregiving with regard to their own aging will not necessarily hold true for
all female caregivers in this age group. In addition, study participants were limited to adult
daughters who self-identified as caregivers. It is possible that potential participants did not
respond to the recruitment flier because they did not identify with the selection criteria or
language used in eligibility requirements.

Another limitation comes from participants’ ability to be reflective and to articulate how
caregiving has influenced their senses of self. The data from some of the interviews was not as
rich as others. These participants provided fewer details about their thoughts and feelings, even
with probing. Caring for an aging parent is stressful, time-intensive, and emotionally taxing. It
is possible some participants were so preoccupied with caregiving that it was difficult to step
back and reflect on how the experience had affected their sense of self. Other participants may
not be reflective by nature. For many, planning for late life includes the possibility of illness or
dependency. This is a sensitive subject and required a great deal of vulnerability on the part of
the participants. Some women may not have felt comfortable discussing this with me, possibly
because I am an outsider and not a caregiver myself, or because I was much younger than they were.

This study also would have been strengthened by including other demographic information from participants. In particular, obtaining participants’ educational background and religious background would have provided additional information about the context of their individual and family situation. Since education often affects a person’s financial situation, which in turn influences their ability to plan, this would be an important factor to include in research about planning behavior (Hooyman, 2006; Pinquart & Sorenson, 2002a; Pinquart, Sorenson, & Davey, 2003). Additionally, a few participants discussed trusting in a higher power which helped them worry less about their future and their lack of planning about aging. The influence that religion or spirituality has on planning behavior is another aspect of this study that might have been examined if information about religious background was obtained from all participants.

Finally, research indicates that planning for later life is strongly dependent on having the resources to plan (McGrew, 2000; Pinquart & Sorenson, 2002a; Pinquart, Sorenson, & Davey, 2003; Pinquart, Sorenson, & Peak, 2004; Sorenson, 1998). A number of participants had limited financial resources and family support so some participants had few concrete plans for later life. Although a lack of planning might result from being unaware of the need to plan, a caregiver might also have few plans for later life because she lacks the means to do so.

Implications for Practice

Research from nationally representative samples indicates that adult children provide the majority of care to impaired elders. At any given time, approximately 1 out of 10 adult children, mostly daughters, are caring for aging parents (Himes, 1994; Wolff & Kasper, 2006). Recent
reports indicate that these caregivers are typically in midlife and around 49 years of age, older than their counterparts were five years ago (NAC & AARP, 2009). Previous studies on how caregiving influences adult children have focused on strain and burden experienced by caregivers. Although there is a growing body of literature addressing the positive rewards of caregiving (Chen & Greenberg, 2004; Cohen, Colantonio, & Vernich, 2002; Kramer, 1997; Peacock et al., 2009; Tarlow et al., 2006), more studies are needed. Examining only the negative consequences of caregiving, rather than the possibility of growth from caregiving, fails to provide a holistic view of the caregiving experience.

The majority of informal caregivers for older persons are women in midlife, particularly daughters, who in the coming decades will comprise the 65 and over population. Consequently, the purpose of this study was to understand how providing care to aging parents influences adult daughters’ perspectives and plans for their own aging. A review of the literature did not uncover any study that looked specifically at female caregivers in late midlife and how caregiving shapes their views on later life. Accordingly, this study provides an alternative to the often emphasized needs, problems, and deficits of the caregiving experience. Papastavrou and colleagues (2007), for example, found that more than half their sample of dementia caregivers were highly burdened and displayed depressive symptoms. Yet as Ott, Sanders, and Kelber (2007) point out, insight into “the complexity of the caregiving experience requires an understanding of the factors that may be associated with positive outcomes as well as negative outcomes” (p. 807). The majority of caregivers in this study experienced positive growth (i.e., becoming more knowledgeable and aware of aging, becoming motivated to plan for later life) as a result of the caregiving experience. This finding adds to what other studies have found on personal growth as a result of caregiving (Sanders, 2005; Tarlow et al., 2006). This study strengthens the research on positive
aspects of caregiving because of its focus on how adult daughters’ perspectives on aging are influenced by the caregiving experience.

Social workers practicing with older adults and their families are in the important position to encourage conversations between relatives about preparing for future care needs of older family members. Failing to think and plan for future needs is associated with premature institutionalization of elders (Gubrium & Lynoth, 1983) as well as neglect and elder abuse (Wilber & Nielson, 2002; Wold, 2000). Data from this study can inform programs and practice strategies aimed at promoting intra-family dialogue. For example, since most participants expressed a preference for professional, rather than family caregivers, service providers can discuss alternative options to family care, rather than assuming family will take care of family. As Whitlach (2008) points out, “practitioners can’t assume they know the care preferences of their clients if these preferences are neither assessed nor discussed” (p. 93).

Several participants in this study expressed a desire to remain in their homes. Although many desired to age in place, only Beverly mentioned making home modifications to ensure she could remain in her home safely. To help people stay in their own home while ensuring their needs are still met, social workers can discuss home modifications and other arrangements with clients and their families. Social workers may perform an in-home assessment of need for home modification. They might also use their brokering skills to connect clients with available resources that provide assistance with home modifications (Ruffin & Kaye, 2006; Stafford & Harlan-Simmons, 2003).

Several women in this study expressed an awareness of the need to plan and yet had few plans for their own aging. This was sometimes due to limited resources, as in Kathleen and Sandra’s case, or a lack of follow through, despite high awareness of the need to plan (as with
Joanie). Research has shown that, compared with planners and avoiders, ruminators (those who are highly aware of the need to plan, yet make no plans) have the lowest levels of psychological well-being (Pinquart & Sorenson, 2002b). Ruminators also exhibit high levels of worry and depression (Steele, Pinquart, & Sorenson, 2003). Social workers, cognizant that ruminating without problem solving can lead to depression and anxiety, can assist clients who are aware of aging needs yet have not planned. Individuals ruminating over potential care needs can benefit from processing (either in a group or individual setting) their fears about aging in order to move beyond paralysis, using their feelings as a motivation to take action. In addition, practitioners’ knowledge about available community resources, options for long-term care, support services for families are of particular value to aging individuals and their families.

Although not a focus of this study, none of the participants in this study had ever attended a caregiver support group. Support groups are one of the most frequently recommended interventions to ameliorate the negative impacts of caregiving. Two of the participants in this study had been caregiving for a decade or more, yet had never met formally with other caregivers. This is particularly interesting considering that many participants commented on the therapeutic value of the interview process. About the interview, Kathleen said, “It really has been…it’s been therapeutic” and “This was a lovely respite.” Likewise, Barbara commented, “It’s been very enlightening. Very enjoyable. You’re a good therapist. You oughta do this once a week.” The value of talking to a social worker one-on-one can extend to a group setting where caregivers can not only share their personal stories but listen to experiences of others.

Support group options should be expanded so as to encourage higher attendance by caregivers. Counseling and support services via telephone hotlines are also provided by many agencies, including the Alzheimer’s Association (Ruffin & Kaye, 2006). Caregivers who are
limited in their ability to access services in person because of making arrangements for an alternate caregiver or worrying about being away from the care recipient can benefit from telephone support. Telephone counseling also provides a way to reach isolated or rural caregivers with few or no available services (Skipwith, 1994; Smith & Toseland, 2006; Smith, Toseland, Rizzo, & Zinoman, 2004).

Another growing alternative for caregiver support is Internet-based support groups. These provide a private and convenient way for caregivers to contact other caregivers and professionals for guidance and mutual support (White, Dorman, Mahoney, Tarlow, & Sandaire, 2000). A workshop using real-time web-based education (AlzOnline) was found to increase the self-efficacy of caregivers and decrease the subjective burden of caregiving (Glueckauf, Ketterson, Loomis, & Dages, 2004). A recent study by Chiu and colleagues (2009) found that caregivers benefited from an Internet-based support service through the professional support via e-mails and a thorough information web site (Chiu, Marziali, Colantonio, Carswell, Gruneir, Tang, & Eysenbach, 2009). The Internet also has a wealth of information for long-term care planning. Such resources that exist for planning are the National Care Planning Council (www.long term carelink.net), the National Clearinghouse for Long-Term Care (http://www.longterm care.gov), and information provided by Medicare (http://www.medicare.gov/LTCPPlanning).

Another practice implication concerns the design and implementation of practical skills training for caregivers. In the course of identifying potential participants and collecting data, several caregivers mentioned a need for training and education around providing care for a parent. Joanie spoke of her aunt, her mother’s sister, offering no help in caring for her mom. About this Joanie said,
[My aunt] will say, “Oh, oh, I can't. I'm afraid I'll drop her. I'm afraid... I've never learned to do...” And I've said to her, “Did anybody teach me to do this?” …And I said, “Nobody taught me how to handle my mother. You just go at it feet first, and you just do what you have to do.”

One caregiver who was not eligible for participation in the study commented on the need for assistance and training for “non-professional caregivers” who find themselves in the situation of assisting a loved one. She said, “It’s much more much more difficult on everybody when you have to learn it all by doing.” More demands are placed on family caregivers due to managed care restrictions on hospital care and home health services (Koerin & Harrigan, 2002). Changes in health care delivery like the early discharge of hospitalized patients mean caregivers often have to provide skilled nursing care that is beyond the scope of their knowledge and comfort level (Kim & Schultz, 2008; Levine & Murray, 2004).

One type of support service provided to family caregivers includes training to assist caregivers in making decisions and solving problems related to their roles (Feinberg, Wolkwitz, & Goldstein, 2006). Psycho-educational interventions consist of structured programs that educate caregivers either an individual or group format. Groups are typically conducted by a trained leader and may include lectures, group discussions, and written materials. Content in the psycho-educational interventions may include the process of the care recipient’s disease, information about resources and services, and training for caregivers to respond effectively to disease-related difficulties (Honea et al., 2008). In the future, caregivers should be included in the program design and implementation, as well as the evaluation of these educational/training services. Additionally, although these services exist, research is needed to determine why caregivers are not utilizing services such as these. This might include community needs
assessments to identify the gaps in services and barriers to service utilization by family caregivers.

Implications for Policy

Like most older adults, many of the participants in this study wanted to receive long-term care services in their home if this became a need (Kassner et al., 2008). Medicaid continues to allocate most of its resources for institutional services rather than provide the range of choices that older adults want. Burr and colleagues (2005) found that older unmarried women with functional limitations were less likely to be institutionalized when states increased spending for home and community-based services (HCBS). More financial support for HCBS would not only be responsive to the public’s preference for these services, but would also be more cost effective. In fact, Kassner and colleagues (2008) note that “Medicaid dollars can support nearly three older people and adults with physical disabilities in ... HCBS for every person in a nursing home” (p. 1).

Although most participants preferred not to ever reside in a facility, Joanie’s mother’s experiences with two different facilities influenced Joanie’s ideas of what a “nice” facility looks like. Joanie spoke of “the atmosphere” which was the first impression one gets when walking into a place. She went on,

Little things like the desk where the receptionist was, I remember this so well the first time I walked in, because I thought I was in the wrong place, had a big thing of lemonade sitting there for people to get. I’m thinking, “What a nice idea.” And it had this big table out in the foyer and this big arrangement of flowers and it had the gold trim stuff and I’m thinking, “How much does this place cost? Can we do this?”
Joanie is not different from many older adults who “want to live in a setting that is home-like and allows them to make decisions they are used to making for themselves” (Alliance for Health Reform, 2008). Continued efforts are needed to improve services in the nation’s nursing homes, particularly through delivering resident-directed care, empowering staff, and providing a home-like setting (Alliance for Health Reform, 2008; Rahman & Schnelle, 2008).

In this study, Barbara and others mentioned ensuring that paid caregivers are dependable and trustworthy: “What I’ve really learned is that you need to be screened and re-screened and be very particular about who you get to care for your loved ones if you are hiring to have it done.” Screening policies for home care workers are an important consideration at both the state and federal level. Medicaid now relies on states to decide how they will screen home care workers. At this time, 46 states (including Georgia) and the District of Columbia require pre-employment criminal background checks for in-home care workers (Galantowicz, Crisp, Karp, & Accius, 2009). Other screening policies would further strengthen the safety of the eldercare workforce. For example, multiple, complimentary tools such as drug and alcohol screenings, reference checks and thorough interviews pre- and post-employment might be considered (Galantowicz et al., 2009). In addition, direct care workers providing care to older people typically receive inadequate training before starting their jobs. Federal guidelines require CNAs and home health aides in Medicaid-and Medicare-certified nursing homes and home health agencies to complete a minimum of 75 hours, or about two weeks, of training and pass an exam. However, aides may work for up to four months before completing their training (Wright, 2005). One benefit of adequate training is a reduced risk of elder abuse. It is recommended that uniform standards for training and supervision be established in long-term care settings as well as
increased funding for training and continuing education. Higher wages and improved working conditions might also strengthen recruitment of the elder care workforce (Nerenberg, 2002).

**Recommendations for Future Research**

The purpose of this study was to understanding how providing care for aging parents shapes informal female caregivers’ beliefs about and desires for their own aging. Based on the findings of this qualitative study, I have five recommendations for future research related to this topic.

This study adds to the current literature on how women become caregivers for a parent, focusing in particular on women in late midlife, between the ages of 50 and 65. Although most caregivers are in their late 40s, increased longevity will likely lead to growing numbers of older caregivers (NAC & AARP, 2009). Some estimates put at least one quarter of caregivers in the 65 and older age group (Decima Research for Health Canada, 2002). Future research should consider how the path to caregiving is similar to and different for younger caregivers.

Second, this study included only female caregivers, adult daughters in particular. Another recommendation is that this research be duplicated with other populations. Moreover, although more men are assuming a caregiving role (Fast, 2005; Leland, 2008), they are underrepresented in the caregiving literature. Future studies should explore the ways in which adult sons come to be caring for their aging parents. Barbara, the second woman interviewed for this study, was actually referred by her husband, Robert, who saw the recruitment flyer at the nursing home where his mother stayed. Although he could not be interviewed formally for the study, he joined his wife’s interview and interjected comments throughout the conversation. It was the longest interview at over two hours. Surely other men like Robert desire to describe
their experiences in caring for an aged parent, and their stories can help researchers and practitioners gain insight into the overall caregiving experience.

Other populations with which this study could be replicated are middle-aged spousal caregivers and former caregivers. In the recruitment phase of this research, individuals from both of these groups had to be turned away from participation in the study. Interviewing former caregivers could be particularly informative because they would not currently have the responsibilities and stress of caregiving. It is possible that the passage of time could promote more reflection about how the caregiving experience has influenced their perspectives on aging.

A third area of future study is exploring the relationship between self-efficacy and planning for later life. Bandura’s (1997) Self-Efficacy Theory posits that self-efficacy or confidence one can perform a behavior is influenced by three main factors: previous success in performing the desired behavior, vicarious experiences of observing others perform the desired behavior, and positive feedback that one can successfully perform the behavior. Research exists that assesses family members’ confidence in making decisions for a terminally ill loved one (Nolan et al., 2009). Being a caregiver likely presents opportunities and experiences that would influence people’s self-efficacy with regard to making decisions and plans for their own aging. For example, successfully making decisions on behalf of an ill family member could increase people’s confidence in making decisions on their own behalf. Research on people’s confidence in planning for their later life would advance assessment of new interventions designed to promote long-term care planning and interventions for social workers to determine how confident people are in planning for their later life.

As baby boomers move into later life, additional research is needed on the planning behaviors of this cohort. One suggestion is a national study of planning to identify both the
prevalence of preparing for later life, as well as health-socio-demographic characteristics (e.g., age, education level, family income, and health status) related to planning. It might also be relevant to determine how different care recipient diagnoses influence caregivers’ decision making about late life. Two instruments that might be utilized or modified to measure planning behaviors are the Preparation for Future Care Needs (PFCN) Instrument developed by Pinquart and Sorenson (2001) and the Long-Term Care Planning (LTCP) Instrument designed by Friedemann and colleagues (2004). Previous or current experience in caring for an older person would be an important independent variable to be examined as it relates to planning behaviors.

Lastly, research is needed to explore the ways that social workers address future care planning with clients. It is important to know the frequency with which social workers talk with clients about preparing for later life. Additionally, future studies could identify in what practice areas and agency settings social workers are most likely to be discussing with clients their plans for aging. A better knowledge of how and to what extent social workers address planning for future care needs would reveal knowledge gaps and education needs for both social work curricula and continuing education.

**Chapter Summary**

The purpose of this study was to understand how providing care for aging parents shapes female caregivers’ beliefs about and desires for their own late-life needs. I conducted in-depth interviews with 15 participants, and analyzed transcripts of the interviews. Based on this interpretive qualitative study, there are four conclusions: (a) assuming care of an ill and disabled parent can occur without planning; (b) caregiving influenced perspectives and plans for aging in five ways; (c) caregivers’ plans for aging are in the areas of finances, living arrangements, health and social network; and (d) caregivers prefer to have non-family caregivers in later life.
The relevance of this study for social work practice is that findings highlight preferences for a growing age cohort, women in late midlife. Theoretically, this study advances the literature on positive consequences of the caregiving experience by revealing how adult children who care for their parents are stirred to not only think about their own aging, but also decide on preferences and make plans for their later life. This study also has implications for long-term care services, especially increased funding needs for home and community-based services.
REFERENCES


Online Journal of Rural and Nursing Health Care, 7(1), 35-46.


Ceria, C.D., Masaki, K.H., Rodriguez, B.L., Chen, R., Yano, K., & Curb, J.D. (2001). The


Clarity. (2007, August). *Attitudes of seniors and baby boomers on aging in place*. Retrieved April 2009 from
http://www.clarityproducts.com/research/Clarity_Aging_in_Place_2007.pdf


http://www.aarp.org/ppi


Frazier, L.D., Johnson, P.M., Gonzalez, G.M., & Kafka, C.L. (2002). Psychosocial influences on


on Aging, 15, 243-278.


http://www.urbaninstitute.org/UploadedPDF/1000795.pdf


in the aged: The index of ADL: A standardized measure of biological and psychosocial function, *JAMA, 185*, 914-919.


costs. Westport, CT: Author.


CA: Academic Press.


http://www.aarp.org/ppo

http://www.caregiving.org/


http://www.cdc.gov/nchs/

http://www.cdc.gov/nchs/

http://www.nchc.org/facts/cost.shtml


important in shaping proactive coping behavior than individual characteristics: A vignette study among adults preparing for aging. *Psychology and Health, 21*(6), 809-825.


U.S. Department of Health and Human Services: Administration on Aging (2003). *National family caregiver support program.* Retrieved April 18, 2007 from...


Allen & Unwin.


APPENDIX A

RECRUITMENT FLIER

Female Caregivers’ Perspectives and Plans for Their Own Aging

My name is Natalie Pope and I am a doctoral student in the School of Social Work at the University of Georgia. I am interested in talking with you about your experience providing assistance for your parent or parent-in-law. In particular, I would like to know how caring for your relative has influenced your own plans and preferences for late life.

Eligible participants must:

- Be women between the ages of 50 and 65
- Be primary caregivers to a parent or parent-in-law with a chronic illness and disability
- Have been a caregiver for at least 6 months
- Have at least 7 hours of in-person contact with care recipient per week
- Be willing and capable of participating in a 60 to 90 minute interview
- Be willing to participate in a follow-up interview (or phone call) if necessary
- Live in Georgia

The interview will take place at a location comfortable for both of us. Interviews will be completely private and confidential. The interviews have to be recorded for transcription purposes but will be destroyed after the research is complete. Names and any other identifying information will be removed from the transcripts, and aliases will be used in my final report.

For more information contact:

Natalie Pope
(706) 254-7691 (telephone)
ndpope@uga.edu (e-mail)
The University of Georgia School of Social Work, Athens, Georgia 30302
APPENDIX B

PRE-SCREENING INTERVIEW

Hi, my name is Natalie Pope. I am conducting a study on caregivers’ beliefs and desires about their own aging. I would like to ask you a few questions to determine if you are eligible to participate in the study. Before I begin the screening, I would like to tell you a little bit about the research. I am interested in talking with you about your experience as a caregiver for your parent or parent-in-law. In particular, I would like to know how caring for your relative has influenced your own plans and preferences for late life.

Would you like to continue with the screening? The screening will take no more than 15 minutes. I would like to ask you about your role as a caregiver, your willingness to participate in the study, and some general background information. You do not have to answer any questions you do not wish to answer or are uncomfortable answering. You may stop at any time. Your participation in the screening is voluntary. Your answers will be kept confidential. No one will know your answers except for me. If you do not participate in the study, your pre-screening information will be destroyed. If you do qualify for the research, decide to participate, and sign the research consent form, your screening answers will be kept in a locked cabinet located in a locked office.

Would you like to continue with the screening?
(If no, thank the individual and hang up) (If yes, continue with the screening)

- What is your full name?
- How is your date of birth?
- What is your race/ethnicity?
- Which of the following best describes your current financial situation: a) We cannot make ends meet, b) We have just enough, c) We have enough with a little left over, d) We always have money left over?
- Who are you providing care for?
- How long (in months) have you been caring for this person?
- Why are you caring for this person?
- Approximately how many hours per week do you provide direct care to this person? (direct care meaning assisting your parent with tasks they cannot do themselves)
- Has providing care to this person influenced your thoughts about your own aging?
- Are you willing to participate in a 60 to 90 minute face to face interview? A follow up telephone call if needed?
- Might you be willing to respond to preliminary findings by attending a focus group or looking at findings via email?
- Where do you live?
- How can I contact you in the future for further participation?
Thank you for answering the screening questions.

(Indicate whether the person is eligible, requires additional screening, or is not eligible and explain why).

Do you have any questions about the screening or the research? I am going to give you a couple of telephone numbers to call if you have any questions later. Do you have a pen? If you have questions about the research screening, you may call me at 706-254-7691 and I will answer your questions. If you have questions about your rights as a research subject, please call the UGA Institutional Review Board (IRB) at (706) 542-3199.

Thank you again for your willingness to answer my questions.
APPENDIX C

INTERVIEW GUIDE

Participant Name: _______________________________ Date of Interview: _____________
Location of Interview: ____________________________ Time of Interview: __________

Demographic Questions

Age ____________________________ Employment ____________________________
Marital Status ____________________________ Hours work/ Week ____________________________
Race/ Ethnicity ____________________________
Number of Children ____________________________ Disability/ Illness of parent (in-law) ____________________________
Ages of Children ____________________________ Living arrang. of care receiver ____________________________
Length of time as a caregiver ____________________________ Health/ Illnesses of caregiver ____________________________
(in months) ____________
Siblings (Birth order, age, gender) ____________________________
Other family members they have cared for ____________________________

Research Question 1: How did the participants come to be caregivers?

Tell me about your parent (in-law).
• What illness(es) does your parent have?

How did you come to be taking care of your parent?
• How parent came to need care
• Formal process (e.g., family meeting) or informal process (volunteered, were asked by parent, expected to be caregiver)
• Role of siblings
• Service providers involved in the process

How long have you been caring for him/ her?
What kind of care do you provide to your parent? [use Katz et al. (1963) ADL checklist and Lawton and Brody’s (1969) Instrumental Activities of Daily Living Scale]

Sounds like a pretty big transition in your life, what was that like for you?

**Research Question 2: How does being caregivers affect their perspectives and subsequent decision making about their own late life?**

What have you learned about yourself through being a caregiver for your parent?

What have you learned about the aging process through your experience as caregiver?

How has your perspective about aging changed since becoming a caregiver.

How has your perspective about yourself changed?

Can you give me an example of how you have changed?

How has caregiving made you view your life and aging differently?

To what extent did you think about your senior years *before* being a caregiver?

How has caring for your parent made you different from other women your age who have not been in this role?

**Research Question 3: What decisions and plans have caregivers made about their aging?**

What do you think it means to plan for aging?

What areas of life are important to plan for?

What would help make it easier for you to plan for aging?

What advice would you give to other women your age regarding planning for late life?

What plans or decisions have you made about your aging (getting older)? Tell me about them.

Let’s imagine you get to a point in the future, where you are unable to care for yourself and need assistance like your relative does now. What would you want that experience to be like for you?

What would you want your caregiver to know that you wish you had known when you started?

- Tasks associated with caring
- Emotional/ Physical strain
- Managing family dynamics issues
- Finances
**KATZ BASIC ACTIVITIES OF DAILY LIVING (ADL) SCALE**

For each area of functioning listed below, check description that applies. (The word “assistance” means supervision, direction of personal assistance.)

**Bathing**—either sponge bath, tub bath, or shower

<table>
<thead>
<tr>
<th>Description</th>
<th>Bathing Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Receives no assistance (gets in and out of tub by self if tub is usual means of bathing)</td>
<td></td>
</tr>
<tr>
<td>Receives assistance in bathing only one part of the body (such as back or a leg)</td>
<td></td>
</tr>
<tr>
<td>Receives assistance in bathing more than one part of the body (or not bathed)</td>
<td></td>
</tr>
</tbody>
</table>

**Dressing**—gets clothes from closets and drawers—including under-clothes, outer garments, and using fasteners (including braces if worn)

<table>
<thead>
<tr>
<th>Description</th>
<th>Dressing Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gets clothes and gets completely dressed without assistance</td>
<td></td>
</tr>
<tr>
<td>Gets clothes and gets dressed without assistance except for assistance in tying shoes</td>
<td></td>
</tr>
<tr>
<td>Receives assistance in getting clothes or in getting dressed, or stays partly or completely undressed</td>
<td></td>
</tr>
</tbody>
</table>

**Toileting**—going to the “toilet room” for bowel and urine elimination; cleaning self after elimination, and arranging clothes

<table>
<thead>
<tr>
<th>Description</th>
<th>Toileting Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goes to the “toilet room,” cleans self, and arranges clothes without assistance (may use object for support such as cane, walker, or wheelchair and may manage night bedpan or commode, emptying same in morning)</td>
<td></td>
</tr>
<tr>
<td>Receives assistance in going to the “toilet room” or in cleaning self or in arranging clothes after elimination or in use of night bedpan or commode</td>
<td></td>
</tr>
<tr>
<td>Doesn’t go to room termed “toilet” for the elimination process</td>
<td></td>
</tr>
</tbody>
</table>

**Transfer**—

<table>
<thead>
<tr>
<th>Description</th>
<th>Transfer Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moves in and out of bed as well as in and out of chair without assistance (may be using object for support such as cane or walker)</td>
<td></td>
</tr>
<tr>
<td>Moves in or out of bed or chair without assistance</td>
<td></td>
</tr>
<tr>
<td>Doesn’t get out of bed</td>
<td></td>
</tr>
</tbody>
</table>
**Continence—**

| Controls urination and bowel movement completely by self | Has occasional “accidents” | Supervision helps keep urine or bowel control; catheter is used, or is incontinent |

**Feeding—**

| Feeds self without assistance | Feeds self except for getting assistance cutting meat or buttering bread | Receives assistance in feeding or is fed partly or completely by using tubes or intravenous fluid |
### LAWTON - BRODY
### INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (I.A.D.L.)

<table>
<thead>
<tr>
<th>A. Ability to Use Telephone</th>
<th>E. Laundry</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Operates telephone on own initiative-looks up and dials numbers, etc.</td>
<td>1. Does personal laundry completely</td>
</tr>
<tr>
<td>2. Dials a few well-known numbers</td>
<td>2. Launders small items-rinses stockings, etc.</td>
</tr>
<tr>
<td>3. Answers telephone but does not dial</td>
<td>3. All laundry must be done by others</td>
</tr>
<tr>
<td>4. Does not use telephone at all</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>B. Shopping</th>
<th>F. Mode of Transportation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Takes care of all shopping needs independently</td>
<td>1. Travels independently on public transportation or drives own car</td>
</tr>
<tr>
<td>2. Shops independently for small purchases</td>
<td>2. Arranges own travel via taxi, but does not otherwise use public transportation</td>
</tr>
<tr>
<td>3. Needs to be accompanied on any shopping trip</td>
<td>3. Travels on public transportation when accompanied by another</td>
</tr>
<tr>
<td>4. Completely unable to shop</td>
<td>4. Travel limited to taxi or automobile with assistance of another</td>
</tr>
<tr>
<td>5. Does not travel at all</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>C. Food Preparation</th>
<th>G. Responsibility for Own Medications</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Plans, prepares and serves adequate meals independently</td>
<td>1. Is responsible for taking medication in correct dosages at correct time</td>
</tr>
<tr>
<td>2. Prepares adequate meals if supplied with ingredients</td>
<td>2. Takes responsibility if medication is prepared in advance in separate dosage</td>
</tr>
<tr>
<td>3. Heats, serves and prepares meals, or prepares meals but does not maintain adequate diet</td>
<td>3. Is not capable of dispensing own medication</td>
</tr>
<tr>
<td>4. Needs to have meals prepared and served</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>D. Housekeeping</th>
<th>H. Ability to Handle Finances</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Maintains house alone or with occasional assistance (e.g., &quot;heavy work domestic help&quot;)</td>
<td>1. Manages financial matters independently</td>
</tr>
<tr>
<td>2. Performs light daily tasks such as dish washing, bed making</td>
<td>(budgets, writes checks, pays rent, bills, goes to bank), collects and keeps track of income</td>
</tr>
<tr>
<td>3. Performs light daily tasks but cannot maintain acceptable level of cleanliness</td>
<td>2. Manages day-to-day purchases, but needs help with banking, major purchases, etc.</td>
</tr>
<tr>
<td>4. Needs help with all home maintenance tasks</td>
<td>3. Incapable of handling money</td>
</tr>
<tr>
<td>5. Does not participate in any housekeeping tasks</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX D

CONSENT FORM

I, ________________________________, agree to participate in a research study entitled "Female Caregivers’ Preferences and Plans for their Own Aging” conducted by Natalie Pope, LMSW from the School of Social Work at the University of Georgia (706-254-7691) under the direction of Dr. Stacey Kolomer, School of Social Work, University of Georgia (706-542-5445). I understand that my participation is voluntary. I can refuse to participate or stop taking part at any time without giving any reason, and without penalty or loss of benefits to which I am otherwise entitled. I can ask to have all of the information about me returned to me, removed from the research records, or destroyed.

Purpose of this Study: I understand that the purpose of this study is to find out how being a caregiver has shaped my beliefs and desires about my own late life needs.

Procedures: If I volunteer to take part in this study, I will be asked to do the following things:
1. Complete a consent form.
2. Participate in an interview with the researcher lasting between 60 to 90 minutes. The interview will involve questions about how I became a caregiver, how being a caregiver affects my perspectives and decision making for my own aging, and my plans for my own aging. I also understand that the researcher may call me to clarify my information on a later date, if needed.
3. Provide feedback on research findings via email.
4. I will be asked permission to be audio taped. If requested, the researcher will stop recording my answers at any time without penalty to me. I also understand that my answers will be transcribed and that the transcriptions will be kept by the researcher indefinitely for research purposes. All transcriptions will use a pseudonym and will not have any individually identifying information. I understand that all audio tapes will be destroyed by January 31, 2010.

___ I consent to have my interview taped.  ___ I would prefer to have the researcher take hand written notes of the interview.

Benefits: The benefit of this study is adding to what is known about caregivers’ experiences, particularly how caregiving affects one’s identity and perception of themselves as an older adult. The direct benefit for me is a chance to share my personal experiences and feelings associated with being an informal caregiver.

Risks: Minimal risk is foreseen from participating in this study. The interview will take 60 to 90 minutes of my time. I also understand that the researcher is a social worker and is required by law to notify adult protective services if she had reason to believe that a disabled adult or elder person is being abused, neglected, or exploited.

Discomforts or Stresses: Minimal discomforts are expected from this study. People may get uncomfortable with discussions about their caregiving experiences. If any questions make me uncomfortable, I can skip the question or stop the interview. The researcher will also assist by suggesting
a change of topic. If needed, the researcher will provide me with information regarding counseling to address any discomforts or stresses.

Confidentiality: The researcher has informed me that all of my individually identifiable information will remain confidential, unless otherwise required by law. My real name will not be used in any study reports. My real name will be replaced with a pseudonym during transcription. I understand that I am 1 of 15 research participants. The master list of research participants will be destroyed by January 2010 at the latest so that the researcher can contact me for participation in the member checking phase of this research. Audio tapes of the interviews will be kept in a secure limited access location until the researcher destroys them. I understand that the research will be made public, but my identity will remain confidential.

Further Questions: The researcher will answer any further questions about the research, now or during the course of the project. The researcher can be reached by telephone at 706-254-7691 or by email at ndpope@uga.edu.

Final Agreement and Consent Form: My signature below indicates that the researcher has answered all of my questions to my satisfaction and that I consent to volunteer for this study. I have been given a copy of this form.

Natalie D. Pope, LMSW  
Name of Researcher  
Signature  
Date  
Telephone: 706-254-7691  
Email: ndpope@uga.edu

Name of Participant  
Signature  
Date

Please sign both copies, keep one and return one to the researcher.

Additional questions or problems regarding your rights as a research participant should be addressed to The Chairperson, Institutional Review Board, University of Georgia, 612 Boyd Graduate Studies Research Center, Athens, Georgia 30602-7411; Telephone (706) 542-3199; E-Mail Address IRB@uga.edu