Spring 2015

Life Interrupted: The Experience of Informal Caregivers of Aging Family Members

Susan Wirka Fox

*University of New Hampshire, Durham*

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LIFE INTERRUPTED:
THE EXPERIENCE OF INFORMAL CAREGIVERS
OF AGING FAMILY MEMBERS

BY

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Bachelor of Science, University of Massachusetts, 1977
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DISSERTATION

Submitted to the University of New Hampshire
in Partial Fulfillment of
the Requirements for the Degree of

Doctor of Philosophy
in
Sociology

May, 2015
LIFE INTERRUPTED:
THE EXPERIENCE OF INFORMAL CAREGIVERS
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The completion of this dissertation and my PhD in Sociology represents the culmination of a lifelong dream. While I thought I would pursue a doctoral degree when I was younger, life took me on a different path. Working at UNH has given me the opportunity to pursue this dream, for which I am eternally grateful. Entering an advanced degree program at the age of fifty was daunting, and the journey was long due to competing work and family demands. However, I am proud to be able to say, now at the age of 60, that you are never too old to pursue your dreams.

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ABSTRACT

LIFE INTERRUPTED: THE EXPERIENCE OF INFORMAL CAREGIVERS
OF AGING FAMILY MEMBERS

by

Susan Fox

University of New Hampshire: May, 2015

While publicly-funded long-term care services have traditionally focused on institutionally-based care, informal family caregivers provide 80% of all long-term care in the US (Thompson 2004). This caregiving is physically and mentally demanding, unpaid, and often performed while the caregiver is balancing work and family responsibilities. With stress process theory (Pearlin 1989) as a guide, this research utilizes a mixed methods approach to study the relationships between the objective demands of caregiving, caregiver burden, and caregiver mental and physical well-being; whether burden mediates these relationships; how caregivers experience the demands of caregiving as stressful; and how they utilize coping strategies to manage these stressors. The study sample consisted of 418 caregiver and care recipient dyads enrolled in the NH Family Caregiver Support Program. Quantitative data were derived from structured social survey data collected on both caregivers and care recipients, first upon entry into the program and again at six months. Qualitative data were derived from semi-structured interviews with 20 caregivers. Findings from the study indicate that burden is significantly related to caregiving well-being and, in fact, mediates the relationship between caregiving demands and caregiver well-being. In addition,
employment is found to be directly related to lower depressive symptoms, and increased age is directly related to lower caregiver burden. Flexible and supportive employers are important in order for caregivers to manage the competing roles of employment and caregiving. Coping strategies utilized by caregivers include efforts to positively frame or change the meaning of the caregiving experience, efforts to change the caregiving situation itself, and seeking and utilizing social supports and resources. Informal, unpaid, family caregivers are the under-recognized cornerstone of the long-term care system in the United States. From both a social and fiscal policy perspective, it is critical that policy makers prioritize supports to these informal, family caregivers.
CHAPTER I

INTRODUCTION: BACKGROUND AND SIGNIFICANCE

Caregiving is a journey experienced by most of us at some point in our lives. Parents are caregivers to their children, and many provide care for extended periods of time to a child with a disability. Many do, or will at some point, provide care for an aging or ailing spouse, parent, relative, or friend. We move in and out of the role of caregiver throughout our lives. While caregiving has been an important subject of research, particularly since the 1980’s, it is particularly salient today. This is due to a convergence of factors including longer life expectancy; the aging of the baby boomers—the largest population cohort in history—and medical advancements that help people live longer but often with chronic, disabling conditions.

While there is a plethora of research on family caregiving, it continues to be an important area of study. The public long-term care system continues to reflect an institutional bias, despite the fact that 80% of long-term care services are provided by informal, family caregivers (Thompson 2004). As our population ages, programs will need to be developed to support an ever growing number of family caregivers. Caregiving is physically and mentally demanding, typically unpaid, and usually performed while the caregiver is balancing other work and family responsibilities. Research that helps to identify factors that contribute to caregiver burden is critical in helping to better understand this phenomena and design public policy and programs to support these families.
IMPORTANCE OF AGING IN SOCIOLOGICAL STUDY

Age has historically been an important concept in sociological study, and it is as salient today as at any point in history. Riley (1987) emphasizes the importance of age in sociological study and argues that utilizing the lens of aging allows us to study the interdependence of aging and social change, from both individualistic and societal perspectives. This seems especially true today as we face an unprecedented aging of the population in the United States, as well as in most developed countries. The United States faces unprecedented growth in the number of older adults in the population over the next 25 years. There has never been as many older adults living as there are today, and this number will only increase. Issues related to the aging of the population and long-term care are becoming more salient as the baby boomers begin to reach retirement age. The first of the almost 77 million baby boomers turned 65 in 2011, and the first baby boomer registered for Social Security on October 15, 2007.

Due to increased longevity and the aging of the baby boomers, the number of individuals aged 65 and older is expected to increase by more than 25%, and the number of the very old (over age 85) is expected to double by 2020. By 2030, one in every five Americans will be over the age of 65, as compared to today where one in eight Americans is over age 65. These demographic changes have been well documented in the literature (Alexxih 2006; Bartels 2004; Kinsella 1995; Kinsella and Velkoff 2001). By 2040, it is projected that 5.5 million people will be in nursing homes, and 11.4 million will be using home care services (Karner 2001).

But the story of the aging of the population is not only about increased numbers. As longevity increases, the average age of the older population will see a dramatic
increase. The number of persons over the age of 85 is expected to increase five-fold by 2040. As the possibility for functional limitations and disability increases with age, the need for long-term, formal and informal, supports is expected to increase as the number of the oldest old increases. In addition, women continue to live longer than men, and, on average, life expectancy for women is three years longer than for men. In 2012, older women (over the age of 65) outnumbered older men as there were 23.4 million older women and 17.9 older men (Administration on Aging). These factors create a complex picture of aging in America which includes a growing population of older adults, a majority of whom will be women, and a growing number of the oldest old who are more likely to require some type of long-term care.

THE BABY BOOMER GENERATION

Baby boomers are just entering “old age” and are redefining our conception of age and aging. Baby boomers are defined as those individuals who were born between January 1, 1946, and December 31, 1964. The 76 million people born in the US during this time period comprise the largest population cohort in the history of the US. In fact, they represent 17 million more people than would have been born if the fertility patterns of the early 1940’s had prevailed (Kingson 1996).

A cohort is defined as a group of people born in the same time interval and aging together (Ryder 1965:844). They experience the same event(s) in the same time interval and share common sociocultural and historical experiences (Karner 2001). As cohorts age, their collective experiences impact structural transformation. Riley (1987:5) notes that “society is composed of successive cohorts of individuals who are themselves aging in new ways and are continually forcing their predecessors into and
out of the roles in the social structure. This flow of cohorts forms the channel that connects the two dynamisms of aging and social change: it ties them both to the forces of history, creates the asynchrony between them, and presses for still further alterations." This is readily apparent when looking at the impact the baby boomer generation has had on society. At each stage this macro-cohort has placed strains on the social institutions they have touched, forcing changes at each stage of their aging, from day care to schools, the job market, housing, health care, etc. (Cornman and Kingson 1996). As baby boomers age, society and the structures that support aging will inevitably change, and attention is now being paid to the structures related to aging as the first of the baby boomers reach retirement age.

Baby boomers are the largest cohort in history, life expectancy is increasing, and baby boomers have fewer children than previous generations (Light 1988). Additionally, many baby boomers are finding themselves at the nexus of caring for aging parents while preparing for their own aging. Many are also still caring for children at home or caring for an adult child with disabilities. These factors will put severe strains on a long-term care system that relies on family caregivers and expensive nursing home care. If changes aren’t made in how long-term care is delivered and financed, it is hard to imagine how the United States will be able to afford the aging of the baby boomers. There has never been a more important time to study issues related to family caregivers of older adults.

THE STRUCTURE OF THE LONG-TERM CARE SYSTEM

Typically “long-term care” has been equated with nursing homes, but this conception of long-term care is changing. For purposes of this research, I am referring
to long-term care as a broad array of supportive medical, personal, and social services needed when a person’s ability to care for themselves is limited due to a chronic illness, disability, or frailty. Long-term care services are for people of all ages and can be provided for a short period of time or for a lifetime. These services can be provided in a variety of settings including the individual’s home, a community residential setting, or an institutional setting such as a nursing home or residential care facility. Services can be provided by formal, paid caregivers such as nurses, certified nursing assistants, and home health aides; by unlicensed paid caregivers such as personal care assistants; and by informal, unpaid caregivers such as spouses, family members, relatives, and friends.

The current structure of long-term care in the United States reflects a variety of values, beliefs, and assumptions and is predicated on the historical, political development of social programs. In recent years there has been strong legal and advocacy support for a shift to a greater emphasis on home and community-based care; however, the current system still reflects a strong medically-oriented, institutional bias. Financing systems for long-term care, particularly Medicare and Medicaid, continue to be predicated on incentives for institutional care with limits and restrictions placed on home and community-based care and sparse funding for caregiver supports.

INFORMAL CAREGIVING

Despite the emphasis on institutionally-based care in the publicly-funded long term care system, the lion’s share of long-term care services are actually provided by informal family caregivers. According to Alecxih (2006), 71% of older adults with disabilities are supported in the community. Of this number, 42% receive unpaid care only, and another 25% receive both paid and unpaid care. Therefore, the majority of
older adults are supported by unpaid caregivers in the community. Moreover, these informal caregivers offset the costs of long-term care services, thus easing the burden on federal and state budgets. In 2004, 28% of nursing home costs and 23% of long-term care costs in general were funded out of pocket, according to the Kaiser Commission Report on Medicaid and the Uninsured. More importantly, 36% of long-term costs were offset by informal caregiving (Lyons, Schneider, and Desmond 2005). NH relies on this informal caregiving network, and it is critical that informal caregivers receive the support they need to care for their family members as long as possible.

Shippee-Rice (2003), in a study of informal support among older adults, reported that, “Families are the primary source of care for older adults” and that care is frequently complex, demanding, and may extend over a long period of time. To maintain this task, families need support if older adults are to remain in communities and not be placed in the institutional long-term care system. The importance of studying informal caregiving and identifying intervention strategies that help support these families is critical. Caregiving impacts all of us, and caregiver supports need to be a core component in any long-term care system.

STRESS PROCESS RESEARCH

Stress process research is critical to any analysis of caregiving and caregiver well-being. According to Pearlin (1989), the stress process consists of three components: stressors, resources, and outcomes. Sources of stress can be single events or an ongoing chronic strain. Resources include personal and social assets, such as coping mechanisms and social support that help to moderate the effects of stressors. Finally, the stress process framework identifies the manifestations of stress,
which can include depression, physical ailments, alcohol and drug use/abuse, or other outcomes, both positive and negative.

Long-term caregiving is considered to be a chronic stressor, and the negative physical and mental health effects of this stress have been well documented (George and Gwyther 1986; Pearlin, Mullan, Semple, and Skaff 1990; Pillemer and Suitor 1996; Skaff and Pearlin 1992; Zarit, Orr, and Zarit 1985; Draper, Poulos, Poulos, and Ehrlich 1996). Coping strategies can help mitigate the stress experienced in the caregiver relationship. Current research suggests that how caregivers adapt to the burdens of caregiving varies considerably and impacts how they perceive caregiver burden (Etters et al. 2008). This study looks at supportive interventions that may help mitigate the impact of caregiver burden and explores the meaning that caregivers place on their caregiving experience in order to help elucidate the coping strategies employed by caregivers.

While caregiving is considered to be a chronic stressor, the outcomes associated with caregiving vary depending on a number of factors such as the age, gender, and employment status of the caregiver; resources and supports available to the caregiver; and caregivers’ perception of the role. The most sophisticated studies of caregiving stressors have shown that stress is an unfolding process dependent on a number of factors (Anshensel, Pearlin, Mullan, Zarit, and Whitlach 1995; Pearlin, Mullen, Semple and Skaff 1990). Studies have documented the relationship between stress and depression as moderated by fundamental statuses such as gender (Pearlin and Schooler 1978; Yee and Schulz 2000), marital status (Feld, Dunkle, and Schroepfer 2004; Litvin, Brody, and Hoffman 1995), education (Pearlin and Schooler 1978;
Hoffman, Lee, and Mendez-Luck 2012), and income (Catalano and Dooley 1977; Papastavrou et al. 2007). A number of researchers have found that the relationship between caregiver and care recipient affects how the caregiver experiences their role and impacts physical and mental health outcomes. This study looks at a number of caregiver characteristics to determine if and how they moderate the relationship between caregiver stress and mental and physical health outcomes.

It is critically important to understand the relationship between the demands of caregiving, caregiver burden, and health outcomes if we are to design programs to address the growing need to support family caregivers as our population ages. Health care and social programs must determine efficacious methods for providing support to these family caregivers. Not only is this important for the quality of care to the individual needing support but for the quality of life and health of the caregiver.

PUBLIC POLICY IMPLICATIONS

The aging demographics present a number of significant social policy issues for New Hampshire and the United States, as well as for the other developed countries in the world. We will face unprecedented demand for long-term care services and funding for health and social programs for older adults over the next 25 years. This crisis may seem distant to some, particularly politicians who are more concerned with the here and now, but it is already upon us. Not only is the baby boomer generation facing old age, but many are currently caregivers for their aging parents.

Much has been written about the retirement of the baby boomers and the impact on Medicare and Social Security. Predictions abound regarding the inevitable bankrupting of the Social Security system and the strain on federal budgets based on
increasing Medicare and Medicaid costs for the elderly, yet little attention has been paid to concerns about the impact on the long-term care system. Van Kleunen and Wilner (2000:115) note that “within the ongoing discussion of how to save Medicare and Social Security, there is an alarming silence about the looming crisis in long-term care.” Caro (2006) agrees that the range of aging policy issues being discussed needs to be broadened to include other areas including long-term care, housing and transportation.

This current study helps to increase our understanding of the impact of long-term caregiving for caregivers and the benefits of supporting informal, unpaid caregivers as part of the long-term care system. Such understanding includes the differential impact of various caregiver and care recipient characteristics, how caregivers may best be supported, and how and why caregivers may require more individualized and personalized approaches to caregiver support.

RESEARCH AIMS

This research project utilizes a mixed methods approach to study the relationships between the objective demands of caregiving, caregiver burden, and caregiver mental and physical well-being; how the nature of these relationships may be conditional on caregiver characteristics; and whether caregiver preferences for supportive interventions are related to caregiver or care recipient characteristics. The study sample consisted of 418 caregiver and care recipient dyads enrolled in the NH Family Caregiver Support Program. Quantitative data were derived from an assessment conducted with both caregivers and care recipients upon entry into the program. Qualitative data were generated from in-depth, semi-structured interviews with 20 caregivers.
The qualitative portion of this study provided an opportunity to include the voice of the caregiver in explaining the complexity of the caregiving experience and the context in which caregiving occurs. Issues that were explored through the qualitative analysis included: how caregivers experience their roles, how they balance other obligations such as work and other caregiving responsibilities, positive and negative feelings towards caregiving, explanations for their feelings about caregiving (i.e. sense of obligation, love, familial responsibility, etc.), and feelings related to caregiving and the transition to the caregiving role (i.e. sense of loss, grieving, role captivity, etc.). These findings help to explain differences found among caregivers in the quantitative data, particularly differences found between spousal and adult child caregivers. Thus, analyses integrated both the quantitative and qualitative data in order to identify relationships among the theoretical constructs of the study and provide a deeper understanding of differences found among caregivers.

The following research questions are assessed:

1. What are the associations among the objective demands of caregiving, caregiver’s subjective appraisal of burden, and physical and mental health outcomes for caregivers of older adults?

2. Do caregiver characteristics have a direct effect on or moderate the relationships among the objective demands of caregiving, caregivers’ subjective appraisal of burden, and physical and mental health outcomes for caregivers of older adults?
3. Is the caregiver’s preference for instrumental or emotion-focused caregiver support interventions related to caregiver or care recipient characteristics?

4. How do meanings ascribed to the caregiving experience help explain how different caregiver statuses; such as kinship, age, and employment, condition whether objective demands of caregiving are perceived as burdensome?
CHAPTER II

LITERATURE REVIEW: INFORMAL FAMILY CAREGIVING FROM A STRESS PROCESS PERSPECTIVE

CAREGIVER PROFILE

Aging occurs in a social context. Our experience of aging is in relation to our social networks of family, friends, and community. These relationships change as we age, and roles are continually redefined as we move through the life course. Caregiving is a role that most of us experience at various points in our lives. Parents are caregivers for their children, and this role is extended well beyond the typical years for some parents with children with disabilities or mental illness who need care into adulthood. Many of us become caregivers for our parents or other relatives as they age and for spouses in later life. Most of us move in and out of the role of caregiver throughout our lives.

Definition of a Caregiver

For purposes of this study, it is important to clarify the definition of caregiver and which caregivers are the subject of this study. In recent years, the Center for Disease Control’s Behavioral Risk Factor Surveillance System (BRFSS), a state-based system of health surveys that collects information on health risk behaviors, preventive health practices, and health care access primarily related to chronic disease and injury, added a caregiver module. In this module, caregiver is defined as a person who provides
“regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability” (http://www.cdc.gov/brfss). In the National Alliance for Caregiving’s (NAC) 2009 report, “Caregiving in the United States,” caregivers are defined as those who provide unpaid care to an adult or a child with special needs. Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. Caregivers may or may not live with the care recipient.

What each of these definitions has in common is the notion that caregivers are unpaid relatives or friends who are caring for a child or adult who experiences a chronic illness or disability and requires assistance with everyday activities such as personal care, household chores, or other daily supports. This study focuses on unpaid, family caregivers of persons over the age of 60 who need assistance with activities of daily living in order to remain living in the community.

The Family Caregiver Alliance (FCA) issued a 2009 National Policy Statement which describes the prevalence of informal family caregiving today. The FCA estimates that more than 65 million Americans provide informal care to family and friends who, due to a disability or chronic illness, are unable to carry out basic daily activities such as personal hygiene, meal preparation, medication management, and basic household tasks.

Mack, Thompson, and Friedland (2005) published a data profile of family caregivers of older adults, utilizing data from the 1999, 1989, and 1984 National Long Term Care Survey and its Informal Caregivers Supplement. They report that the majority of caregivers of older adults are spouses and adult children. While more adult
children are providing care than a decade ago, spouses continue to provide more hours of care per week. They also found that, while women are still more likely to be the primary caregiver, the number of men taking on this caregiver role has increased. They found that primary caregivers are likely to live with the care recipient, and caregivers who live with their care recipient report higher levels of caregiver stress. About one third of caregivers are employed, and the majority of these are employed full time. Despite their work schedule, employed caregivers provide an average of 17 hours of care per week.

The NAC provides a profile of caregivers in the United States in their 2009 report, “Caregiving in the United States.” Some key findings about caregivers from this report include:

- More than 65 million people, 29% of the U.S. population, provide care for a chronically ill, disabled, or aged family member or friend during any given year and spend an average of 20 hours per week providing care for their loved one.

- The typical family caregiver is a 49-year-old woman caring for her widowed 69-year-old mother who does not live with her. She is married and employed. Approximately 66% of family caregivers are women. More than 37% have children or grandchildren under 18 years old living with them.

- 20 hours per week is the average number of hours family caregivers spend caring for their loved ones, while 13% of family caregivers are providing 40 hours of care a week or more.

- 51% of care recipients live in their own home, 29% live with their family caregiver, and 4% live in nursing homes and assisted living.

- 36% of family caregivers care for a parent, and seven out of 10 caregivers are caring for loved ones over 50 years old.
The demographic data collected in this current study allows for a comparison of the caregivers in this sample to the population of caregivers in the United States, as described above.

A Snapshot of New Hampshire Caregivers

A number of studies have been completed in the past few years that help to describe the characteristics of New Hampshire caregivers. Findings from a 2006 survey of family respite applicants, conducted by the NH Bureau of Elderly and Adult Services, indicated that:

- Caregivers spend an average 135 hours per week providing care;
- 78% experienced stress from their caregiving;
- 54% were alone in providing care and had no one to help;
- 54% were experiencing poor health as a result of providing care; and
- 40% either quit their jobs, reduce their hours at work, or use up leave time to provide care.

In 2009, a series of questions related to caregiving were included in the Granite State Poll (GSP) to provide New Hampshire with a description of the state’s caregivers and the types of care given. The GSP is a quarterly survey conducted by the UNH Survey Center of New Hampshire adults with a working phone. The GSP gathers 500 responses each quarter, thereby compiling a representative sample of over 2000 NH residents per year. The GSP is an omnibus survey that allows for targeted questions to be added to the general questions asked each quarter. The caregiver questions that were included came from the Centers for Disease Control and Prevention (CDC) caregiver module, which was added to the Behavioral Risk Factor Surveillance Survey.
(BRFSS) in 2009. The BRFSS is a state-based system of health surveys that collects information on health risk behaviors, preventive health practices, and health care access primarily related to chronic disease and injury. It is conducted each year within all 50 states. The CDC developed the caregiver module because research demonstrated that caregivers “neglect their own health, (do) not obtain preventive care, and (do) not get well when sick” (http://www.cdc.gov/brfss).

As part of the 2009 GSP, 2,182 New Hampshire adults were surveyed and asked if they had provided care in the last month to a friend or family member who has a health problem, long-term illness, or disability. Almost 30% of those surveyed indicated that they had provided such assistance. If we extrapolate this percentage to the entire NH population over the age of 18, it can be estimated that as many as 308,771 adults in New Hampshire provide some type of care to a friend or family member who has a health problem, long-term illness, or disability (based on 2010 US Census figures for NH adults over the age of 18). AARP, in their 2009 policy brief on Long-Term Care in NH, estimated that 147,000 NH residents provide family caregiving to a loved one at home. While these studies define caregiving differently and thus arrive at vastly differing estimates, they do indicate a large number of family caregivers in NH. The 418 caregivers in this current study are a small sub-sample of these caregivers and are caregivers who sought out and received caregiver support services. The fact that they sought services may make them a particularly unique sub-sample of the overall population of caregivers, but I argue that they are an important sub-sample in terms of program development and public policy considerations.
The GSP provides a snapshot of caregivers in New Hampshire which allows us to compare NH caregivers to the national caregiver samples described earlier as well as to the sub-group who participated in this research study. Based on the GSP survey results, NH caregivers are predominately female and over the age of 50. Care recipients are also predominately female and over the age of 55. Caregivers are spread across all income brackets with 16% reporting annual household incomes below $30,000; 25% between $30,000 to $59,999; 14% each between $60,000 to $74,999 and $75,000 to $99,999; and 30% over $100,000. The majority of respondents (59%) had been providing care for one year or longer. Respondents reported providing an average of 13 hours of care per week, with a range from less than five hours (28%) to more than 41 hours (14%). The most common caregiving arrangement reported is taking care of a parent, with one third of respondents falling into this category. Other arrangements include caring for a non-relative (19%), a child (10%), a parent-in-law (10%), a spouse (9%), and other relative (10%). These caregivers report that they provide assistance in taking care of the residence (68%), providing personal care (34%), and "learning and remembering" (27%). These findings provide important benchmarks to compare the caregivers in this study with caregivers in the general NH population.

The Caregiver Career

From a life course perspective, caregiving is a role that people move in and out of throughout their lives. Many of us enter the caregiving role with the birth of a child, and for some this caregiving experience is extended into adulthood if the child is born with, or acquires, a lifelong disability. In later life, many of us re-enter the role of caregiver when a spouse or parent requires caregiving support due to age or chronic
illness. Caregiving for an older adult can last for an extended period of time, the average length of time spent caregiving being five to seven years (Quadagno 2008).

The caregiving career has been defined by Pearlin (1992) and Pearlin and Aneshensel (1994) as comprised of three stages, as well as the transitions between these stages. These stages are: preparing for and moving into the role of caregiver, performing the care-related tasks and responsibilities, and disengaging from the caregiving role (Aneshensel, Pearlin, Mullan, Zarit, and Whitlatch 1995). When this model of caregiving careers was first conceptualized, it was presumed that the third stage of disengagement entailed institutional placement of the care recipient in many cases. With the advent of more extensive caregiver supports and hospice programs, more older adults are able to remain living in the community. This does not negate the validity of this third stage, but it likely alters how caregivers experience it.

Despite common belief that many older adults live far from family and that children no longer provide care to their aging parents, older adults who need assistance generally have at least one family member who provides them with some level of support (Johnson and Catalano 1983). Approximately 78 - 80% of all care provided at home is provided by family and friends (Thompson 2004). It is most commonly provided by adult children, followed by a spouse (Quadagno 2008). Women make up the majority of caregivers, specifically wives and daughters (Brody 1981; Johnson and Catalano 1983), although many husbands and adult sons do provide care. While some research studies have included the experiences of husbands as caregivers, few were found to include sons as caregivers.
The type of support provided, however, often varies depending on the familial relationship and other responsibilities. Daughters provide more hours of care than sons and tend to provide more hands-on personal care, while sons provide more help with house repairs, yard work, and managing finances (Chang and White-Means 1991). This is not true when comparing the care provided by husbands and wives. While more women provide care for their husbands, men do provide care for their wives and tend to provide more hours of care as compared to women (Chang and White-Means 1991). Spouses often provide the most intensive level of care, but may have their own age-related physical, mental, or social limitations. Support provided by adult children varies, depending on the situation of the adult child and their other commitments, such as living arrangement, work, and family.

*The Costs of Caregiving*

Caregiving exacts physical, emotional, and financial tolls on caregivers. Caregivers are the backbone of the long-term care system, and the economic contribution of this care to the system is significant. The Family Caregiver Alliance (FCA) estimates that approximately 37.1 billion hours of care are provided by informal caregivers of older adults each year. The value of these family caregiver services is estimated to be $375 billion a year, almost twice as much as is actually spent on homecare and nursing home services combined ($158 billion) (Evercare 2009; Feinberg et al. 2011).

In 2004, 28% of nursing home costs and 23% of long-term care costs in general were funded out of pocket, according to the Kaiser Commission Report on Medicaid and the Uninsured. More importantly, 36% of long-term costs were offset by informal
caregiving (Lyons, Schneider, and Desmond 2005). Family caregivers are the foundation of long-term care nationwide, exceeding Medicaid long-term care spending in all states (Evercare 2009).

There is a very real financial cost to caregivers who leave the workforce, or cut back on hours, in order to care for ailing family members. The economic cost to individual caregivers is estimated at $659,139 over a lifetime, which includes $25,494 in lost Social Security benefits, $67,202 in lost pension benefits, and $566,443 in lost wages. In addition, it is estimated that caregivers spend an average of $5,531 a year on caregiving expenses (Houser and Gibson 2008).

It is also important to consider the economic situation of older adults living in the community to understand the impact on the long-term care system. As Medicaid is the only funder of long-term nursing home services, once an individual’s private funds are exhausted, it is important to support persons of low and moderate income to remain home as long as possible and delay nursing home placement. Lyons, Schneider and Desmond (2005) found that 57% of older adults living in the community had assets under $5000, and 33% had sufficient assets to pay for only one year of nursing home care. Extrapolating these findings to NH’s population over the age of 65, it is estimated that almost 84,000 older adults would be unable to afford more than one month of nursing home care, and over 49,000 would spend down to Medicaid within a year of nursing home placement. These numbers underscore the importance of assuring that family caregivers are supported to continue to provide this critical component of the long-term care system, if states hope to delay nursing home placement and avoid increased Medicaid costs.
STRESS PROCESS RESEARCH

Stress process theory is critical to any analysis of caregiving and caregiver well-being and has been widely used in caregiving research. Pearlin (1989) describes the stress process as combining three major conceptual domains: the exposure to sources of stress and the meaning attached to these stressors; the moderators of stress; and the psychological, physical, and behavioral manifestations of stress. Sources of stress can be single events or an ongoing chronic strain. A single event may be any traumatic experience such as divorce, death of a loved one, loss of a job, etc. Ongoing chronic strains may be considered to be long term strains such as caregiving, extended unemployment, or poverty. Typically, in stress process research, two resources to help moderate the effect of stress are identified: social supports and coping. Social supports refer to the network of people and organizations available for support. Coping refers to the internal mechanisms available to a person to control and manage stress. Much sociological research has focused on these resources, and all have been found to buffer the effects of stress (Thoits 1995; Pearlin 1989; Pearlin and Schooler 1978). Finally, stress process theory identifies the manifestations of stress including a variety of psychological, physical, and behavioral outcomes.

Aneshensel et al. (1995:35) note that “The conceptual framework of the stress process is particularly useful in capturing the dynamic features of problematic life experience, caregiving being an excellent case in point.” Early studies of caregiver stress utilized a simple process model showing the relationship between caregiver stress or burden and health outcomes. Caregiving in and of itself was considered a chronic stressor and was studied in its relationship to outcomes such as depression and
physical health. This was eventually found to be a much too simplistic approach to studying the stress process, and one of the most enduring findings in caregiver research is that stressors have a surprisingly modest association with outcomes (Zarit 2005).

Caregiving as a chronic stressor has been widely studied. Numerous studies have documented the high levels of emotional and economic strain experienced by caregivers, leading to negative effects on physical and mental well-being (George and Gwyther 1986; Pearlin, Mullan, Semple, and Skaff 1990; Pillemer and Suitor 1996; Skaff and Pearlin 1992; Zarit, Orr, and Zarit 1985; Casserta, Lund and Wright 1996; Evans, Bishop and Ousley 1992; Kiecolt-Glaser et al. 1991; Mittelman et al. 1996; Sisk 2000). In one study of caregivers for older adults with cognitive or physical impairments, deFrias, Tuokko, and Rosenberg (2005) found that older caregivers and those with health problems of their own were at increased risk of negative mental health outcomes and depressive symptomatology. They also found that the caregiving experience is influenced by the health of both the caregiver and care recipient, and they suggest that caregiving research should focus on the characteristics and well-being of both parties in the caregiving dyad.

Caregiving is a complex process, and we see caregivers responding differently to similar stressors. While caregiving is considered to be a chronic stressor, the outcomes associated with caregiving vary depending on a number of factors such as the age, gender, and employment status of the caregiver; resources and supports available to the caregiver; and caregivers’ perception of the role. The most sophisticated studies of caregiving stressors have shown that stress is an unfolding process dependent on a
number of factors (Aneshensel, Pearlin, Mullan, Zarit, and Whitlach 1995; Pearlin, Mullen, Semple and Skaff 1990). As an example, Malone-Beach, Zarit, and Farbman (1995) found varying levels of distress in their study of 43 caregivers of older adults with dementia. While some caregivers in their study were highly distressed, others reported moderate or no levels of distress due to their caregiving responsibilities.

An important variable in any study of caregiver stress is the subjective appraisal of the situation by the caregiver. How caregivers perceive their situation impacting their life shapes their response and ultimately the outcomes they experience. In other words, two caregivers could experience the same behavior problem, same disease, same events; yet their response to those events could be very different, based on how they perceive those events and the resources available to them to cope with those events.

Depressive symptoms are one of the most commonly studied manifestations of stress, but researchers caution against focusing on a single outcome. Early studies of the stress process posited that women were more susceptible to caregiver stress and negative outcomes than men. Aneshensel, Rutter, and Lachenbruch (1991) demonstrated that women and men are equally susceptible to stress but may experience different outcomes as a result of this stress. They found that women exhibit more depressive symptoms than men as a result of exposure to stress, and men experience more drug and alcohol abuse. This study considered a variety of caregiver characteristics and resources available to the caregiver, as well as the caregiver's subjective appraisal of the caregiving experience in relation to caregiver physical and mental health outcomes.
Objective Demands of Caregiving: Care Recipient Functional Status

My study considers objective measures of caregiver demands and their relationship to caregivers’ subjective perceptions of burden and caregiver outcomes. Objective measures of caregiver demands include measures of the mental and physical functioning of the care recipient. These measures include the level of physical care required by the care receiver as measured by assessments of Activities of Daily Living; the level of cognitive impairment of the care receiver; and the frequency of problem behaviors related to memory, depression, and disruption.

Many studies of caregiver stress have focused on a particular population of care recipient, the most common being caregivers of persons with Alzheimer's Disease and related disorders (Schulz, et al. 1995; George and Gwyther 1986; Pillemer and Suitor 1996; Skaff, Pearlin, and Mullan 1996; Morrisey, Becker, and Rupert 1990; Malone-Beach, Zarit, and Farbman 1995; Etters, Goodall, and Harrison 2008). Other studies have focused on caregivers of persons with Parkinson Disease (Martinez-Martin et al. 2008); elderly parents caring for adult children with developmental disabilities (Seltzer, Greenberg, Floyd, Pettee, and Hong 2001; Seltzer, Krauss, Choi, and Hong 1996; Seltzer and Krauss 1989; Hayden and Heller 1997); parents of adult children with mental illness (Seltzer, Greenberg, and Krauss 1995); and caregivers of persons with AIDS (Pearlin, Aneshensel, and LeBlanc 1997; Turner, Pearlin, and Mullen 1998), heart disease (Schulz, et al. 1995), and other chronic conditions. Although most studies have primarily focused on caring for persons with a specific diagnosis such as dementia, stroke, cancer, or Parkinson’s disease, more research is being conducted with heterogeneous groups of caregivers. This current study does not focus on a specific
disease or condition but includes caregivers caring for a person over the age of 60 who has a need for functional support, regardless of diagnosis.

Many researchers have proposed that behavioral problems exhibited by the care recipient are a strong predictor of caregiver burden (Gallicchio et al. 2002; Gaugler et al. 2007; Savundranaygam, Hummert, and Montgomery 2005; Chappell and Reid 2002). Ankri, et al. (2005) found a significant relationship between caregiver burden and severity of the care recipient’s dementia. Etters et al. (2008) completed a comprehensive review of literature related to caregiver burden and dementia. Their review found that the research indicates that behaviors that are perceived as problematic to the caregiver are greater predictors of caregiver burden than cognitive or physical limitations. The assumption is that behaviors such as wandering, incontinence, behavioral outbursts, aggressive behaviors, and agitation create greater stress for the caregiver and result in higher levels of perceived burden. They also reported that most studies found either no or weak relationships between caregiver burden and the care recipient’s cognitive abilities (Annerstedt et al. 2000; Gonyea et al. 2005; Rinaldi et al. 2005).

The functional status of the care recipient, both physical and behavioral, is often used as an indicator of caregiver strain. The concept is that the greater the care recipient’s functional and behavioral needs are, the higher the demands that are placed on the caregiver, resulting in higher levels of burden. Researchers have studied a range of care recipient factors in relation to caregiver burden with mixed findings. Many argue that behavior problems and how the caregiver perceives those problems are the most predictive factors of caregiver burden (Clyburn et al. 2000; Annerstedt et al. 2000).
Schulz et al. (1995) in their review of the dementia caregiving literature, found that care recipient behavior problems were the only care recipient characteristic that was consistently linked with poor physical and mental health outcomes for caregivers. They also found that cognitive impairment was consistently linked with poor physical health of the caregiver. Similarly, Suk-Young Kang (2008) found that the care recipient’s disruptive behavior was predictive of caregiver emotional strain, but that the care recipient’s level of cognitive impairment was not a predictive factor. In addition, Goode et al. (1998) found that changes in the care recipient’s functional status did not directly predict changes in the caregiver’s physical or mental health status over time.

Several researchers have found that problematic behaviors exhibited by persons with dementia are related to caregiver burden and mental health well-being (Clyburn et al. 2000; Bertrand et al. 2006; Papastavrou et al. 2007) as well as poor health outcomes for the caregiver (Son et al. 2007). Similarly, Schulz et al. (1995), found in their comprehensive literature review that few care recipient characteristics, other than behavior problems, are consistently related to caregiver outcomes. Connell, Janevic, and Gallant (2001), in their review of the literature on dementia caregiving, reported that behavioral problems, not cognitive functioning, are related to caregiver outcomes. They also noted that this relationship is mediated by how the caregiver perceives the burden resulting from the care recipient’s cognitive and behavioral problems. This current study includes measures of the care recipient’s mental and functional abilities as well as a measure of the caregiver’s perception of how problematic these behaviors are to them. As noted earlier, this allows for an analysis of the relationship among the objective
demands of caregiving, the caregiver’s subjective appraisal of burden, and caregiver outcomes.

**Caregiver Burden**

Family members provide 80% of all long-term care in the US (MetLife Mature Market Institute 2001). This caregiving is physically and mentally demanding, unpaid, and usually performed while the caregiver is balancing work and family responsibilities. The concept of caregiver burden has been the subject of numerous studies and has been defined as “physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults” (George and Gwyther 1986:253). Caregiver burden typically refers to the addition of tasks and worries that caregiving can trigger. In addition, the caregiver may experience a feeling of role captivity, the loss of one’s familiar routine, financial strains, and physical ailments, all of which can add to the caregiver’s sense of burden.

The literature on caregiving uses the terms “caregiver stress,” “caregiver burden,” and “caregiver strain,” and the differences between these terms are sometimes difficult to discern. While these terms are inter-related, for purposes of this study, I make the following distinction in relation to caregiver burden. Caregiving places specific demands on a caregiver. These demands place stress or strain on the caregiver which, if they continue over an extended period of time, can be considered chronic. Caregiver burden refers to how the caregiver experiences the chronic stress of being a caregiver. That is, how burdened they feel as a result of the strain that caregiving places on them. As such, caregiver burden reflects subjective appraisals of caregiving demands.
Researchers have noted that it is often a caregiver’s subjective appraisal or perception of caregiver burden that has the greatest association with caregiver strain or burnout, rather than any objective assessment of the care recipient’s functioning (Zarit, Todd, and Zarit 1986). Caregiver burden has been defined as “a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience” (Kasuya, Polgar-Bailey, and Takeuchi 2000:119). Research also indicates that persistent burden, lasting over a period of time, is predictive of higher depressive symptomology (Epstein-Lubow et al. 2008). The concept of persistent burden is particularly important in considering caregiving as a long-term chronic stressor. Thus, measures of caregiver burden are critical to any study of caregiver stress and well-being.

The importance of subjective appraisals of the stress experienced by caregivers was assessed by J. Son et al. (2007) in a study of 234 caregivers of older adults with dementia who were living in the community. Caregivers’ subjective feelings of burden were assessed along with a more objective measure of care recipients’ behavior problems. The study looked at the impact of these variables across three dimensions of caregiver health: self-reported health, health behaviors, and use of health care services. They found that both caregiver-perceived burden and care-recipient behavior problems were related to poorer self-reported health, more negative health behaviors, and greater use of health services. They also found that the relationship between care recipient behavior problems and health was mediated by the level of burden perceived by the caregiver. This study underscores the importance of alleviating the subjective burden of caregiving in order to mitigate negative health outcomes for caregivers.
Caregiver well-being is another concept that is typically used in relation to caregiver burden and outcomes. Caregiver well-being is typically defined in terms of a range of dimensions including the caregiver’s ability to function and carry out activities of daily living, physical health, mental health, social resources, and financial resources (George and Bearon 1980; Duke Center for the Study of Aging 2012; Berg-Weger, Rubio, Tebb 2000). While early research suggested that caregiver burden and well-being were essentially opposite sides of the same coin (Montgomery 1989), other researchers have considered them as distinct concepts. Chappell and Reid (2002) found support for the concept that burden and well-being are distinct concepts in their research that found that caregivers’ well-being can be positively impacted even with high levels of reported burden.

Coping Strategies

Current research suggests that how caregivers adapt to the burdens of caregiving varies considerably and impacts how they perceive caregiver burden (Etters et al. 2008). The ability to accommodate or adapt to the caregiving role is very important in looking at outcomes for caregivers. Pearlin and Schooler (1978) identify both efforts to change the meaning of the stressful situation and efforts to manage or change the situation as coping mechanisms within stress process theory. These coping strategies help mitigate the stress experienced in the caregiving relationship.

Supportive interventions/services are important resources in helping caregivers cope with their caregiving responsibilities. The types of supports that are requested/needed by caregivers fall in a range of social supports. House (1981) distinguishes among four types of social supports: emotional, instrumental,
informational, and appraisal. Emotional support involves the provision of empathy, trust, and caring and includes services such as support groups and counseling. Instrumental support refers to tangible aid and services that directly assist the caregiver or care recipient and can include in-home services, adaptive equipment, respite care, etc. Informational support refers to advice, suggestions, and information that a caregiver can use to address their needs. Appraisal support involves the assessment of caregiver and care recipients needs in order to develop a plan of action to meet those needs. This study will look at the types of supports that are preferred by caregivers and if this varies by caregiver gender, age, or relationship to care recipient.

Alternately, Lazarus and Folkman (1984) group the coping processes used by caregivers into emotion-focused and problem-focused strategies. Problem-focused strategies are active approaches to managing the situation and addressing problems and can include accessing services, respite care, education, and other tangible supports. Emotion-focused strategies refer to actions that relieve the emotional impact of the situation and can include support groups and counseling. Caregivers have been found to use both problem solving and emotion-focused strategies in coping with burden. Problem-focused coping skills include active coping, planning, positive reinterpretation and growth, and suppression of competing activities. These skills allow a person to change the stressful situation and derive meaning from it. They help a person to exert mastery and control over the situation which is very important to moderate the outcomes of stress (Pearlin 1989). Emotion-focused coping skills include a focus on and venting of emotion, denial, behavioral disengagement, and mental
disengagement to moderate stress. These types of coping skills are considered to be less positive.

Numerous studies have found that caregivers who use problem solving strategies felt less burdened and experienced more positive outcomes (Almberg, Grafstrom, and Winblad 1997; Papastavrou et al. 2007) while emotion-focused strategies are connected with poorer mental health outcomes (Vitaliano et al. 1991; Pruchno and Kleban 1993). Emotion-focused strategies include approaches such as worrying, self-blame, guilt, etc. Problem-focused strategies include actions such as seeking information and services, seeking social support, and actively addressing the problems faced.

Many studies have looked at whether caregiver characteristics are related to the types of coping mechanisms employed or services utilized. Suk-Young Kang (2008) found that adult child caregivers of older adults found the availability of respite care more beneficial in relieving emotional strain than did spousal caregivers. Cantor (1983) found that children and younger relatives who are caregivers often have multiple role demands and expressed the greatest need for assistance, such as information on community resources, in-home services, and other social services.

Support from a network of family and friends has been identified as an important coping mechanism to moderate the impact of caregiver burden. Caregivers with strong support networks of family and friends are less likely to turn to the formal service system and are able to delay seeking services. Caregivers with limited networks are at the highest risk for looking to institutional care when informal and formal community supports are not available. Several studies have found that older adults without support
networks are at the highest risk for institutionalization (Weissert, Chernew, and Hirth 2003; Biegel and Blum 1990). Similarly, Clyburn et al. (2000) found that caregivers with lower levels of informal support experienced higher levels of perceived burden. Chappell and Reid (2002) considered caregiver burden and caregiver well-being as distinct concepts and studied their relationship to informal, social supports. They found that the level of social support was positively associated with caregiver well-being but did not impact caregiver burden. Thus, caregivers who have a high level of social support can still experience high levels of caregiver burden while maintaining positive health and well-being.

Many studies have shown the importance of providing effective intervention supports to caregivers in order to decrease caregiver burden, increase resiliency, and decrease negative physical and mental health outcomes (deFrias et al. 2004; Mittelman 2006). These studies note that respite care is seen as one of the critical supports to provide a break to caregivers. While caregivers need support and a break from their caregiving role, they are often reluctant to ask for assistance. While services are available, practitioners often report that caregivers are reluctant to ask for help. Van Exel et al. (2008) found, in a study of 273 Dutch informal caregivers, that a large proportion of caregivers need support and respite care, but few ask for assistance.

The long-term care system relies on this network of informal caregivers, and it is critical that informal caregivers receive the support they need to care for their family members as long as possible. Shippee-Rice (2003), in a study of informal support among elders, reported that, “Families are the primary source of care for older adults” and that care is frequently complex and demanding and may extend over a long period.
of time. To maintain this task, families need support if older adults are to remain in communities and not be placed in the institutional long-term care system. Caregivers with strong support networks from family and friends are less likely to turn to the formal service system or, at least, may delay turning to the formal service system. Caregivers with limited networks are at the highest risk for looking to institutional care when informal and formal community supports are not available. Older adults without support networks are at the highest risk for institutionalization (Weissert, Chernew, and Hirth 2003; Biegel and Blum 1988).

**Caregiver Outcomes**

Much research has focused on the negative outcomes of caregiver burden and the coping skills utilized by caregivers. There is little debate in the research that caregiving places a burden on the caregiver, and a large percentage of caregivers are highly burdened. Papastavrou et al. (2007), in their study of 172 caregiver/care recipient dyads in Greece, found that 68% of the caregivers caring for family members with dementia were highly burdened, and 65% exhibited depressive symptoms. They found that burden was related to care recipient functioning as well as caregiver gender, income, and education. Many studies have shown that the level of perceived burden has an impact on the health behavior of the caregiver. Sisk (2000), in a study of 121 caregivers, found that caregivers who perceived lower levels of burden practiced more positive health behavior. Those with high levels of perceived burden were less likely to seek routine care for themselves.

A large study, utilizing population data from the 2000 national Behavioral Risk Factor Surveillance System, found that caregivers have poorer health related outcomes
than non-caregivers (Neugaard et al. 2008). This study measured both physical and mental health related quality of life from a national sample of 184,450 adults. They also found that younger caregivers experienced health related declines more than older caregivers. George and Gwyther (1986) found that caregivers were similar to other community populations in relation to physical health outcomes. They did find, however, that caregivers were significantly more likely to experience negative outcomes related to mental health and social participation.

Most studies on caregiver stress have focused on the psychological outcomes of caregiving burden; however, a number have looked at physical health outcomes as well. It has been reported that caregivers report poorer physical health than non-caregivers (Pruchno and Potashnik 1989). Pinquart and Sorensen (2007) conducted a meta-analysis of 176 studies that address caregiver physical health outcomes. They found a number of factors that impact caregivers’ physical health, including higher age, lower socioeconomic status, gender, care recipient behavior problems, and level of informal, social support.

While most studies have focused on the negative outcomes of caregiving, others have stressed the importance of assessing both the positive and negative aspects of caregiving (Nijboer et al. 2000). Many caregivers indicate feelings of increased self-esteem, closer bonds with their family member, a sense of purpose, a sense of family responsibility/reciprocity, and personal growth. Lopez et al. (2005) found high levels of satisfaction among the 111 informal caregivers in their study. They found that satisfaction was more related to characteristics of the caregiver rather than the stressors of the situation. Caregiver satisfaction was related to positive previous
relationships between the caregiver and care recipient, caregiver’s feeling that they had chosen to provide care, caregiver taking time for themselves, less venting of emotions, and not working outside the home.

Noonan and Tennstedt (1996) conducted a qualitative study that involved interviews of 48 informal caregivers of older adults who were participating in the Massachusetts Elder Health Project. They identified a number of themes of caregiver meaning including satisfaction with the role, a sense of family responsibility/reciprocity, the friendship and company provided, and a sense of commitment. They concluded that caregiving meaning has both a cognitive and an emotional dimension, or, put another way, caregivers both search for meaning and find meaning in the caregiving role. The caregiving role is complex and demanding, and researchers must utilize a variety of methods to capture the complexity of the experience to truly understand it.

FACTORS THAT MAY IMPACT CAREGIVER OUTCOMES

Research on caregiver outcomes has focused primarily on the negative outcomes of long-term caregiving, although positive outcomes have been noted. Additionally, the impact of caregiving is not consistent across caregivers. Etters et al. (2008), in their meta-analysis of the caregiver literature, found that current research suggests that how caregivers adapt to the burdens of caregiving varies considerably. There are a variety of factors that have been found to be related to how caregivers perceive and cope with the stressors of caregiving and the outcomes they experience. These include, but are not limited to: gender, age, caregiver relationship, living arrangements, amount of formal and informal support available, caregiver health, social participation, length of time caregiving, and care recipient characteristics. Various
studies have looked at each of these factors with varying conclusions in terms of their impact on caregiver outcomes. Studies of general populations have documented the relationship between stress and depression as moderated by fundamental statuses such as gender (Pearlin and Schooler 1978; Yee and Schulz 2000), marital status (Feld, Dunkle, and Schroepfer 2004), education (Pearlin and Schooler 1978; Hoffman, Lee, and Mendez-Luck 2012), and income (Catalano and Dooley 1977; Papastavrou et al. 2007).

Prior research has identified multiple risk factors for caregiver burden and negative health and mental health outcomes. Draper, Poulos, Poulos, and Ehrlich (1996), in their study of caregivers for older adults with dementia or stroke, found risk factors for higher levels of perceived caregiver burden, and mental health problems included: the quality of the relationship between the caregiver and care recipient, being a spouse, being new to the caregiver role, and greater physical or behavioral health needs of the care recipient. Behavior problems in the care recipient and a lack of informal support have also been identified as increasing the risk for depressive symptoms (Clyburn, Stones, Hadjistavropoulos, Tuokko 2000). Papastravrou et al. (2007), in their study of 172 caregiving dyads in Greece, found that caregiver burden was related to caregiver sex, income, and level of education. It is important that any study of caregiver burden include an analysis of these various factors related to caregiver characteristics.

The health of the caregiver has also been found to be correlated to caregiver burden. In a national survey conducted by the National Alliance for Caregiving and AARP, 17% of all caregivers surveyed reported that their health was fair or poor. Of
those reporting fair or poor health, 35% reported that they do the most intense caregiving, and 34% reported that caregiving had made their health worse (Evercare 2006). These caregivers identified stress as the most pervasive health problem in their lives and that they lack the time to take care of their own health needs. In another study of caregivers, researchers found that caregivers with poorer health were more likely to suffer negative outcomes from caregiving. DeFrias, Tuokko, and Rosenberg (2005) found, in their study of 133 family caregivers of older adults, that those caregivers who reported health problems also reported poorer mental health and greater depressive symptomatology.

Robinson (1983) surveyed a sample of 85 spouses, family, friends, and neighbors, aged 22 to 83, who provided varying degrees of care to individuals post-hospitalization in order to validate a Caregiver Strain Index (CSI). She found few factors that were significantly correlated to caregiver strain, except employment. Her findings suggest that younger caregivers who have competing demands, such as jobs, may experience greater strain than other caregivers.

In summary, caregiver characteristics are an important variable in any study of caregiver burden and well-being. This current study considers a range of caregiver factors including age, gender, relationship to the care recipient, employment, other caregiving responsibilities, and living arrangement and how they impact the relationship among the demands of caregiving and caregiver burden and well-being.

Gender

The literature suggests that certain types of caregivers are apt to experience more strain than others. As the majority of caregivers are women, gender differences in
the stress process have been the focus of many studies. Not only are women more likely to be the primary caregivers, they are also more likely to be providing more extensive care than men and would, as such, be expected to experience more strain. A number of studies have indicated that female caregivers do experience more psychological distress as a result of caregiving than men. However, as noted earlier, Aneshensel et al. (1991) found that a focus on depression as a sole outcome in these studies is problematic and can result in gender bias in the findings. Research findings related to gender and caregiver burden are mixed.

Etters et al. (2008), in their comprehensive literature review of caregiver burden and dementia, reported mixed results on the relationship between gender and caregiver burden. They noted that several studies found that female caregivers report more physical and mental health symptoms than male caregivers, while other studies found no differences. Zarit, Todd, and Zarit (1986), in an early study comparing the caregiving experience of spouses, found that wives reported greater burden than husbands, although both groups reported similar levels of burden at a two-year follow-up.

Many researchers have not found gender differences in their studies of caregiver outcomes (Chumbler et al. 2003; Robinson 1983; Taylor et al. 2008). While research suggests that both male and female caregivers experience caregiver burden and exhibit negative outcomes as a result, gender differences have been found in how caregiver burden is experienced. In a study comparing 52 caregivers and 66 non-caregivers in Stockholm, Almberg et al. (1998) found that female caregivers experienced more strain than male caregivers and female or male non-caregivers. They also found that male and female caregivers experienced this strain differently. Male caregivers reported a
lack of positive outlook and a need for social support, while female caregivers reported
greater difficulty in their relationships with other family members and increased health
problems.

*Caregiver Employment*

Little research focused on employment as a factor related to burden for
caregivers of older adults, prior to the early 1990’s. Since that time, several researchers
studying the impact of caregiver burden on outcomes have included employment-
related factors in their research models. More recently, researchers have focused on
role conflict and role overload (Edwards, Zarit, Stephens, and Townsend 2002; Martire,
Stephens and Atienza 1997; Scharlach 1994); health (Duxbury, Higgins, and Smart
2011); job satisfaction (Martire, Stephens and Atienza 1997), and caregiver stress
(Orodenker 1990; Dellasega 1990; Scharlach, Sobel, and Roberts 1991) for employed
caregivers. With the aging of the baby boomers, it is expected that the number of adult
children caring for their aging parents while still employed will increase, which heightens
the importance of studying the relationship between work-related factors and caregiver
burden.

The literature reveals a number of both negative and positive benefits of
employment for caregivers. Several studies have found that employed caregivers report
lower levels of stress (Orodenker 1990) and depressive symptoms (Edwards et al.
2002; Stephens and Townsend 1997) as compared with non-employed caregivers;
while other studies have reported greater burden and poorer health outcomes for
employed caregivers (Martire, Stephens and Atienza 1997; Scharlach 1994; Duxbury,
Higgins, and Smart 2011). Still other studies (Dellasega 1990) found no differences in
caregiver stress between employed and non-employed caregivers. Scharlach (1994) interviewed 94 employed caregivers and found both positive and negative impacts of employment. The caregivers in his study reported negative impacts related to lack of time to provide care, poorer quality of care, impact on their relationship with the care recipient, and greater caregiver burden. However, more caregivers reported positive impacts, which included income to help support the cost of their loved one’s care, satisfaction at work which improved their relationship with the care recipient, and support and advice from co-workers.

These studies present conflicting findings, some reporting that employment contributes to greater burden and depressive symptoms for caregivers, while other studies have found few differences between employed and unemployed caregivers. Several researchers suggest that rather than look at employed and non-employed caregivers as distinct groups, it is important to look at dimensions of employment that may impact the caregiving experience. For example, Edwards et al. (2002) found that beneficial work experiences did moderate the relationship between role overload and depressive symptoms. Orodenker (1990) suggests that stress is greater for employed caregivers who are unable to balance the demands of both the caregiver and employee roles and are forced to alter their work schedules to meet caregiving demands. Edwards et al. (2002) suggests that these findings may indicate that employed and non-employed caregivers both experience burden and negative health outcomes, but the process by which they experience these outcomes differs. They recommend that studies look at both individual caregiver differences and caregiving as a process in order to better understand how roles such as employment impact caregiver outcomes.
Caregiver/Care Recipient Relationship

A number of researchers have found that the relationship between caregiver and care recipient affects how caregivers experience their role and impacts the physical and mental health outcomes they experience. Not surprisingly, the most commonly found, and studied, caregiver relationships are those of spousal and adult children. Numerous studies have found variations in predictors of strain, coping mechanisms, and caregiver outcomes between spousal and adult children caregivers. This is an important consideration in research and public policy as the number of baby boomers caring for their aging parents increases. While the current literature around caregiver relationship provides conflicting results, it is clear that spouses and adult children experience the caregiving relationship differently, have divergent expectations, and ultimately experience diverse outcomes.

In an early study on caregiver relationships, Zarit, Reever, and Bach-Peterson (1980) found that wives experienced higher levels of caregiver burden when compared to other family caregivers. A number of subsequent studies have substantiated this finding that spousal caregivers experience more burden or emotional strain than adult child caregivers (Miller et al. 1991; Cantor 1983; Zarit, Todd, and Zarit 1986). Other researchers have found that spousal caregivers report higher levels of depressive symptoms (Schulz et al 1995; George and Gwyther 1986), lower levels of life satisfaction and participation in social activities (George and Gwyther 1986; Connell, Janevis, and Gallant 2001), and more negative health outcomes (Connell, Janevis, and Gallant 2001) than other family caregivers. George and Gwyther (1986) found that spousal caregivers exhibited lower levels of caregiver well-being on all four well-being
dimensions measured (physical health, mental health, financial resources, and social participation) than adult child caregivers or other relative caregivers.

In general, researchers have found that kinship does affect how the caregiver role is experienced and the outcomes reported. Cantor (1983) interviewed 111 caregivers served by homemaker services in New York City. Her findings suggest that the relationship between the caregiver and care recipient has a significant correlation to caregiver stress and burden. In general, she found that the closer the filial bond (spouse and children) was, the more stressful the caregiving role. She also found differences in how spouses and children experience the caregiving role and the types of supports they desire. Thus, the caregiving relationship appears to be a critical factor to consider in any study of caregiving.

Some studies have not found a significant difference in caregiver burden between spousal and adult child caregivers (Robinson1983; Zarit et al. 1980; Gort et al. 2007), while others found that adult children caregivers fared more poorly than spousal caregivers. Johnson and Catalano (1983) found that adult children caring for their aging parents over a long period of time felt a high level of strain in their role, even though they typically did not provide levels of support as intensive as spousal caregivers.

Similarly, Coen et al. (2002), in their study of caregivers in Ireland, found that daughters were more likely to experience higher caregiver burden, greater psychological distress, and lower quality of life than other caregiving relatives. Harper and Lund (1990) also found that adult daughters who lived with their parent with dementia reported higher levels of burden than either wives or husbands caring for a spouse with dementia. Chumbler et al. (2003) studied 305 caregivers in Arkansas of adults over the age of 70.
with memory impairments and found significant differences in caregiver burden related to kinship. They reported that both male and female adult children experienced similar levels of caregiver burden as spouses but higher than more distant relatives.

More recent research has reported mixed results, while still documenting differences in burden, strain, and outcomes in relation to caregiver relationship. Suk-Young Kang (2006) examined the predictors of emotional strain between spouse and adult child caregivers using data from the 1999 National Long-term care Survey. Applying the frameworks of role theory and the stress process model, she analyzed if and how emotional strain differed between the groups and what the predictors of emotional strain were for each group. She did not find a significant difference in the level of emotional strain experienced by the two groups, but she did find differences in predictors of strain. She identified a number of predictors of emotional strain that were common across spousal and adult child caregivers, including elder's disruptive behaviors, caregiver's perceived overload, family disagreement, limitations on the caregiver's life, and utilization of personal coping strategies by the caregiver. She found that the caregiver/care recipient relationship does affect coping strategies and emotional strain. She found unique predictors of emotional strain for spouses and that the elders' race and respite availability were unique predictors of adult child caregiver's emotional strain.

Ankri et al. (2005) studied caregiver burden in 152 dyads of community-dwelling older adults with dementia and their primary caregivers in France. They found no difference in overall burden scores based on gender or between spousal and adult children caregivers but did find differences when looking at dimensions of caregiver
burden. They found that spouses experienced greater difficulty with the social consequences of caregiving, and children experienced greater difficulty with feelings of guilt, especially when they were not involved in the day to day caregiving. While it is well documented that many adult children provide some level of support to their aging parents, the amount and types of support that they provide varies based on their own personal situation, such as employment, children, and family obligations. Cicerilli (1983) found that adult children who were divorced, widowed, or remarried provided significantly less help than adult children with intact marriages. All of these factors may help explain the guilt felt by some adult children and the differing outcomes experienced by adult children and spousal caregivers.

There is some evidence that age may have an impact on the caregiver experience and that younger spousal caregivers may have similar experiences as adult child caregivers. Fitting et al. (1986) found that younger spousal caregivers were lonelier and more resentful of their role than the older caregivers in the study. Despite the mixed findings, there is general agreement in the literature that there is a strong relationship between close kinship ties and higher caregiver burden (Etters et al. 2008). This study considered both age and the caregiver relationship as key variables in explaining the caregiver experience in relation to the stress process model.

_Living Arrangement_

It would be expected that caregivers who live with the care recipient would experience greater stress and thus more negative physical and mental health outcomes. Whether the caregiver and care recipient live in the same household is an important factor to consider in caregiver research, and several studies have included...
living arrangement as a key variable. Yet findings related to the relationship between living arrangement and caregiver well-being are mixed. George and Gwyther (1986) found that caregivers who lived with the care recipient exhibited lower levels of well-being in the dimensions of mental health, social participation, and financial resources. Harper and Lund (1990) considered gender, kinship, and living arrangement as factors associated with caregiver burden in their study of a national sample of caregivers. They found that living arrangement was related to caregiver outcomes, especially for adult daughters caring for a parent with dementia. In contrast, Gort et al. (2007) found that caregivers who did not live with the care recipient experienced the highest caregiver burden, likely due to the added stress of maintaining their own home while providing care to their loved one. Soldo and Myllyluoma, (1983) found that care recipient characteristics had an impact on whether living arrangement was related to caregiver burden.

Other researchers have not found differences in burden related to living arrangement. Papastavrou et al. (2007) found that caregivers experience burden whether they live with the care recipient or not. They also found that nursing home placement did not relieve burden for these caregivers. Similarly, Almberg et al. (1997) did not find that living arrangement had an impact on how caregivers cope with burden and burnout. Robinson (1983) found no significant differences in scores on measures of caregiver strain between caregivers who lived with the care recipient and those who did not.
SUMMARY

Stress process theory provides a strong theoretical framework for studying caregiving. Long-term caregiving is considered to be a chronic stressor that often leads to adverse physical and mental health outcomes for the caregiver. Yet caregiving is a complex process, and research must be designed in a way that captures this complexity. Caregiving has many dimensions, and caregiver outcomes are related to characteristics of both the caregiver and care recipient, which must be considered as a dyadic unit. Outcomes for caregivers are related to many factors including kinship ties; age and gender of the caregiver; other caregiver responsibilities such as work and family; health of the caregiver; the care recipient’s health, behavior, and physical and cognitive functioning; living arrangements; perceived burden; and supportive interventions.

This study assesses the relationship among the objective demands of caregiving, the caregiver’s subjective appraisal of burden, and caregiver physical and mental well-being. A number of caregiver factors were assessed to identify the extent to which different caregiver characteristics may moderate the relationship between caregiving demands and caregiver burden. Whether, and which, supportive interventions may moderate the relationship between burden and caregiver well-being were also considered.

Due to the complexity of the caregiving role, qualitative analysis is also employed to more fully understand the caregiving experience and help explain differences found among caregivers through the quantitative analysis, particularly differences between spousal and adult child caregivers. The qualitative portion of this study is intended to
help discover how the nature of the caregiving relationship may impact whether the
objective demands of caregiving are perceived as burdensome. The qualitative
interviews are designed to help illuminate differences among adult child and spousal
caregivers, such as work and family caregiving responsibilities, motivations for
caregiving, and meanings ascribed to the caregiving experience, that may impact on
perceptions of burden. Interpretation of these more subjective experiences cannot be
easily measured through structured social surveys and assessments, making the
addition of the in-depth interviews a critical and important aspect of this study. This
study integrates the quantitative and qualitative data to provide a rich understanding of
the caregiving experience of the study participants.
CHAPTER III

RESEARCH DESIGN

PURPOSE

The purpose of this research is to study the relationship among the objective demands of caregiving, caregivers’ subjective appraisal of burden, and physical and mental health outcomes for caregivers of older adults; whether caregivers’ subjective appraisal of burden mediates the relationship between caregiving demands and caregiver outcomes; and whether caregiver characteristics moderate these relationships. Utilizing qualitative data obtained during the initial and six-month assessment surveys, the study analyzes how preferences for supportive services varied across caregivers. Finally, through in-depth semi-structured interviews with 20 caregivers, the study explores the meaning caregivers ascribe to the caregiving experience to provide a contextual understanding of the quantitative findings.

This study utilizes a mixed methods design in order to fully understand the complex experience of family caregivers and the meaning they attribute to this experience. The literature supports the use of mixed methods design in research designed to evaluate the effectiveness of caregiver intervention programs due to the complexity of the caregiving experience (Noonan and Tennstedt 1996; Ducharme et al. 2006). Prevalence and other quantitative data cannot adequately describe or explain the depth and breadth of caregiving. Huyck, Ayalon, and Yoder (2007) also make a case for using mixed methods when evaluating outcomes of caregiver support.
programs. They note that a mixed method design enabled them to make better assessments of the efficacy of the caregiver support program being studied and supported the usefulness of the screening measures utilized in the study. By employing a mixed methods design, this study allows for a deeper exploration of the caregiving experience in real-life contexts. Factors that are explored to further explain differences in caregiver outcomes include: differing expectations based on role (spousal vs. adult child caregivers); caregiving contexts such as employment, living arrangement, or other caregiving responsibilities that may impact feelings of burden; and how and why caregivers experience burden differently.

The specific aims of this study are:

1. Utilizing data from the initial assessment survey (n=418) examine:
   a) The relationship among the objective demands of caregiving, caregivers’ subjective appraisal of burden, and physical and mental health outcomes for caregivers of older adults;
   b) Whether caregivers’ subjective appraisal of burden mediates the relationship between caregiving demands and caregiver outcomes; and
   c) Whether, and which, caregiver characteristics have a direct effect upon or moderate the relationships among the objective demands of caregiving, caregivers’ subjective appraisal of burden, and physical and mental health outcomes for caregivers of older adults.

2. Utilizing data from the assessment survey data at Time 2 (n=243), examine whether the preference for instrumental or emotion-focused caregiver support interventions is related to caregiver or care recipient characteristics.
3. Using qualitative data (n = 20), identify contextual factors that may explain differences in the relationships described above; and themes that help explain the meaning that caregivers ascribe to the caregiving experience.

SAMPLE

The sample for the quantitative portion of this study is made up of 418 caregivers and care recipient dyads enrolled in The New Hampshire Transitions in Caregiving (TIC) research project. The initial TIC research project was implemented in partnership among the University of New Hampshire, Institute on Disability (IOD); the NH Bureau of Elderly and Adult Services (BEAS); and the NH ServiceLink Resource Center (SLRC) network. Participants in the TIC study were recruited through their local SLRC upon their application for the NH Family Caregiver Support Program (NHFCSP), administered by BEAS.

The NHFCSP is funded through the federal Administration on Community Living (ACL) and is intended to divert older adults from spend down to Medicaid and nursing home placement. The aim of the program is to improve, or at minimum maintain, the family caregiver’s ability to continue to provide care without sacrificing their health and well-being. NH’s program was informed by the work of Mary Mittelman et al. (2006). Their work provided evidence that a combination of individual counseling and additional support interventions improved overall caregiver well-being, delaying the necessity for nursing home placement. Effective interventions used in their research were instrumental in helping NH planners to design the NHFCSP.

Family caregivers who receive services through the NHFCSP are caring for an individual who is over the age of 60 and meets the medical eligibility criteria for nursing
home placement in New Hampshire. Often these individuals are at risk of nursing home admission and spend down to Medicaid. The NHFCSP incorporates a number of components including information and referral; a comprehensive caregiver assessment; one-on-one counseling and support; ad-hoc telephone assistance; funding for respite care; flexible funding for caregiving related goods and services; caregiver support programs and training; and an evidence-based caregiver education program, Powerful Tools for Caregivers (Boise, Congleton, and Shannon 2005). Participants in the program may choose to receive any or all of the above services and supports, although financial support for respite care and caregiver supports are limited to those who meet program eligibility criteria.

All caregivers who enrolled in the NHFCSP program between August 2008 and August 2011 were invited to participate in the TIC research study. Their decision to participate in the research study had no impact on their eligibility for or participation in the NHFCSP. Four hundred eighteen caregivers agreed to participate and were interviewed upon enrollment. A second wave of interviews was conducted six months later, and 243 caregivers were interviewed at Time 2. Attrition was due to a number of factors including death of the care recipient, no longer needing services, institutionalization of the care recipient, and refusal to continue participation (Sundar, Fox, and Phillips 2013).

PROCEDURES

A baseline assessment of the caregiver’s physical and emotional status (including caregiver burden, health status, and depressive symptoms) and the care recipient’s physical, functional, and mental status was conducted upon enrollment in the
program. The assessment protocol was developed by UNH researchers along with a team comprised of state agency program and policy staff and SLRC caregiver support specialists. The protocol includes demographic information and questions regarding caregiving roles and needs, care recipient functional status, support networks, and other concerns. Included in this protocol are five validated tools: The Zarit Caregiver Burden Inventory (ZBI), the Center for Epidemiologic Studies Depression Scales (CESD), the Revised Memory and Behavior Checklist (RMBPC), the General Health Survey Questionnaire Short Form 12 (SF-12), and the Short Portable Mental Status Questionnaire (SPSMQ). The assessment of Activities of Daily Living is the tool utilized by the State of New Hampshire to determine eligibility for Medicaid funded long term care services. The assessment tool is based on the Centers for Medicaid and Medicare Services Minimum Data Set (MDS) which is used to determine eligibility for Medicaid and Medicare funded nursing facility and home and community based services. As part of this assessment process, the interviewer also wrote descriptive answers to a number of questions that provide substantial data for qualitative analysis. A copy of the assessment tool is included in Appendix A.

Assessment interviews were conducted by the SLRC caregiver support specialists. They were trained in the interview protocol by a UNH researcher and had regular peer supervision meetings to discuss assessment issues and strategies. The completed protocols were reviewed by UNH researchers for accuracy and completeness. Surveys that were suspect, i.e. not filled out correctly, large sections left blank, etc., were not included in the final data set. Additional quality checks were performed on the database on a quarterly basis to assure data entry accuracy and as a
further check for data consistency. In this way, quality and accuracy were assured to the
best of the research team’s ability.

As part of the current research study an in-depth, follow-up interview was conducted with 20 caregivers. Based on initial analysis of data from the TIC research project, which found differences in outcomes between spousal and adult child caregivers, interview subjects were selected to represent a cross section of these caregivers. Caregivers were selected to participate in the follow-up interviews based on the following groupings: spousal caregivers who reported high burden scores; spousal caregivers who reported low burden scores; adult child caregivers who reported high burden scores; and adult child caregivers who reported low burden scores. High burden scores were considered to be one standard deviation above the mean score for all caregivers in the sample, and low burden scores were considered to be one standard deviation below the mean score for all caregivers in the sample. I used random number assignment through Excel to determine a random sample of these caregivers. Caregivers who met the above criteria were contacted by a caregiver specialist or NHFCSP manager to see if they would be willing to participate in a follow up interview. If they agreed, their contact information was shared with me, and an interview was scheduled at their convenience and at a location of their choice. A copy of the interview protocol is included in Appendix B.

Setting

Participants in the research study were interviewed in a variety of settings, depending on their wishes and comfort. They could be interviewed at a SLRC site, in their own home, or at a mutually agreed upon site. Follow-up survey interviews could be
conducted by telephone or in person. The majority of initial and follow-up assessments were conducted in the caregiver's home. In-depth qualitative interviews were conducted in person at a location chosen by the caregiver.

Consent

Approval from the UNH Institutional Review Board (IRB) was received for the initial TIC study on August 5, 2008. Additional renewals with modifications were obtained in each subsequent year, through June 2012, when the study closed. This current study utilizes data collected through the initial TIC study as well as additional in-depth interviews of caregivers. Approval from the UNH IRB for this current study was received on August 6, 2013, and renewed on July 14, 2014, with an extension through August 6, 2015. Copies of IRB approval letters for the current study are found in Appendix C.

The protection of the confidentiality of respondents is of the highest importance. All quantitative data in this study are reported in the aggregate so no data is individually identifiable. Respondent names are not included in the data set. Completed surveys are kept in a locked file cabinet at the IOD. The key containing participant names is locked in a separate location and only accessible to the state program director and the principal investigator. Pseudonyms are used in the qualitative analysis, and no information that could potentially identify a participant, such as where they live, is reported.

For the initial TIC research project, the caregiver specialists at each SLRC site reviewed the purpose of the research study and explained the consent/assent forms with all participants prior to conducting the assessment interview. Consent was obtained from both the caregiver and care recipient; for those care recipients who could not
consent, guardian consent and care recipient assent were received. Caregivers agreeing to participate in the in-depth follow-up interviews for this dissertation research signed an additional consent form which is attached in Appendix D.

Caregivers and their care recipients were not provided any monetary compensation for their participation. However, participants in the in-depth qualitative interview were offered a $25 gift card. All participants could be eligible to receive funding for respite care through the NH Family Caregiver Support Program and were encouraged to apply for this benefit. The decision to participate in the research study did not affect the questions they were asked, the application process, or their eligibility for the NHFCSP funds.

MEASURES

*Objective Measures of Caregiving Demands*

For this study, I utilized a number of assessments of the functional and behavioral status of the care recipient as measures of the objective demands of caregiving. The presumption is that the amount of care required by the care recipient, as measured by the number of activities of daily living for which they require assistance, is a good measure for the demands placed on the caregiver in providing that care. In addition, the number of behavior problems exhibited by the care recipient serves as another objective measure of demands placed on the caregiver. Numerous studies have used similar measures of care recipient functioning as an objective measure of caregiver demands (Ingersoll-Dayton and Raschick 2004; Pioli, 2010; Pinquart and Sorensen 2003).
Care recipient problem behaviors are measured by the Revised Memory and Behavior Problems Checklist (RMBPC). The RMBPC is a 24-item caregiver report that measures observable behavioral and memory problems in persons with dementia and their caregivers' reaction to these problems. The RMBPC is a reliable and valid tool for the clinical and empirical assessment of behavior problems in dementia patients. It provides a total score and three subscale scores for problems (memory-related, depression, and disruptive behaviors) and parallel scores for caregiver reaction (Roth et al. 2003). The frequency of problem behaviors is utilized as a measure of care recipient functioning (an objective measure of caregiving demands) and the caregiver’s reaction scores are utilized as a measure of the caregiver’s subjective appraisal of burden.

Care recipient functional status is measured by the Activities of Daily Living (ADL) Assessment. This assessment is a series of questions that measure the level of assistance needed in personal care tasks including transfers, lifting, walking, dressing, hygiene, eating, toileting, and bathing. The assessment protocol utilized in this study was developed by the NH Bureau of Elderly and Adult Services to determine eligibility for nursing home and home and community based services. It mirrors the ADL assessment which is part of the Long-Term Care Minimum Data Set (MDS) designed by the Centers on Medicare and Medicaid Services (CMS). The MDS is a standardized, primary screening and assessment tool of health status that forms the foundation of the comprehensive assessment for all residents in a Medicare and/or Medicaid-certified long-term care facility (CMS 2015). Measurement of a person’s ability to perform ADLs is a standard variable included in most research related to older adults (Weiner et al.)
The scores on this tool reflect the caregiver’s assessment of the functioning of the care recipient on each of the items.

*Care recipient mental status* is measured by the Short Portable Mental Status Questionnaire (SPMSQ). The SPMSQ is a 10-item screening test for dementia and delirium among older adults. It is a short, reliable instrument to detect the presence and degree of intellectual impairment and has been designed, tested, standardized, and validated. The standardization and validation procedure included administering the test to 997 elderly persons residing in the community; to 141 elderly persons referred for psychiatric and other health and social problems to a multipurpose clinic; and to 102 elderly persons living in institutions such as nursing homes, homes for the aged, or state mental hospitals. It was found that educational level and race had to be taken into account in scoring individual performance. On the basis of the large community population, standards of performance were established for: 1) intact mental functioning, 2) borderline or mild organic impairment, 3) definite but moderate organic impairment, and 4) severe organic impairment. In the 141 clinic patients, the SPMSQ scores were correlated with the clinical diagnoses. There was a high level of agreement between the clinical diagnosis of organic brain syndrome and the SPMSQ scores that indicated moderate or severe organic impairment (Pfeiffer 1975).

*Subjective Appraisal of Burden*

*Caregiver burden* is measured by The Zarit Burden Interview (ZBI). The ZBI is one of the oldest and most often used instruments to measure caregiver burden, and high ZBI scores have been significantly related to high depressive symptoms and low physical well-being (Schreiner, Morimoto, Arai, and Zarit 2006). Developed as a 29-item
questionnaire (Zarit, Reever, and Bach-Peterson 1980), it has been revised to a 22-item questionnaire, utilizing a five-point scale. Caregivers are asked to rate their experience on a scale from zero (never) to four (nearly always) on the 22 items related to caregiver burden. Schreiner et al. (2006) have determined that a cut-off score of 24-26 on the ZBI has significant predictive validity for identifying caregivers at risk for depressive symptoms.

As the ZBI is the most comprehensive measure of burden utilized in my study, I conducted a Chronbach’s alpha test on the results. A reliability coefficient score of .8798 and inter-item covariance score of .3409414 was obtained, indicating a high level of internal consistency. In addition, specific dimensions of burden were identified through a factor analysis of the ZBI burden scores. These factors were utilized for further analysis of the relationships between caregiver and care recipient characteristics and caregiver outcomes. The most frequently endorsed factor structure utilizes a two-model, considering personal strain and role strain (Herbert, Bravo, and Preville 2000).

*Caregiver reaction to problem behaviors.* The Revised Memory and Behavior Problems Checklist (RMBPC) provides three measures of caregivers’ reaction to the problem behaviors exhibited by their care recipient. The RMBPC is a 24-item caregiver report that measures observable behavioral and memory problems in persons with dementia and their caregivers' reaction to these problems. The RMBPC is a reliable and valid tool for the clinical and empirical assessment of behavior problems in dementia patients. It provides three subscale scores for caregiver reaction to problem behaviors related to memory, depression, and disruptive behaviors (Roth et al. 2003).
**Outcome Variables**

*Caregiver physical and mental health well-being* is measured by the General Health Survey Questionnaire, Short Form 12 (SF-12). The SF-12 Health Survey is a 12-item questionnaire that measures eight domains of health. These domains include physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health. It is a brief, reliable measure of overall health status. The SF-12 provides two scores, the Physical Composite Score (PCS) which is a measure of physical health well-being and the Mental Composite Score (MCS) which is a measure of mental health well-being. It has been used extensively as a screening tool and has high reliability and validity. The test-retest reliability of summary measures was 0.890. Fourteen validity tests involving physical criteria ranged from 0.43 to 0.93 with a median of 0.67 (Ware, Kosinski, Turner-Bowker, and Gandek 2009).

*Caregiver depressive symptoms* is measured by the Center for Epidemiologic Studies Depression Scales (CESD). This scale was developed by Lenore Radloff in 1977, has been widely used, has been proven to be a valid and reliable screen for clinical depression in adults, and discriminates well between clinically depressed and normal respondents. The scale has been found to correlate well with other depression scales. During developmental testing, Radloff (1977) reported coefficient alpha for internal consistency of 0.85 in the general population and 0.90 for psychiatric patients. She also reported test-retest reliabilities ranging from 0.32 at 12 months retesting and 0.67 at four weeks (Bowling 2001).

As the CESD is the primary outcome variable within my study, I conducted a Chronbach’s alpha test on the results of the CESD. A reliability coefficient score of
.8978 and inter-item covariance score of .2686073 was obtained, indicating a high level of internal consistency for both administrations. The CESD and the Mental Composite Score of the SF-12 serve as alternative measures of the essentially the same construct of mental health well-being.

**Moderating Variables**

*Kinship ties* refers to the relationship between the caregiver and care recipient. For analysis related to kinship wife, husband and partners are considered spousal caregivers and dummy coded as 0; daughter, daughter-in-law, son, and son-in-law are considered as adult child caregivers and dummy coded as 1. Other caregivers are not included in the kinship related analyses. Other variables that are considered as possible moderating factors in this study include *employment* status (1 = employed and 0 = not employed) and *age* of the caregiver (a continuous variable).

**Other Caregiver Characteristics**

Other caregiver characteristics considered in the theoretical model include caregiver *gender* (male = 0; female = 1); *age* (reported in years); *employment* (not employed = 0; employed = 1); the *length of time caregiving* (reported in months); *other caregiving responsibilities* such as children, other relatives, individuals with disabilities, etc. (reported as a simple count); and *living arrangement* (Lives with care recipient = 1; Does not live with care recipient = 0).

**Supportive Services Variable: Instrumental and Emotion-Focused Supports**

The types of services received through the NHFCSP included information and referral, assessment, one-on-one counseling, ad hoc phone counseling, flexible funding for respite care, and other caregiver supports, caregiver support groups, and caregiver
education programs. Other community-based social services that caregivers may have accessed include services such as Meals on Wheels, Adult Day Programs, Senior Companion Program, etc. Instrumental supports are considered to be services such as respite care, meals on wheels, adult day programs, money for home modifications, etc. Emotion focused supports are considered to be services such as counseling and caregiver support groups. Caregivers were asked which supports they found most helpful and their responses were coded as either instrumental supports (coded as 1) or emotion focused supports (coded as 2).

Qualitative Measures: Explanatory Themes Related to Caregiving

Qualitative data is collected from the semi-structured interviews completed with 20 caregivers. These interviews were transcribed and coded for themes related to the caregiving experience. A copy of the semi-structured interview protocol is attached in Appendix E. The protocol was designed to further explore differences found through the quantitative data analysis, with a particular focus on differences in subjective appraisals of burden and outcomes between spousal and adult child caregivers. The interviews were designed to explore possible explanations for these differences such as demands of employment or other caregiving responsibilities, different senses of obligation, role expectations, etc. The interviews were transcribed and coded for themes, with specific focus on differences related to caregiver characteristics such as kinship. These findings are triangulated with the quantitative data to look for themes that identify possible explanations for differences found among caregivers.
DATA ANALYSIS

Quantitative data analysis is completed on the assessment data collected upon entry into the NHFCSP using STATA. A descriptive analysis of the data is conducted to provide an overview of caregiver and care recipient characteristics. Correlation coefficients are utilized to determine the strength of relationships among all key variables in the model. Ordinary least squares (OLS) regression analysis is the primary quantitative methodology utilized to test for the relationships depicted in the conceptual model in Figure 1 below and to fully investigate the research questions outlined in this study.

Qualitative data analysis is facilitated through the use of NVIVO software to help categorize and organize the interview data. Qualitative analysis includes the coding of transcripts from the 20 caregiver interviews for themes related to the meaning that caregivers attach to the caregiving experience as well as themes that might help explain differences in caregiver outcomes. I conducted semi-structured interviews with 20 caregivers who had completed the initial caregiver survey. These interviews were audiotaped and transcribed. Once the interviews were completed and transcribed, I organized and prepared the data for analysis and saved each interview as a case record in NVIVO. A detailed description of the qualitative data analysis is included in Chapter V. Qualitative Findings.

The qualitative portion of the study consists of a phenomenological study of the caregiving experience which helps to capture the diverse nature of family relationships and allows for a deeper understanding of the unique and personal aspects of family caregiving. As Mancini and Blieszner (1989) note, much of the research on family
caregiving utilizes the structured social survey as the primary research method, and, due the complexity of these family relationships, research would be greatly enhanced through the inclusion of qualitative approaches. Specifically, the qualitative analysis in this study is utilized to better understand how differences in caregiver characteristics; such as kinship, gender, age, and employment, condition the caregiver’s perception of their caregiver role. For example, the qualitative analysis explore how the caregiver’s sense of obligation, perception of burden, or feelings about their caregiving experience differ based on statuses such as kinship, gender, or age. It also explores how employment may alter the context for caregiving in terms of balancing the demands of caregiving and work, role strain, and/or social supports.

I utilize a sequential explanatory strategy as the process for my research, as outlined by Creswell (2003). This strategy entails the collection and analysis of quantitative data followed by the collection and analysis of qualitative data. The qualitative data is intended to explain and interpret results found in the quantitative portion of the study. Both the quantitative and qualitative data are integrated during the interpretation phase of the study. The utilization of both quantitative and qualitative methods provides for an analysis of both objective and subjective data in order to identify relationships among the theoretical constructs presented and to provide for a deeper explanation of how and why these associations exist. Figure IV.1 outlines the steps that were followed in this study.

**Figure III.1: Mixed Methods Study Design**
CONCEPTUAL MODEL DESIGN

Figures III.2 below illustrates the conceptual model of this research design. It illustrates an analysis of the relationships among caregiving demands, caregiver burden, and caregiver mental and physical well-being. The model assesses the direct relationship between caregiving demands and caregiver well-being, and whether this relationship is mediated by caregiver perceptions of burden. The model also includes demands of caregiving, caregiver burden, or caregiver outcomes; and whether kinship, employment, or age moderate the relationships among caregiving demands, burden, and well-being.

Figure III.2: Theoretical Model

Qualitative analysis is utilized to help explain differences found in caregiver burden and well-being. This analysis provides additional data to describe the meaning
caregivers ascribe to their experience and help explain differences found among caregivers. Qualitative data also helps to identify coping strategies utilized by caregivers and whether these strategies vary across caregivers. Qualitative data is also used to further analyze differences found based on caregiver characteristics such as employment, other caregiving responsibilities, kinship, and living arrangements. Quantitative analysis can identify differences in outcomes among caregivers, but it doesn’t provide an explanation for why these differences are found. It is important to include the voice of the participants to provide a rich understanding of the meaning they ascribe to their caregiving experience to help explain the differences found. The semi-structured interview protocol and choice of participants is designed to capture whether and how factors such as age, kinship, employment, and living arrangements impact the relationship among objective demands of caregiving, perceptions of burden, and caregiver outcomes. This study integrates quantitative and qualitative data to provide a rich understanding of the caregiving experience of the study participants.
CHAPTER IV

QUANTITATIVE RESULTS

CHARACTERISTICS OF STUDY PARTICIPANTS

Participants in this study consist of 418 caregiver and care recipient dyads who were enrolled in New Hampshire’s Transitions in Caregiving Project between August 2008 and August 2011 and provided consent to be included in the research project. Participants were recruited from all 10 counties in New Hampshire. Both the caregiver and care recipient completed an extensive interview upon enrollment in the program (T1) and a second interview approximately six months later (T2). Of the participant dyads, 243 were interviewed at T2. Attrition was due to a number of factors including death of the care recipient, caregivers no longer needing services, institutionalization of the care recipient, and refusal to continue participation (Sundar, Fox, and Phillips 2013).

An analysis was conducted to determine if there were any significant differences among caregivers who continued in the program and those who did not complete a second interview. Analysis indicates that 68% of those who participated in the second interview were female, while 73% of those in the no-follow-up group were female. This difference is not found to be statistically significant. Similarly, no significant difference is found between the two groups based on employment or age of the caregiver. An analysis of differences across key outcome variables indicates small differences among the two groups. Caregivers who were part of the follow-up study are found to report lower levels of depressive symptoms and caregiver burden, although the differences in
levels of burden are not found to be statistically significant between the two groups. Interestingly, the functional level of the care recipients at baseline in the follow-up group, as measured by the number of ADL's requiring assistance, is significantly higher than those in the no follow-up group. This raises some interesting questions about the reasons for attrition from the program. The data reported in Table IV.1 indicate that the care recipients in the follow-up group are more impaired than those in the attrition group, while their caregivers report significantly lower levels of depressive symptomology. At first glance, these findings seem counterintuitive as I would have expected that those with greater care needs would be more likely to pass away or be admitted to a nursing facility. However, an alternative interpretation could be that caregivers of those with greater care needs are more motivated to continue in the program and are more likely to appreciate the visit from the caregiver specialist to conduct the follow-up assessment.

Table IV.1: Differences in Means on Caregiver Age, Depressive Symptoms, Burden, and Care Recipient Functional Status between Follow-Up and Attrition Groups

<table>
<thead>
<tr>
<th></th>
<th>Total Group (SD)</th>
<th>Follow Up (SD)</th>
<th>No Follow Up (SD)</th>
<th>t-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Age</td>
<td>65.12 (12.8)</td>
<td>65.27 (12.4)</td>
<td>64.91 (13.4)</td>
<td>-0.2874</td>
</tr>
<tr>
<td>Depressive Symptoms</td>
<td>14.61 (10.86)</td>
<td>13.85 (10.71)</td>
<td>15.70 (11.02)</td>
<td>1.6955*</td>
</tr>
<tr>
<td>Caregiver Burden</td>
<td>33.21 (13.67)</td>
<td>32.82 (13.38)</td>
<td>33.78 (14.09)</td>
<td>0.7075</td>
</tr>
<tr>
<td>Care Recipient ADL</td>
<td>3.56 (3.21)</td>
<td>3.89 (3.31)</td>
<td>3.11 (3.03)</td>
<td>-2.267*</td>
</tr>
</tbody>
</table>

*p < .05
**p < .01
***p < .001

Characteristics of the 418 caregivers and care recipients who participated in this study are illustrated in Table IV.2. Both the caregiver and care recipient participants in this study are primarily female, married, and older. Females comprise 70.3% of the caregivers and 56.5% of the care recipients; while 82.1% of the caregivers and 58.6%
of the care recipients are married. The median age of caregivers in the program is 65, with a range from 25-92 years. Care recipients median age is 82, with a range of 46 to 102. A slight majority (51%) of the caregivers are the spouse or domestic partners of care recipients. Of the total sample, wives care for their husbands in 33% of the cases, while husbands care for wives in 18%. Adult children caring for their parents comprise another 44% of the sample, including daughters (31%), sons (10%), and daughters-in-law (3%). Other family members, friends, and neighbors make up the remaining 5% of the caregivers. Caregivers report that they have been in their caregiving role for an average of five and a half years, with a range from two months to 50 years; spending anywhere from one to 24 hours per day providing care, with the average being 17.6 hours each day. While this average number of hours seems high, caregivers talked about how they feel they are providing 24 hours of care each day as they are always “on-call” and often get little sleep as their care recipient wakes frequently during the night.

Caregivers live with their care recipients in 87% of the living arrangements, while only 6% of care recipients live alone. Among caregivers, 34% indicate that the living arrangement is a source of some difficulty. Of those who live with the care recipient, 33% report that the living arrangement is a source of some difficulty. While the number of caregivers who do not live with their care recipient was smaller, over 40% report difficulty with this living arrangement. About one quarter of the caregivers have additional informal caregiving responsibilities, either to family members or other individuals. Almost one third (32%) maintain jobs outside the home; about half of these working full-time, and half working part-time.
Table IV.2: Participant Characteristics (Sample = 418)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Caregiver (CG)</th>
<th>Care Recipient (CR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years; mean, median, (range)</td>
<td>65, 65 (25 – 92)</td>
<td>81, 82 (46 – 102)</td>
</tr>
<tr>
<td>Female; %</td>
<td>70.3</td>
<td>56.5</td>
</tr>
<tr>
<td>Marital Status; %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/Partner</td>
<td>82</td>
<td>60</td>
</tr>
<tr>
<td>Single</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>Divorced</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Widowed</td>
<td>4</td>
<td>36</td>
</tr>
<tr>
<td>Length of Time Caregiving in years; mean (range)</td>
<td>5.5 (.1 – 50)</td>
<td></td>
</tr>
<tr>
<td>Hours of caregiving per day; mean (SD)</td>
<td>17.6 (7.5)</td>
<td></td>
</tr>
<tr>
<td>Caregiver Relationship to Care Recipient; %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Husband</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>Wife</td>
<td>33</td>
<td></td>
</tr>
<tr>
<td>Daughter</td>
<td>31</td>
<td></td>
</tr>
<tr>
<td>Son</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Daughter-in-law</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Living Arrangement; Freq (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lived with care recipient</td>
<td>359 (87%)</td>
<td></td>
</tr>
<tr>
<td>Difficulty with living arr.</td>
<td>117 (33%)</td>
<td></td>
</tr>
<tr>
<td>Not live with care recipient</td>
<td>52 (13%)</td>
<td></td>
</tr>
<tr>
<td>Difficulty with living arr.</td>
<td>21 (40%)</td>
<td></td>
</tr>
<tr>
<td>Other caregiving responsibilities</td>
<td>102 (24%)</td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td>133 (32%)</td>
<td>50%/50%</td>
</tr>
<tr>
<td>Annual Income; %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;= $20,000</td>
<td>37</td>
<td>62</td>
</tr>
<tr>
<td>$20,001 – 40,000</td>
<td>38</td>
<td>35</td>
</tr>
<tr>
<td>$40,001 – 60,000</td>
<td>16</td>
<td>3</td>
</tr>
<tr>
<td>&gt;$60,000</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>Total Assets; %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;= $5,000</td>
<td></td>
<td>40</td>
</tr>
<tr>
<td>$5,001 – 10,000</td>
<td></td>
<td>12</td>
</tr>
<tr>
<td>$10,001 – 20,000</td>
<td></td>
<td>12</td>
</tr>
<tr>
<td>$20,001 – 30,000</td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>&gt;$30,000</td>
<td></td>
<td>29</td>
</tr>
</tbody>
</table>

Participants in this study primarily fall into lower income ranges. Thirty-seven percent of caregivers and 62% of care recipients report incomes of less than $20,000 per year. Only 10% of caregivers and no care recipients report incomes over $60,000 per year. Care recipients were asked about asset levels as this is a key financial determinant of Medicaid eligibility, and Medicaid is the primary payer source for nursing home care. Only 29% of care recipients in this study report assets of over $30,000. This indicates that the care recipients in this study have both low incomes and low asset
levels and would quickly spend down to Medicaid eligibility if they were to be institutionalized. This is important to public policy considerations in relation to the value of supporting family caregivers to delay nursing home placement.

DESCRIPTIVE STATISTICS ON CAREGIVER WELL-BEING

Measures of caregiver well-being include caregiver burden as measured by the Zarit Burden Interview (Copyright (c) 1983 Steven Zarit) and the Revised Memory and Behavior Problems Checklist (RMBPC) caregiver reaction scores, depressive symptoms as measured by the Center for Epidemiologic Studies Depression Scale (CESD), mental well-being as measured by the SF12 Mental Composite Score (MCS), and physical well-being as measured by the SF12 Physical Composite Score (PCS).

As the ZBI is the most commonly used measure of burden, I focused much of my analysis on this measure rather than the three reaction scores on the RMBPC. Guidelines for interpretation of scores on the ZBI are provided by the author (Copyright (c) 1983 Steven Zarit) but are not intended to serve as strict cut-off scores. Based on these guidelines, I utilized the following scale in analyzing ZBI scores: 0 – 21 = little or no burden; 21 – 40 = mild to moderate burden; 41 – 60 = moderate to severe burden; and 61 – 88 = severe burden. Levels of burden utilizing this scale are portrayed in Table IV.3.

<table>
<thead>
<tr>
<th>Burden Score</th>
<th>Frequency/TI</th>
<th>Percent/TI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Little or None</td>
<td>86</td>
<td>20.62</td>
</tr>
<tr>
<td>Mild to Moderate</td>
<td>205</td>
<td>49.16</td>
</tr>
<tr>
<td>Moderate to Severe</td>
<td>116</td>
<td>27.82</td>
</tr>
<tr>
<td>Severe</td>
<td>10</td>
<td>2.4</td>
</tr>
<tr>
<td>TOTAL</td>
<td>417</td>
<td>100</td>
</tr>
</tbody>
</table>

Close to 21% of the caregivers in this study report little to no burden upon entry into the program. Almost 77% of the caregivers report mild to severe burden (scores of
21 -60) and only 2.4% of the caregivers report severe levels of burden (scores of 61 or more). The largest number of caregivers (49%) report mild to moderate levels of burden (scores of 21 – 40).

Schreiner, Morimoto, Arai, and Zarit (2006) found that a score on the ZBI in the range of 24 – 26 was predictive of risk of depression and suggest utilizing a cut-off score of 24 to identify caregivers at risk. Analysis of caregiver data at entry into the program, utilizing 24 as a cut-off score, indicates that 75% of the caregivers in the study experience high levels of burden related to their caregiving and are potentially at risk of depression.

Figure IV.1, below, depicts the distribution of burden scores. The distribution shows a normal bell curve distribution of scores.

Depressive symptoms in caregivers are measured by the CESD. I used a cut-off score of 16 or greater as an indicator of risk for clinical depression, as suggested by the scale author (Radloff, 1977) and confirmed in subsequent studies that verified the
sensitivity and high internal consistency of this instrument (Lewinsohn, Seeley, Roberts, and Allen, 1997). Clinically significant levels of depressive symptoms (scores on the CESD of 16 or higher) are reported by 41.46% of caregivers in this study. An analysis of caregiver CESD scores are weighted towards the lower end of the scale, as depicted in Figure IV.2 below, with a positive skew and a kurtosis score of 3.22, just slightly more than a normal score of 3. This is a relatively typical distribution of scores on the CESD when administered to a general population sample. Radloff (1977) reported in her early validation studies that general population distributions were skewed, with a larger proportion of lower scores, indicating few depressive symptoms. She also noted that scores above 20 are rarely observed (Radloff & Locke, 1986). More recent studies (Foley, Reed, Mutram and DeVellis (2002) and Rozario and Menon (2010)) have confirmed the finding that responses on the CESD are skewed towards lower levels of depressive symptoms, and the instrument is a valid and reliable instrument for the measurement of depressive symptoms.
Mental and physical well-being of caregivers is measured through administration of the SF-12 Health Survey. The survey is scored in relation to US population norms by age group. Generally, caregivers in the study fall below the average, at statistically significant levels, for all age groups on the Mental Component Summary (MCS) of the SF-12 Survey. The older the caregivers, the smaller the difference scores between the sample and the population mean, indicating that the younger the caregiver, the greater the threat to his/her mental well-being. In terms of physical well-being, caregivers did not score significantly different from the average for their age groups on the Physical Component Summary (PCS) except for those under age 55, who report lower levels of physical health than same-age population counterparts. Table IV.4 shows the difference scores from population average by age group and the corresponding statistical analyses.

<table>
<thead>
<tr>
<th>Caregiver Age Range</th>
<th>Mental Component Score</th>
<th>Physical Component Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 55</td>
<td>-8.1***</td>
<td>-4.3***</td>
</tr>
<tr>
<td>55 – 64</td>
<td>-8.3***</td>
<td>ns</td>
</tr>
<tr>
<td>65 – 74</td>
<td>-5.3***</td>
<td>ns</td>
</tr>
<tr>
<td>75 and up</td>
<td>-3.3**</td>
<td>ns</td>
</tr>
</tbody>
</table>

*p < .05  
**p < .01  
***p < .001  
ns = not statistically different from population average

As can be seen in the table, caregivers under the age of 55 score significantly lower than the population mean on measures of both mental and physical well-being. These findings indicate that, for the caregivers in this study, the younger caregivers fare more poorly than the older caregivers when compared to their age peers. Caregivers in the sample score lower than the population mean on the mental well-being scale,
across all age groups, indicating that caregivers in this study experience significantly lower mental well-being than the general population, across all age groupings.

The distribution of scores on the SF-12 measures of physical and mental health do not follow a normal bell curve distribution pattern, as noted in Figures IV.3 and IV.4 below. On the physical well-being scale, caregiver scores reveal two peaks, a lower one for caregivers who scored around 10 points below their age peers and a higher one for caregivers who scored five to 10 points above their age peers. Scores were negatively skewed with a kurtosis value of 2.25, lower than the normal score of 3. Scores on the mental well-being revealed a flatter distribution, with a negative skew, indicating that the majority of caregivers in the study scored lower than their age peers on this scale. This is consistent with findings reported in the paragraph above, that caregivers in this study report significantly lower mental well-being than the general population, across all age groupings.
DESCRIPTIVE STATISTICS ON CARE RECIPIENT FUNCTIONING

Measures of care recipient functioning are included in this study as objective measures of caregiver burden. These measures include assessments of the care recipient’s functional and mental status, and the frequency of behavior problems exhibited by the care recipient. The measure of “Activities of Daily Living” (ADLs) represents the number of ADLs for which the care recipient is dependent on others to perform. The care recipient’s mental status is measured using the Short Portable Mental Status Questionnaire (SPMSQ), a short 10-item screening test to detect the presence and degree of intellectual impairment in older adults. The Revised Memory and Behavior Problems Checklist (RMBPC) is utilized to measure the frequency of care recipient behavior problems. This 24-item caregiver report measures observable behavioral and memory problems. It provides a total score and three subscale scores for problems (memory-related, depression, and disruptive behaviors).
As depicted in Table IV.5 below, the care recipients in this study exhibit high levels of functional, behavioral, and cognitive need. Care recipients average 3.56 ADL’s requiring assistance from a caregiver with a range from zero to 11. ADLs include assistance with personal care such as dressing, eating, hygiene, and toileting. Of note, nursing home level of care in New Hampshire is defined as needing assistance with at least two ADLs. Care recipients in this study also need high levels of assistance with Instrumental Activities of Daily Living. These activities include meal preparation, housekeeping, using the phone, and transportation. On average, care recipients require assistance with 7.61 instrumental activities of daily living. These findings indicate that the majority of care recipients in this study have high care needs and would qualify for nursing home level of care in New Hampshire.

The RMBPC measures the number of behavior problems that have been observed over a week. The data in Table IV.5 below indicate that the care recipients in this study exhibit relatively high frequency of behaviors, the highest being the frequency of behaviors related to memory problems (average of 4.68 behaviors per week), followed by depression (average of 3.69 behaviors per week), and then disruptive behaviors (average of 2.49 behaviors per week). The mean score of 1.52 on the SPMSQ indicates that care recipients exhibited mild to moderate cognitive impairment on average. It is particularly enlightening to look at the breakdown of these scores, noting that 113 (30.79%) care recipients exhibited no cognitive impairment, while 112 (30.52%) exhibited severe cognitive impairment, and 142 (38.7%) exhibited mild to moderate cognitive impairment.
Table IV.5: Measures of Care Recipient Functioning (Objective Demands of Caregiving)

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td># of Dependent ADL’s (n=353)</td>
<td>3.56</td>
<td>3.21</td>
<td>0 - 11</td>
</tr>
<tr>
<td># Dependent IADL’s (n=243)</td>
<td>7.61</td>
<td>1.81</td>
<td>0 - 9</td>
</tr>
<tr>
<td>Frequency of Care Recipient Behaviors (RMBPC)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memory (n=380)</td>
<td>4.68</td>
<td>1.86</td>
<td>1 - 7</td>
</tr>
<tr>
<td>Depression (n=358)</td>
<td>3.69</td>
<td>2.06</td>
<td>1 - 9</td>
</tr>
<tr>
<td>Disruption (n=338)</td>
<td>2.49</td>
<td>1.53</td>
<td>1 - 8</td>
</tr>
<tr>
<td>Mental Status (SPMSQ) (Total) (n=367)</td>
<td>1.52</td>
<td>1.22</td>
<td>0 - 3</td>
</tr>
</tbody>
</table>

ASSOCIATIONS AMONG KEY STUDY VARIABLES

In order to get a picture of the relationships among the key variables being studied, I conducted an analysis of correlations among the measures of the objective demands of caregiving, caregiver burden, caregiver outcomes, and caregiver characteristics. Results of this correlational analysis can be found in Appendix E. A number of statistically significant associations among these factors are found that are worth noting. The direction and strength of the correlations are noted in the table.

Consistent with the literature on caregiving, I found statistically significant correlations among scores on burden, depressive symptoms, and physical and mental well-being for caregivers. Specifically, for caregivers in this study, high levels of depressive symptoms, lower scores on measures of mental well-being, and having lower mental well-being than population age norms are significantly associated with high levels of caregiver burden. Lower scores related to physical well-being are not found to be significantly related to caregiver burden. However, lower ratings on both physical and mental well-being are found to be significantly related to higher levels of
depressive symptoms, and lower levels of mental well-being are found to be related to lower levels of physical well-being. As noted earlier, the MCS of the SF-12 and the CESD are essentially alternative measures of the same construct of mental well-being, so the strong association between these variables is expected.

The frequency of depressive and disruptive behaviors in the care recipient is significantly related to caregiver depressive symptoms; however, the frequency of memory related behaviors is not. Neither the care recipient’s mental status nor their need for assistance with activities of daily living is found to be significantly related to depressive symptoms. However; burden and the caregivers reaction to behaviors related to memory, depression, and disruption are all significantly related to depressive symptoms. These findings are indicative that depressive symptoms are more related to how the caregiver reacts to or perceives the demands of caregiving rather than how impaired or needy the care recipient is. Of note is the association between age and depressive symptoms and gender and depressive symptoms; that is, female caregivers and younger caregivers are associated with higher levels of depressive symptoms.

A number of significant associations are found among caregiver characteristics and the measures of caregiver burden and well-being. Kinship is found to be significantly associated with burden, length of time caregiving, age, gender, and employment. That is, adult child caregivers report higher burden, have been caregiving for a shorter period of time, are younger, are more likely be female, are more likely to be employed, and are more likely to have other caregiving responsibilities. Gender is found to be significantly related to depressive symptoms, burden, age, and kinship, in that female caregivers are found to report higher levels of depressive symptoms and burden,
be younger, and to be caring for a parent. Employment is found to be associated with burden, age, and kinship. Adult child caregivers are more likely to be employed, and caregivers who are employed are younger and report higher levels of caregiver burden. Age is significantly associated with many of the variables in this matrix. Older caregivers are associated with lower levels of depressive symptoms and burden, longer periods of caregiving, and lower levels of employment. Age is also found to be significantly associated with kinship and gender. These correlational findings between caregiver characteristics and the core variables of interest indicate the need to control for caregiver characteristics in the multivariate analyses.

DIFFERENCES BETWEEN SPOUSAL AND ADULT CHILD CAREGIVERS

Based on these initial descriptive analyses, I was particularly interested in whether there were differences in outcomes between spousal and adult child caregivers. Spousal caregivers represented 51% (n = 211) of the initial sample, and adult child caregivers comprised 44% (n = 181), providing adequate sample sizes in order to test for differences between the two groups. T-tests to determine the differences among means for these two groups were conducted on measures of caregiver well-being and produced a number of statistically significant findings. These findings are represented in Table IV.6 below. Adult child caregivers report higher levels of depressive symptoms, higher levels of caregiver burden, and lower levels of mental well-being than the spousal caregivers in this study. Differences found between the two groups on physical well-being are not significant. In addition, analysis of caregivers’ reaction to memory, depression, and disruptive behaviors of the care recipient are not found to be significant.
Table IV.6: Differences Found Between Spousal and Adult Child Caregivers on Measures of Caregiver Well-Being and Burden

<table>
<thead>
<tr>
<th>Measure</th>
<th>Total Group Mean (SD)</th>
<th>Spousal Mean (SD)</th>
<th>Adult Child Mean (SD)</th>
<th>t-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depressive Symptoms (CESD)</td>
<td>14.53 (10.71)</td>
<td>13.59 (9.87)</td>
<td>15.64 (11.56)</td>
<td>-1.87*</td>
</tr>
<tr>
<td>Caregiver Burden (ZBI)</td>
<td>33.07 (13.46)</td>
<td>31.42 (13.20)</td>
<td>34.99 (13.56)</td>
<td>-2.65**</td>
</tr>
<tr>
<td>Well-Being (SF-12)†</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical (PCS)</td>
<td>-0.84 (12.07)</td>
<td>0.03 (12.63)</td>
<td>-1.82 (11.33)</td>
<td>1.49</td>
</tr>
<tr>
<td>Mental (MCS)</td>
<td>-6.25 (11.89)</td>
<td>-4.17 (10.52)</td>
<td>-8.67 (11.89)</td>
<td>3.96***</td>
</tr>
<tr>
<td>Reaction to Care Recipient Behaviors (RMBPC)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memory</td>
<td>6.54 (6.15)</td>
<td>6.77 (6.33)</td>
<td>6.29 (5.95)</td>
<td>.7488</td>
</tr>
<tr>
<td>Depression</td>
<td>7.23 (6.06)</td>
<td>6.78 (5.82)</td>
<td>7.77 (6.31)</td>
<td>-1.488</td>
</tr>
<tr>
<td>Disruption</td>
<td>4.8 (4.3)</td>
<td>4.58 (4.49)</td>
<td>5.05 (4.08)</td>
<td>-0.9899</td>
</tr>
</tbody>
</table>

* p< .05  
** p < .01  
*** p < .001  
† Deviation from norm scores

Figure IV.5, below, illustrates differences found in levels of depressive symptoms, as measured by scores on the CESD, by level of burden and kinship. The chart shows that the higher the caregiver burden experienced, the higher the level of depressive symptoms reported. This is true for both spousal and adult child caregivers. However, more adult child caregivers report severe levels of caregiver burden and high depressive symptoms than spousal caregivers.
These findings indicate that while the spousal caregivers in this study are older, have been providing care longer, and provide care for more hours each day than the adult child caregivers, they also report lower caregiving burden. In order to identify possible explanatory factors that might elucidate the differences found between spousal and adult child caregivers, further analyses were conducted. The results of these analyses are illustrated in Table IV.7 below.

Table IV.7. Differences on Caregiver Characteristics between Spousal and Adult Child Caregivers

<table>
<thead>
<tr>
<th></th>
<th>Spousal Caregivers (n = 211)</th>
<th>Adult Child Caregivers (n = 181)</th>
<th>t-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (mean)</td>
<td>74</td>
<td>56</td>
<td>20.92***</td>
</tr>
<tr>
<td>Gender</td>
<td>Female 64% Male 36%</td>
<td>Female 77% Male 23%</td>
<td></td>
</tr>
<tr>
<td>Caring for</td>
<td>Wife 37% Husband 63%</td>
<td>Mother 78% Father 22%</td>
<td></td>
</tr>
<tr>
<td>Mean Age of Care Recipient</td>
<td>77</td>
<td>85</td>
<td>-9.4758****</td>
</tr>
<tr>
<td>Hours/day Providing Care</td>
<td>19.2</td>
<td>15.7</td>
<td>4.362***</td>
</tr>
<tr>
<td>Years Providing Care</td>
<td>6.3</td>
<td>4.7</td>
<td>2.54*</td>
</tr>
<tr>
<td>Employment Outside the Home (%)</td>
<td>11%</td>
<td>53%</td>
<td>-9.1845***</td>
</tr>
<tr>
<td>If employed: Full Time (%)</td>
<td></td>
<td>55%</td>
<td></td>
</tr>
<tr>
<td>Other Caregiving Responsibilities (%)</td>
<td>13%</td>
<td>42%</td>
<td>-6.655***</td>
</tr>
<tr>
<td>Out of Pocket Expenses Incurred (%)</td>
<td>75%</td>
<td>54%</td>
<td>4.3503***</td>
</tr>
<tr>
<td>Expenses are Problematic (%)</td>
<td>31%</td>
<td>36%</td>
<td>-0.8719</td>
</tr>
<tr>
<td>CG Lives with CR (%)</td>
<td>98%</td>
<td>75%</td>
<td>6.9583***</td>
</tr>
<tr>
<td>Living Arrangement is Difficult</td>
<td>29%</td>
<td>40%</td>
<td>-2.2663*</td>
</tr>
</tbody>
</table>

*Differences in how adult child and spousal caregivers experience burden may be somewhat explained by other differences that are found between the two groups as shown in Table IV.7 above. Differences are found in age of the care recipient, employment status, other caregiving responsibilities, and income / out-of-pocket expenses. The average age of care recipients being cared for by a spouse in this sample is 77, while adult children are caring for parents with an average age of 85. As
problems related to aging increase with age, it may be that these care recipients exhibit more challenging caregiving needs. Care recipient functioning will be further explored to determine if there is support for this hypothesis.

Many of the adult child caregivers in the study are still members of the work force and report other caregiving responsibilities. As noted in Table IV.7 above, 53% of adult children in this study work outside the home, as compared to 11% of spousal caregivers who are employed. More than half (55%) of the adult child caregivers who are employed work full-time. Additionally, 44% of the adult child caregivers report other caregiving responsibilities above and beyond their parent(s), while only 10% of spousal caregivers indicate that they have other caregiving responsibilities.

Income and out-of-pocket expenses associated with caregiving could also have an impact on differences found between adult child and spousal caregivers. Adult children in the study have statistically significantly higher incomes than the spousal caregivers ($20,000 – $40,000 as opposed to less than $20,000, respectively). This is not surprising since more adult children are still employed full time. While spousal caregivers report higher levels of out-of-pocket spending than adult children, it was the adult children who find this spending to be more problematic. This may be due to feeling that spousal income is shared, and payment for care needs is an expected expense as a couple ages together. But for adult child caregivers, it represents a shift in roles and an additional financial burden added to their household.

Living arrangements may also provide some explanation for differences found between spousal and adult child caregivers. While 98% of spousal caregivers and 75% of adult child caregivers live with the care recipient, more adult children (40%) find the
living arrangement to be difficult than spousal caregivers (29%). One explanation may be that when adult children do not live with their parent, visiting them and providing care is an added responsibility in their already busy day.

Multivariate analyses are needed to determine which of these caregiver characteristics may explain higher levels of caregiver burden and depressive symptoms among adult children. The results of these analyses are presented later in this chapter.

Factors related to the functional and mental status of the care recipient were further analyzed to identify care recipient characteristics that might be possible explanatory factors for the differences found between spousal and adult child caregiver outcomes. Multivariate analyses, utilizing these factors, are reported later in this chapter. Results from an analysis of the differences in means on measures of care recipient functioning between spousal and adult child caregivers are represented in Table IV.8 below.

Table IV.8: Differences in Means on Measures of Objective Demands of Caregiving Between Spousal and Adult Child Caregivers

<table>
<thead>
<tr>
<th>Measure</th>
<th>Total Group Mean (SD)</th>
<th>Spousal Mean (SD)</th>
<th>Adult Child Mean (SD)</th>
<th>t-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Dependent ADL's</td>
<td>3.55 (3.21)</td>
<td>3.68 (3.30)</td>
<td>3.4 (3.11)</td>
<td>0.7948</td>
</tr>
<tr>
<td>Mental Status (SPMSQ)</td>
<td>5.18 (6.02)</td>
<td>5.40 (7.57)</td>
<td>4.92 (3.46)</td>
<td>0.7464</td>
</tr>
<tr>
<td>Frequency of Care Recipient Behaviors (RMBPC)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memory</td>
<td>4.64 (1.86)</td>
<td>4.54 (1.86)</td>
<td>4.74 (1.87)</td>
<td>-1.0229</td>
</tr>
<tr>
<td>Depression</td>
<td>3.68 (2.05)</td>
<td>3.47 (2.05)</td>
<td>3.92 (2.03)</td>
<td>-1.999*</td>
</tr>
<tr>
<td>Disruption</td>
<td>2.46 (1.50)</td>
<td>2.42 (1.55)</td>
<td>2.50 (1.46)</td>
<td>-0.454</td>
</tr>
</tbody>
</table>

*p < .05  
**p < .01  
***p < .001

Care recipient functioning is measured through several tools, including an assessment of activities of daily living, an assessment of mental status (the SPMSQ),
and an assessment of the frequency of problem behaviors (the RMBPC). No significant differences are found among the two groups, except for the frequency of depressive symptoms. Care recipients being cared for by their adult children are reported to have a higher frequency of depressive symptoms, although this difference is not large. In general, these findings do not support the hypothesis that the care recipients being cared for by adult children exhibit more challenging caregiving needs. Thus, factors related to the functional and mental status of the care recipient do not appear to differ across adult child and spousal caregivers. Whether these factors help explain greater levels of burden or depressive symptoms among caregivers as a whole will be further explored utilizing multivariate analyses which are reported later in this chapter.

RESEARCH QUESTIONS

*Relationships among Caregiving Demands, Burden, and Caregiver Outcomes*

My first research question addresses the relationships among the objective demands of caregiving, caregiver’s subjective appraisal of burden, and physical and mental health outcomes for caregivers of older adults. Past studies have convincingly demonstrated that caregiving is often a stressful and demanding responsibility and that caregiver burden is predictive of poor physical and mental health outcomes. This study attempts to identify the direct effect of the objective demands of caregiving on caregiver’s subjective appraisal of burden and caregiver outcomes, and whether caregiver’s subjective appraisal of burden mediates the relationship between objective demands of caregiving and caregiver outcomes. Based on the theoretical model which is the basis of this study, I ran a number of OLS regression models to test for these relationships.
Objective demands of caregiving predicting caregiver burden. The first set of regressions look at the relationship between the objective demands of caregiving and caregiver burden, controlling for the study’s key caregiver characteristics. Regressions were run for the ZBI, the primary measure of caregiver burden, and each of the three reaction scores from the RMBPC which measure how bothersome the caregiver finds problem behaviors exhibited by the care recipient.

The results of these regression analyses provide some interesting findings. Results indicate that the functional and mental status of the care recipient is not predictive of caregiver burden. However, the frequency of disruptive behaviors exhibited by the care recipient is significantly predictive of higher caregiver burden, and increased age is predictive of lower caregiver burden. The finding that care recipient functional and mental status is not predictive of caregiver burden is of note, as it would be expected that the amount of care required by the care recipient would be related to burden. This relationship is explored further in this study.

In the other three regression models, the only factor related to each measure of caregiver reaction score is the problem behavior related to that reaction. In other words, caregivers who report high levels of depressive behaviors in their care recipient also report that they found these behaviors to be bothersome; caregivers who report high frequencies of memory problems in their care recipient find these behaviors to be bothersome; and caregivers who report high frequencies of disruptive behaviors in their care recipient find these behaviors to be bothersome. This is not surprising and indicates that these variables are most likely conflated. Of note, however, is that caregivers with other caregiving responsibilities are less bothered by problem behaviors.
related to depression in their care recipient. Results of these regression models are represented in Table IV.9 below.

Table IV.9: Predicting Caregiver Burden from Objective Demands of Caregiving

<table>
<thead>
<tr>
<th></th>
<th>Burden (ZBI)</th>
<th>Reaction to Memory Behaviors</th>
<th>Reaction to Depressive Behaviors</th>
<th>Reaction to Disruptive Behaviors</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADL</td>
<td>-.06</td>
<td>.21</td>
<td>-.04</td>
<td>-.02</td>
</tr>
<tr>
<td>Mental Status</td>
<td>.06</td>
<td>-.04</td>
<td>-.09</td>
<td>.06</td>
</tr>
<tr>
<td>Memory Freq</td>
<td>.93</td>
<td>1.90***</td>
<td>-.04</td>
<td>.15</td>
</tr>
<tr>
<td>Depressive Freq</td>
<td>.56</td>
<td>.01</td>
<td>2.46***</td>
<td>-.08</td>
</tr>
<tr>
<td>Disruptive Freq</td>
<td>2.36***</td>
<td>.44</td>
<td>.08</td>
<td>2.30***</td>
</tr>
<tr>
<td>Gender (Female)</td>
<td>1.44</td>
<td>-.51</td>
<td>.62</td>
<td>.57</td>
</tr>
<tr>
<td>CG Age</td>
<td>-.25*</td>
<td>.03</td>
<td>.02</td>
<td>.01</td>
</tr>
<tr>
<td>Kinship (Adult Child)</td>
<td>-1.76</td>
<td>-.76</td>
<td>.78</td>
<td>.03</td>
</tr>
<tr>
<td>CG Employed</td>
<td>2.67</td>
<td>-.39</td>
<td>-.49</td>
<td>.38</td>
</tr>
<tr>
<td>Length of Time Caregiving</td>
<td>-.02</td>
<td>-.00</td>
<td>.00</td>
<td>-.02</td>
</tr>
<tr>
<td>CG Live with CR</td>
<td>-.78</td>
<td>-.98</td>
<td>.20</td>
<td>-.47</td>
</tr>
<tr>
<td>Other CG Responsibilities</td>
<td>-.55</td>
<td>-.29</td>
<td>-1.41*</td>
<td>-.08</td>
</tr>
<tr>
<td>Constant</td>
<td>39.00***</td>
<td>-4.11</td>
<td>-3.01</td>
<td>-2.25</td>
</tr>
<tr>
<td>$R^2$</td>
<td>.2218</td>
<td>.3445</td>
<td>.6654</td>
<td>.6564</td>
</tr>
</tbody>
</table>

*p<.05; **p <.01; ***p < .001

Note: Presented are OLS regression coefficients.

**Predicting caregiver outcomes.** In order to assess the relationship between the objective demands of caregiving and caregiver outcomes and whether caregiver’s subjective appraisal of burden mediates this relationship, I ran a series of ordinary least squares (OLS) regressions, utilizing various measures of caregiver well-being as the outcome variables. As the distributions for some of the outcome measures were skewed, I also ran robust regressions for all following analyses to test if outliers or influential cases were affecting the results. The results utilizing robust regression were very similar to the OLS results. For simplicity and consistency sake, I present only OLS regressions results here.
The first set of regressions looks at mental health outcomes utilizing scores on the CESD as the outcome measure. The second and third sets look at mental and physical well-being as the outcome measures, utilizing the difference scores on the SF-12 PCS and MCS. The difference scores measure the difference between the caregiver’s norm-based score and the population norms based on age and gender. The SF-12 provides norm-based summary measures of physical and mental well-being, based on studies conducted with the general US population. The scoring manual also provides specific norms based on age, gender, and presence of disease. According to Ware et al. (2009), since health status varies by age, gender, and presence of disease, it is important to consider these variations in interpreting scores on the SF-12. Therefore, by utilizing the difference between the caregiver’s scores and the population norm for their age and gender, we are able to determine the extent to which their score differs from what would be expected for them in relation to their specific peer group. As this study did not collect information on the medical condition of the caregiver, specific disease-related norms were not utilized.

Measures of caregivers’ subjective appraisal of burden include scores on the Zarit Burden Inventory and the reaction scores on the RMBPC. The ZBI measures how burdensome the caregiver perceives the caregiving situation, and the RMBPC measures how bothersome they find problem behaviors exhibited by their care recipient. Table IV.10 illustrates the series of OLS regressions for these analyses. The first column shows the regression of the objective demands of caregiving on depressive symptoms controlling for caregiver characteristics. The mental status of the care recipient, level of need for assistance with activities for daily living, and frequency of
memory related problems are not significantly predictive of depressive symptoms. However, the frequency of depressive behaviors and the frequency of disruptive behaviors of the care recipient are found to be significantly related to depressive symptoms. In the second regression analysis, caregiver burden and the caregiver’s reaction to the behaviors exhibited by the care recipient are added to the regression model. In this model, burden is the only variable that is significantly predictive of depressive symptoms, and the relationship between the frequency of depressive and disruptive behaviors of the care recipient and depressive symptoms is no longer significant. These findings provide support to my hypothesis that caregivers’ subjective appraisal of burden mediates the relationship between caregiving demands and caregiver outcomes.

The next set of regression models utilizes measures of caregiver physical and mental well-being as the outcome measure. As can be seen in the first model, utilizing physical well-being as the outcome measure, none of the variables related to caregiving demands or caregiver characteristics are found to be significantly related to physical well-being. When burden and caregiver reactions to problematic behaviors are added to the model, the caregivers’ reaction to care recipients’ memory problems is the only variable found to be significantly related to lower physical well-being of the caregiver. Surprisingly, burden is not found to be predictive of physical well-being in this model. In the final two models, mental well-being is utilized as the outcome measure. In relation to mental well-being, age and the length of time caregiving is found to be predictive of mental well-being, but this relationship loses its significance when burden and caregiver
reactions to behavior problems are added to the model. In the final model, only burden is found to be significantly related to mental well-being.

Table IV.10: Predicting Caregiver Outcomes from Objective Demands of Caregiving and Caregiver Burden, both Direct and Mediating Effects

<table>
<thead>
<tr>
<th></th>
<th>Depressive Symptoms</th>
<th>Physical Well-Being</th>
<th>Mental Well-Being</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Model One (n=199)</td>
<td>Model Two</td>
<td>Model One</td>
</tr>
<tr>
<td>ADL</td>
<td>-.02</td>
<td>-.02</td>
<td>-.55</td>
</tr>
<tr>
<td>Mental Status</td>
<td>-.31</td>
<td>-.32</td>
<td>.13</td>
</tr>
<tr>
<td>Memory Freq</td>
<td>-.16</td>
<td>-.47</td>
<td>-.45</td>
</tr>
<tr>
<td>Depressive Freq</td>
<td>.89*</td>
<td>.29</td>
<td>-.55</td>
</tr>
<tr>
<td>Disruptive Freq</td>
<td>1.29**</td>
<td>-1.18</td>
<td>.77</td>
</tr>
<tr>
<td>Gender (Female)</td>
<td>-.03</td>
<td>-.69</td>
<td>-2.02</td>
</tr>
<tr>
<td>CG Age</td>
<td>-.14</td>
<td>-.07</td>
<td>.18</td>
</tr>
<tr>
<td>Kinship (Adult Child)</td>
<td>1.34</td>
<td>2.06</td>
<td>2.56</td>
</tr>
<tr>
<td>CG Employed</td>
<td>-2.11</td>
<td>-2.84</td>
<td>1.80</td>
</tr>
<tr>
<td>Length of Time Caregiving</td>
<td>-.00</td>
<td>.00</td>
<td>.01</td>
</tr>
<tr>
<td>CG Live with CR</td>
<td>1.29</td>
<td>1.96</td>
<td>.27</td>
</tr>
<tr>
<td>Other CG Responsibilities</td>
<td>-1.27</td>
<td>-.72</td>
<td>-.24</td>
</tr>
<tr>
<td>Burden</td>
<td>.36***</td>
<td>.07</td>
<td>-.33***</td>
</tr>
<tr>
<td>React Memory</td>
<td>.14</td>
<td>-.43*</td>
<td></td>
</tr>
<tr>
<td>React Depression</td>
<td>.17</td>
<td>-.11</td>
<td></td>
</tr>
<tr>
<td>React Disruption</td>
<td>.24</td>
<td>.05</td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>19.63*</td>
<td>6.84</td>
<td>-12.15</td>
</tr>
<tr>
<td>$R^2$</td>
<td>0.1327</td>
<td>0.337</td>
<td>0.0594</td>
</tr>
</tbody>
</table>

*p < .05; **p < .01; ***p < .001
Note: Presented are OLS regression coefficients.

These analyses indicate that the objective demands of caregiving alone do not account for the depressive symptoms or physical or mental well-being experienced by caregivers. However, when we consider the caregiver’s subjective appraisal of burden, statistically significant relationships are found between burden and caregiver outcomes. This supports the research findings reported earlier in this paper that caregivers can be exposed to the same caregiving demands but experience different outcomes. These findings support the argument that caregiver outcomes are most directly related to how
the caregiver perceives and reacts to the demands of caregiving and not to the physical demands of caregiving, per se.

_Factor analysis of Zarit Burden Inventory._ Since caregiver burden was the one predictor that was consistently associated with poor caregiver outcomes across these analyses, I decided to conduct a factor analysis of the ZBI items in an attempt to identify specific dimensions of burden and determine whether they offer any further explanation for differences found in caregiver outcomes. The ZBI provides an overall score for burden, but the 22 questions that make up this survey measure different aspects of burden. Some studies have found it informative to consider multiple dimensions when studying caregiver burden (Ankri et al. 2005). Therefore, in order to further explore the idea that specific dimensions of burden might impact caregiver outcomes, a factor analysis was completed on the results of the Zarit Burden Inventory. Principal component factor analysis with varimax rotation was utilized, resulting in four retained factors which accounted for 51% of the total variation. The results of the factor analysis can be found in Appendix F.

The first factor identified had an eigenvalue of 6.81 and accounted for 31% of the total variation. Factor two had an eigenvalue of 1.92 and accounted for 9% of the variation; factor three had an eigenvalue of 1.27 and accounted for 6% of the variation; and factor four had an eigenvalue of 1.12 and accounted for 5% of the variation. I determined to retain the first two factors and identified the ZBI items relating to each. With the assistance of the Caregiver Specialists who work in the ServiceLink Resource Center Network, these factors were identified as: (Factor 1) Personal Impact and (Factor 2) Relational Impact and new variables were constructed with the individual
scores on each of these factors. The findings from this study are consistent with previous research which has found that the most frequently endorsed factor structure for the ZBI utilizes a two-factor model, considering personal strain and role strain (Herbert, Bravo, and Preville 2000).

The survey items that comprised the dimension of personal impact included items related to the effect of caregiving on the caregiver’s personal life. These items included statements such as not having enough time for oneself, ability to meet other family and work responsibilities, effect on relationships with others, impact on health, and a loss of control. The relational impact dimension included items related to the caregiver’s relationship with both the care receiver and others. Items that comprise this factor included feeling embarrassed about the care receiver, being uncomfortable having friends over, and feeling that the care receiver asks for more help than they need.

To assess whether spousal caregivers and adult child caregivers differ on these burden factors, a series of t-tests were performed. The results are shown in Table IV.11.

Table IV.11: T-tests on differences between spousal and adult child caregivers on dimensions of burden (n=395)

<table>
<thead>
<tr>
<th>Factor</th>
<th>Total Group Mean (SD)</th>
<th>Spousal Mean (SD)</th>
<th>Adult Child Mean (SD)</th>
<th>t-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Impact</td>
<td>20.35 (8.38)</td>
<td>19.27 (8.35)</td>
<td>21.62 (8.27)</td>
<td>-2.7933**</td>
</tr>
<tr>
<td>Relational Impact</td>
<td>3.21 (2.82)</td>
<td>2.85 (2.92)</td>
<td>3.63 (2.65)</td>
<td>-2.7519**</td>
</tr>
</tbody>
</table>

*p < .05
**p < .01
***p < .001

Results indicate that adult children experience significantly higher levels of burden related to personal and relational impact than spousal caregivers. Based on other findings in this dissertation, these findings are not surprising. Adult children experience a greater impact on their personal life when they become caregivers for their
parents, especially in relation to other caregiving responsibilities and employment. It also stands to reason that adult children experience greater relational impact as parental caregiving means a substantial shift in the parent/child relationship, as well as adding strain to spousal and other family relationships.

Ordinary Least Square (OLS) regression analyses were conducted utilizing these factors of burden as the outcome measures in order to determine whether the findings differed from the regression models utilizing the overall ZBI burden score as the outcome measure. No significant differences were noted, and the frequency of care recipient disruptive behaviors continued to be the only significant factor related to any of the burden measures. Therefore those results are not presented here.

Moderating Effects of Caregiver Characteristics

The regression models described previously show the significant relationship between caregiver burden and depressive symptoms. However, these analyses do not support the hypothesis that the objective demands of caregiving, as measured by the mental status, functional limitations, or problem behaviors of the care recipient, are directly related to negative caregiver outcomes. They do provide support for the argument that it is the caregiver’s reaction to or perception of how challenging these caregiver demands are that affect outcomes.

In this section, I explore whether certain caregiver characteristics moderate the relationship between caregiving demands, caregiver burden, and caregiver outcomes. In other words, do the associations examined above differ for different types of caregivers? To test for moderating effects, I ran a series of OLS regression models. The first set of regressions (illustrated in Table IV.12 below) analyzes the relationship
between the objective demands of caregiving and caregiver burden and whether caregiver age, kinship or employment status moderates this relationship. The second set of regression models (illustrated in Table IV.13 below) analyzes the relationship between burden and depressive symptoms and whether caregiver age, kinship or employment status moderates this relationship.

### Table IV.12 Moderating Effects of Caregiver Employment, Age, and Kinship on Association between Care Recipient Disruptive Behavior and Caregiver Burden

<table>
<thead>
<tr>
<th></th>
<th>Burden No Interaction</th>
<th>Employment Interaction</th>
<th>Age Interaction</th>
<th>Kinship Interaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disruptive Behavior</td>
<td>3.13***</td>
<td>3.02***</td>
<td>3.49</td>
<td>3.29***</td>
</tr>
<tr>
<td>Gender</td>
<td>2.34</td>
<td>2.31</td>
<td>2.37</td>
<td>2.28</td>
</tr>
<tr>
<td>CG Age</td>
<td>-.21*</td>
<td>-.21*</td>
<td>-.20</td>
<td>-.22*</td>
</tr>
<tr>
<td>Kinship</td>
<td>-1.25</td>
<td>-1.24</td>
<td>-1.24</td>
<td>-.41</td>
</tr>
<tr>
<td>CG Employed</td>
<td>1.43</td>
<td>.50</td>
<td>1.4</td>
<td>1.42</td>
</tr>
<tr>
<td>Length of Caregiving</td>
<td>-.01</td>
<td>-.01</td>
<td>-.01</td>
<td>-.01</td>
</tr>
<tr>
<td>CG Lives with CR</td>
<td>- .27</td>
<td>- .24</td>
<td>- .27</td>
<td>- .27</td>
</tr>
<tr>
<td>Other CG Responsibilities</td>
<td>-.80</td>
<td>-.82</td>
<td>-.80</td>
<td>-.81</td>
</tr>
<tr>
<td>Employment/Disruption Interaction</td>
<td></td>
<td>.37</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age/Disruption Interaction</td>
<td></td>
<td></td>
<td>-.01</td>
<td></td>
</tr>
<tr>
<td>Kinship/Disruption Interaction</td>
<td></td>
<td></td>
<td>-.34</td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>40.35***</td>
<td>40.68***</td>
<td>39.37***</td>
<td>40.14***</td>
</tr>
<tr>
<td>$R^2$</td>
<td>.2063</td>
<td>.2067</td>
<td>.2063</td>
<td>.2067</td>
</tr>
</tbody>
</table>

*p < .05  
**p < .01  
***p < .001

In the first set of regression models, analyzing the relationship between caregiving demands and caregiver burden, I chose the frequency of disruptive behaviors as the measure for objective demands of caregiving as it was the only care recipient characteristic that was found to be significantly associated with high levels of caregiver burden. In the first regression model, disruptive behavior is found to be significantly related to caregiver burden, even when controlling for a number of caregiver characteristics, including gender, age, kinship, employment, length of time
caregiving, living arrangement, and other caregiving responsibilities. In this model, age is also found to be significantly related to caregiver burden, such that burden is lower among older caregivers. In the following three regression models, I test for moderating effects of employment, age, and kinship. I created interaction variables for employment and disruptive behaviors, age and disruptive behaviors, and kinship and disruptive behaviors. In these equations, age has a significant main effect (except in the Burden/Age model), but the interaction among disruptive behaviors and employment, age, or kinship is not significant in any of the models, indicating that none of the caregiver characteristics in the model moderate the relationship between disruptive behavior and caregiver burden.

The second set of regressions test for moderating effects on the relationship between caregiver burden and depressive symptoms, illustrated in Table IV.13 below.

Table V.13: Moderating effects of Caregiver Employment, Age, and Kinship on Association Between Caregiver Burden and Depressive Symptoms (CESD)

<table>
<thead>
<tr>
<th></th>
<th>Burden</th>
<th>Gender</th>
<th>CG Age</th>
<th>Kinship</th>
<th>CG Employed</th>
<th>Length of Time Caregiving</th>
<th>CG Lives with CR</th>
<th>Other Caregiving Responsibilities</th>
<th>Employment/Burden Interaction</th>
<th>Age/Burden Interaction</th>
<th>Kinship/Burden Interaction</th>
<th>Constant</th>
<th>R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Interaction</td>
<td>.42***</td>
<td>.06</td>
<td>-.05</td>
<td>.91</td>
<td>-3.54**</td>
<td>-.00</td>
<td>-.55</td>
<td>.70</td>
<td>.04</td>
<td>-.00</td>
<td>.09</td>
<td>5.16</td>
<td>.2996</td>
</tr>
<tr>
<td>Employment Interaction</td>
<td>.41***</td>
<td>.07</td>
<td>-.05</td>
<td>.93</td>
<td>-4.73</td>
<td>-.00</td>
<td>-.58</td>
<td>.67</td>
<td>.04</td>
<td>-.00</td>
<td>.09</td>
<td>5.49</td>
<td>.30</td>
</tr>
<tr>
<td>Age Interaction</td>
<td>.69***</td>
<td>.26</td>
<td>.08</td>
<td>.88</td>
<td>-3.58**</td>
<td>-.00</td>
<td>-.52</td>
<td>.83</td>
<td>.04</td>
<td>-.00</td>
<td>.09</td>
<td>-3.73</td>
<td>.30</td>
</tr>
<tr>
<td>Kinship Interaction</td>
<td>.38***</td>
<td>.23</td>
<td>-.05</td>
<td>-2.05</td>
<td>-3.52**</td>
<td>-.00</td>
<td>-.44</td>
<td>.73</td>
<td>.04</td>
<td>-.00</td>
<td>.09</td>
<td>6.16</td>
<td>.30</td>
</tr>
</tbody>
</table>

*p < .05; **p < .01; ***p < .001
As seen in the first model, caregiver burden and employment are found to be significant predictors of depressive symptoms. Employment is predictive of lower depressive symptoms, while burden is positively associated with depressive symptoms, with all other caregivers characteristics controlled. The next three regression models test for moderating effects of employment, age, and kinship on the relationship between caregiver burden and depressive symptoms. I created interaction variables for employment and caregiver burden (ZBI score), age and caregiver burden, and kinship and caregiver burden. In these equations, the interactions between caregiver burden and employment, age, or kinship are not significant, indicating that none of the caregiver characteristics in the model moderate the relationship between caregiver burden and depressive symptoms.

And finally, I tested for the moderating effects of kinship, age, and employment on the relationship between caregiving demands and depressive symptoms. The results are found in Table IV.14 below. In the first model, with no interaction variable, disruptive behavior is significantly predictive of higher depressive symptoms, and employment and increased age are predictive of lower depressive symptoms. The next three regression models test for moderating effects of employment, age, and kinship on the relationship between caregiving demands and depressive symptoms. In these equations the interactions between disruptive behavior and employment, age, or kinship are not significant, indicating that none of the caregiver characteristics in the model moderate the relationship between caregiving demands and depressive symptoms. However, the direct effect between age depressive symptoms remains significant in all models, except the one including the age/disruptive behavior interaction. The direct effect of
employment on depressive symptoms is also found to be significant in the no interaction and kinship/disruptive interaction models.

Table IV.14: Moderating effects of Caregiver Employment, Age, and Kinship on Association Between Caregiver Demands and Depressive Symptoms (CESD)

<table>
<thead>
<tr>
<th></th>
<th>No Interaction (n=259)</th>
<th>Employment Interaction (n=259)</th>
<th>Age Interaction (n=259)</th>
<th>Kinship Interaction (n=259)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disruptive Behaviors</td>
<td>1.55***</td>
<td>1.42**</td>
<td>3.61</td>
<td>1.69**</td>
</tr>
<tr>
<td>Gender</td>
<td>1.07</td>
<td>1.02</td>
<td>1.2</td>
<td>.99</td>
</tr>
<tr>
<td>CG Age</td>
<td>-.17*</td>
<td>-.17*</td>
<td>-.09</td>
<td>-.17*</td>
</tr>
<tr>
<td>Kinship</td>
<td>1.30</td>
<td>1.31</td>
<td>1.34</td>
<td>2.05</td>
</tr>
<tr>
<td>CG Employed</td>
<td>-3.14*</td>
<td>-4.27</td>
<td>-3.08</td>
<td>-3.16*</td>
</tr>
<tr>
<td>Length of Time</td>
<td>-.00</td>
<td>-.00</td>
<td>-.00</td>
<td>-.00</td>
</tr>
<tr>
<td>Caregiving</td>
<td>-.31</td>
<td>-.25</td>
<td>-.29</td>
<td>-3.18</td>
</tr>
<tr>
<td>Employment/Disruption Interaction</td>
<td>.46</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age/Disruption</td>
<td></td>
<td></td>
<td>-.03</td>
<td></td>
</tr>
<tr>
<td>Interaction</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kinship/Disruption</td>
<td></td>
<td></td>
<td>-.31</td>
<td></td>
</tr>
<tr>
<td>Interaction</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>23.35**</td>
<td>23.74**</td>
<td>17.79</td>
<td>23.17**</td>
</tr>
<tr>
<td>R²</td>
<td>.1149</td>
<td>.1158</td>
<td>.1180</td>
<td>.1154</td>
</tr>
</tbody>
</table>

*p< .05
**p < .01
***p < .001

The findings from all three sets of regressions do not support my hypotheses that caregiver characteristics (age, employment, and kinship) would moderate the relationships among objective demands of caregiving, caregiver burden, and depressive symptoms. The results do, however, show that age has a direct effect on caregiver burden in that older caregivers experience lower levels of burden. Employment is also found to have a direct effect on caregiver depressive symptoms in that caregivers who are employed experience lower levels of psychological distress.
**Caregiver Support Preferences**

The final research question in the quantitative section of this study is whether the caregiver’s preference for instrumental or emotion-focused caregiver support interventions is related to caregiver or care recipient characteristics. As part of the six-month follow-up assessment, caregivers were asked what caregivers support services were most helpful. Responses, reported by 225 caregivers, were then coded into three categories: instrumental supports, emotional supports, and other. These codes were then confirmed by a second researcher. The results of this analysis are shown in Table IV.15. Instrumental supports represented material services such as respite care, funds for modifications or supplies, and referral to services such as adult day care or Meals on Wheels. These types of instrumental supports were named as “most helpful” by 146 caregivers (65%). Emotional supports represented counseling and supportive resources that help a caregiver to handle the emotional consequences of caregiving and could include one-on-one visits or telephone conversations with the Caregiver Specialist. Comments that were coded as emotional supports included: “knowing there was someone I could talk to;” “knowing someone cared;” and “knowing that I wasn’t alone.” Emotional supports were named as “most helpful” by 73 caregivers (32%).

<table>
<thead>
<tr>
<th></th>
<th>Total (n=225)</th>
<th>Adult Child Caregiver (n=113)</th>
<th>Spousal Caregivers (n=112)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Instrumental Support</strong></td>
<td>146 (65%)</td>
<td>76 (67%)</td>
<td>70 (62%)</td>
</tr>
<tr>
<td><strong>Emotional Support</strong></td>
<td>73 (32%)</td>
<td>34 (30%)</td>
<td>39 (35%)</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>6 (3%)</td>
<td>3 (3%)</td>
<td>3 (3%)</td>
</tr>
</tbody>
</table>

The data suggest that spousal caregivers are more likely than adult children to appreciate emotional support, while adult children cite preferences for instrumental supports more often than spouses; however, the differences were not found to be
statistically significant. Further analyses, using t-tests to determine differences in means, indicate that the care recipients’ cognitive ability and the care recipients’ age were predictive of whether caregivers would find instrumental or emotional supports more helpful. As depicted in Table IV.16, caregivers whose loved ones were older and exhibited more cognitive impairment were significantly more likely to name instrumental supports as most helpful. No significant differences were found in preferences for support based on kinship, functional levels of the care recipient as measured by ADL’s, or levels of burden or depressive symptoms experienced by caregivers.

Table IV.16: Preference for Instrumental or Emotional Support by Care Recipient Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Kinship Mean (SD)</th>
<th>CR Cognitive Mean (SD)</th>
<th>CR ADL’s Mean (SD)</th>
<th>CR Age Mean (SD)</th>
<th>Burden Mean (SD)</th>
<th>CESD</th>
<th>t-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Instrumental Support</td>
<td>.5205 (.5013)</td>
<td>5.41 (3.28)</td>
<td>3.68 (3.16)</td>
<td>82.58 (8.18)</td>
<td>34.51 (14.12)</td>
<td>14.86 (11.4)</td>
<td>0.7620</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>.4658 (.5023)</td>
<td>3.78 (3.32)</td>
<td>3.62 (3.54)</td>
<td>79.64 (9.33)</td>
<td>32.87 (13.43)</td>
<td>15.1 (11.14)</td>
<td>3.2899***</td>
</tr>
<tr>
<td>t-value</td>
<td>0.7620</td>
<td>3.2899***</td>
<td>0.1119</td>
<td>2.4054**</td>
<td>.8485</td>
<td>-0.1534</td>
<td></td>
</tr>
</tbody>
</table>

* p < .05  
** p < .01  
*** p < .001

SUMMARY OF FINDINGS

The analyses conducted so far have uncovered a number of interesting findings. Both the caregivers and care receivers in this study are primarily female, married, and older. Most caregivers in the study have been caregiving for an extended period of time, with an average of five and a half years. Most of the caregivers (87%) live with the care recipient, and 34% report that they find the living arrangement to be problematic.

Caregivers who did not live with the care recipient were more likely to find their living arrangement to be problematic, although this difference is not found to be statistically significant. About one quarter of the caregivers have additional caregiving responsibilities, and 32% maintain jobs outside the home. Both the caregivers and care
recipients in this study report relatively low income levels. Thirty-seven percent of caregivers and 62% of care recipients report incomes of less than $20,000 per year.

Caregivers in this study experience high levels of caregiver burden and depressive symptoms. Over three-quarters of the caregivers report mild to severe levels of burden on the ZBI and are at risk for depression. In fact, almost 42% of the caregivers in the study report clinical levels of depressive symptoms. Consistent with the high scores on the CESD, caregivers of all ages scored lower on the measure of mental well-being on the SF-12, as compared to their age norms. Interestingly, the caregivers in this study are not found to have lower levels of physical well-being as compared to their age norms on the SF-12, except for those under the age of 55, who report statistically significant lower levels of physical well-being as compared to their age peers.

The care recipients in this study are found to present with high levels of functional, behavioral, and cognitive need. Care recipients average 3.56 activities of daily living (personal care) and 7.61 instrumental activities of daily living (cooking, housekeeping, transportation) requiring assistance from a caregiver. As nursing home level of care in New Hampshire is defined as needing assistance with at least two activities of daily living, the care recipients in this study have high care needs and would qualify for nursing home level of care in New Hampshire.

Care recipients in this study are also found to exhibit relatively high frequencies of challenging behaviors and high levels of cognitive impairment. The highest frequency of reported behaviors are related to memory problems (average of 4.68 behaviors per week), followed by depression (average of 3.69 behaviors per week), and then
disruptive behaviors (average of 2.49 behaviors per week). Care recipients in this study exhibit mild to moderate cognitive impairment on average, with over 30% assessed as having severe cognitive impairment.

I began this study with a number of research questions related to the relationships among the objective demands of caregiving, caregivers’ subjective appraisal of burden, and physical and mental health outcomes for caregivers; whether caregivers’ subjective appraisal of burden mediates the relationship between caregiving demands and caregiver outcomes; and whether certain caregiver characteristics moderate these relationships. I use correlation, t-test, and regression analyses to address these questions.

In line with the existing body of research on caregiver burden, I found significant relationships among the core factors of interest: caregiving demands, caregiving burden and caregiver well-being. Regression analyses indicate that the frequency of both depressive and disruptive behaviors exhibited by the care recipient are predictive of higher levels of caregiver depressive symptoms; however, this relationship is mediated by the caregiver’s subjective appraisal of burden. Thus, the objective demands of caregiving alone do not account for the depressive symptoms experienced by caregivers. When the caregiver’s subjective appraisal of burden is considered, statistically significant relationships are found between burden and caregiver outcomes. These findings suggest that caregivers can be exposed to the same objective caregiving demands, but caregiver outcomes are mediated by how they perceive and react to these demands.
Factor analysis of the ZBI items identified specific dimensions of burden and provided some additional insights about the differences found in caregiver outcomes. Principal component factor analysis with varimax rotation resulted in two retained factors. These factors were labeled, with the help of professionals who work with caregivers on a daily basis, as Personal Impact and Relational Impact. Results indicate that caregivers who are younger, employed, have other caregiving responsibilities, and who find their living arrangement to be difficult, experience the greatest burden associated with caregiver’s personal life. Caregivers who are younger and have other caregiving responsibilities experience the greatest burden associated with relational impact.

My next set of analyses focused on caregiver characteristics and their association with caregiving demands, caregiver burden, and depressive symptoms. I started by doing correlational analyses which indicated a number of associations among the variables being studied. Kinship is found to be significantly associated with burden, length of time caregiving, gender, and employment. Gender is found to be significantly associated with depressive symptoms, burden, and kinship, in that female caregivers report higher levels of depressive symptoms and burden. Employment is found to be significantly associated with both burden and kinship; that is, caregivers who are employed report higher levels of burden, and more adult child caregivers are employed.

Of particular interest to me were differences found between adult child and spousal caregivers in this study, and I wondered if kinship was an explanatory factor in caregiver outcomes. I conducted t-tests to determine differences among means across these two groups of caregivers and discovered a number of statistically significant
findings. Adult child caregivers report statistically higher levels of depressive symptoms and caregiver burden as compared to spousal caregivers. Adult child caregivers are younger, care for older care recipients, provide fewer hours of care, and have been caregiving for a shorter period of time. They are more likely to be employed and to have other caregiving responsibilities. They are less likely to incur out of pocket expenses, but more likely to find these expenses to be problematic, although this latter difference was not found to be statistically significant. Finally, they are less likely to live with the care recipient, but more likely to find their living arrangement to be problematic. Of note, there are few differences found among measures of care recipient functioning between the two groups, so the level of care required by the care recipient does not appear to be an explanatory factor.

To study these relationships further, I ran a number of regression models to determine if caregiver characteristics--namely age, employment status, or kinship--, moderated the relationships between caregiving demands, caregiver burden, and mental well-being. The results of these analyses did not support the presence of moderating effects for these variables and did not corroborate my hypothesis that the effect of demands on burden or the effect of burden on well-being differed by kinship, age, or employment. However, these analyses did show that employment is predictive of lower depressive symptoms for all caregivers and that caregiver age is predictive of lower levels of caregiver burden and depressive symptoms. How and why employment and age may affect caregiver outcomes is further explored in the qualitative portion of this study.
Finally, an analysis of preference for instrumental or emotional supports indicates that spousal caregivers are more likely than adult children to appreciate emotional support, while adult children cite preferences for instrumental supports more often than spouses. The differences, however, were not statistically significant. Further analyses indicated that the care recipients’ cognitive ability and the care recipients’ age are associated with whether caregivers would find instrumental or emotional supports more helpful. That is, caregivers whose loved ones are older and exhibit more cognitive impairment are significantly more likely to name instrumental supports as most helpful.

Although the quantitative findings outlined in this chapter demonstrate important associations between caregiver and care recipient characteristics, caregiver burden, and caregiver outcomes, they cannot address the meanings that caregivers attribute to the caregiving experience. To better understand the processes, attitudes, and experiences behind the quantitative data, I also include a qualitative component to my dissertation research. Specifically, I interview 20 caregivers in order to further illuminate how these caregivers experience caregiving and to provide additional descriptive data on the dynamics of the caregiving process. The results of this part of my research are elaborated in the next section.
CHAPTER V

QUALITATIVE FINDINGS

Based on the findings reported in Chapter IV, I conducted a series of interviews of caregivers to further explore the meanings that caregivers ascribe to the caregiving experience. My purpose was to identify contextual factors that may further explain the findings from the quantitative portion of this study. Of specific interest was to further explore differences found between adult child and spousal caregivers and how employment and age affect caregiver outcomes. The in-depth interviews also provide a rich set of data to describe and understand how these caregivers experience their roles as caregivers.

The research question that I hoped to answer through these interviews is:

How do meanings ascribed to the caregiving experience help explain how different caregiver statuses, such as kinship, age, and employment, condition whether objective demands of caregiving are perceived as burdensome?

For this portion of my study, I interviewed 20 caregivers. Five caregivers are spouses who reported high burden scores at entry into the program, and five caregivers are spouses who reported low burden scores at entry. Five caregivers are adult children caring for their parents who reported high burden scores at entry into the program, and five are adult children caring for their parents who reported low burden scores. High burden scores are considered to be one standard deviation above the mean score for all caregivers in the sample, and low burden scores are considered to be one standard deviation below the mean score for all caregivers in the sample. I used random number
assignment through Excel to determine a random sample of these caregivers. Caregivers who were selected in the sample were contacted by a caregiver specialist or program manager to ask if they would be willing to be interviewed and if they agreed to share their contact information with me. Once they agreed to be a part of the study, I contacted them directly to set up an appointment for the interview.

I oversampled knowing that many caregivers would no longer be available for an interview, but finding willing interview participants was more challenging than I anticipated. Ultimately, I had to pull four rounds of caregiver names from the sample in order to achieve a sample of 20 caregivers. There were a number of reasons for this difficulty. Many phone numbers were no longer in service, several of the caregivers had passed away, some caregivers were unwilling to be interviewed, some caregivers had moved away, and many simply never returned the call after repeated attempts to reach them. Out of a total sample of 146 caregivers who were eligible to be included in the sample, 87(60%) were contacted to obtain a final sample of 20 caregivers who agreed to be interviewed. Interestingly, it was easier to find caregivers from the high burden groups than the low burden groups. This may be indicative of their need for contact with outside people and desire to talk about their experience. We contacted 74% of spousal and 78% of adult child caregivers who were part of the sample based on low burden scores in order to find ten willing interview subjects.

Table V.1 Caregiver Sample

<table>
<thead>
<tr>
<th>Caregiver Category</th>
<th>Number in Sample</th>
<th>Number Contacted</th>
<th>Percent of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spousal High Burden</td>
<td>29</td>
<td>16</td>
<td>55%</td>
</tr>
<tr>
<td>Adult Child High Burden</td>
<td>43</td>
<td>15</td>
<td>35%</td>
</tr>
<tr>
<td>Spousal Low Burden</td>
<td>47</td>
<td>35</td>
<td>74%</td>
</tr>
<tr>
<td>Adult Child Low Burden</td>
<td>27</td>
<td>21</td>
<td>78%</td>
</tr>
<tr>
<td>Total</td>
<td>146</td>
<td>87</td>
<td>60%</td>
</tr>
</tbody>
</table>
CHARACTERISTICS OF INTERVIEW PARTICIPANTS

Despite the challenges in obtaining 20 willing participants, the final sample is a diverse and interesting group of caregivers, each with an intriguing story to tell. My travels for these interviews took me all over New Hampshire. I visited Colebrook, the Mount Washington Valley, the Lakes region, the Monadnock region, the Seacoast, and Grafton County, as well as Concord, Manchester, and Nashua. Table V.2 provides a snapshot of the caregivers interviewed, as well as factors related to their care recipient.

Table V.2: Characteristics of Caregivers Interviewed and Their Care Recipient

<table>
<thead>
<tr>
<th>Pseudo-Name</th>
<th>CG Rel to CR</th>
<th>CG Age</th>
<th>GEN</th>
<th>BUR</th>
<th>DEP</th>
<th>CG Trans</th>
<th>EMP</th>
<th>MOS. CG</th>
<th>Still CG</th>
<th>CR Age</th>
<th>CR Dx</th>
<th>ADL</th>
<th>Cogn</th>
</tr>
</thead>
<tbody>
<tr>
<td>Martha</td>
<td>SP</td>
<td>70</td>
<td>F</td>
<td>54</td>
<td>22</td>
<td>Grad</td>
<td>N</td>
<td>84</td>
<td>N</td>
<td>89</td>
<td>Alzheimers</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Nora</td>
<td>SP</td>
<td>71</td>
<td>F</td>
<td>52</td>
<td>29</td>
<td>Grad</td>
<td>N</td>
<td>108</td>
<td>N</td>
<td>74</td>
<td>Chronic Illness</td>
<td>9</td>
<td>0</td>
</tr>
<tr>
<td>Marsha</td>
<td>SP</td>
<td>82</td>
<td>F</td>
<td>48</td>
<td>20</td>
<td>Grad</td>
<td>N</td>
<td>60</td>
<td>Y</td>
<td>82</td>
<td>Brain Disease</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Tom</td>
<td>SP</td>
<td>69</td>
<td>M</td>
<td>55</td>
<td>16</td>
<td>Rapid</td>
<td>N</td>
<td>72</td>
<td>Y</td>
<td>63</td>
<td>Brain Injury</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Jane</td>
<td>SP</td>
<td>68</td>
<td>F</td>
<td>55</td>
<td>38</td>
<td>Rapid</td>
<td>N</td>
<td>12</td>
<td>Y</td>
<td>80</td>
<td>Stroke</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Janet</td>
<td>SP</td>
<td>78</td>
<td>F</td>
<td>19</td>
<td>6</td>
<td>Rapid</td>
<td>N</td>
<td>96</td>
<td>N</td>
<td>86</td>
<td>Stroke</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>Herman</td>
<td>SP</td>
<td>80</td>
<td>M</td>
<td>10</td>
<td>7</td>
<td>Rapid</td>
<td>N</td>
<td>12</td>
<td>Y</td>
<td>78</td>
<td>Stroke</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>Robert</td>
<td>SP</td>
<td>78</td>
<td>M</td>
<td>15</td>
<td>1</td>
<td>Grad</td>
<td>Y</td>
<td>72</td>
<td>N</td>
<td>73</td>
<td>Alzheimers</td>
<td>10</td>
<td>3</td>
</tr>
<tr>
<td>Debra</td>
<td>SP</td>
<td>57</td>
<td>F</td>
<td>15</td>
<td>6</td>
<td>Grad</td>
<td>Y</td>
<td>360</td>
<td>Y</td>
<td>61</td>
<td>Disabled Veteran</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>Joseph</td>
<td>SP</td>
<td>91</td>
<td>M</td>
<td>18</td>
<td>5</td>
<td>Grad</td>
<td>N</td>
<td>60</td>
<td>N</td>
<td>92</td>
<td>Alzheimers</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Karen</td>
<td>AC</td>
<td>60</td>
<td>F</td>
<td>55</td>
<td>13</td>
<td>Grad</td>
<td>Y</td>
<td>6</td>
<td>N</td>
<td>83</td>
<td>Vascular Dementia</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Diana</td>
<td>AC</td>
<td>62</td>
<td>F</td>
<td>54</td>
<td>22</td>
<td>Grad</td>
<td>Y</td>
<td>48</td>
<td>Y</td>
<td>89</td>
<td>Falls, Chronic Illness</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Jim</td>
<td>AC</td>
<td>71</td>
<td>M</td>
<td>53</td>
<td>33</td>
<td>Grad</td>
<td>N</td>
<td>118</td>
<td>N</td>
<td>93</td>
<td>Stroke</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Kelly</td>
<td>AC</td>
<td>59</td>
<td>F</td>
<td>66</td>
<td>43</td>
<td>Grad</td>
<td>Y</td>
<td>24</td>
<td>N</td>
<td>89</td>
<td>Dementia</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Jean</td>
<td>AC</td>
<td>59</td>
<td>F</td>
<td>59</td>
<td>7</td>
<td>Grad</td>
<td>Y</td>
<td>132</td>
<td>N</td>
<td>70</td>
<td>Dementia</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Doreen</td>
<td>AC</td>
<td>56</td>
<td>F</td>
<td>19</td>
<td>1</td>
<td>Grad</td>
<td>Y</td>
<td>6</td>
<td>N</td>
<td>87</td>
<td>Alzheimers</td>
<td>NR*</td>
<td>0</td>
</tr>
<tr>
<td>Amy</td>
<td>AC</td>
<td>57</td>
<td>F</td>
<td>14</td>
<td>0</td>
<td>Grad</td>
<td>Y</td>
<td>24</td>
<td>N</td>
<td>84</td>
<td>Parkinsons</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Ellen</td>
<td>AC</td>
<td>48</td>
<td>F</td>
<td>15</td>
<td>0</td>
<td>Grad</td>
<td>Y</td>
<td>276</td>
<td>N</td>
<td>85</td>
<td>Chronic Illness</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Jill</td>
<td>AC</td>
<td>68</td>
<td>F</td>
<td>18</td>
<td>3</td>
<td>Grad</td>
<td>N</td>
<td>20</td>
<td>N</td>
<td>93</td>
<td>Alzheimers</td>
<td>NR*</td>
<td>2</td>
</tr>
<tr>
<td>Susan</td>
<td>AC</td>
<td>68</td>
<td>F</td>
<td>14</td>
<td>11</td>
<td>Rapid</td>
<td>Y</td>
<td>2</td>
<td>N</td>
<td>93</td>
<td>Stroke</td>
<td>11</td>
<td>3</td>
</tr>
</tbody>
</table>

*NR = No Response from Care Recipient
The caregivers interviewed represent a fairly diverse sample of the 418 caregivers involved in the larger study. The age of the caregivers ranges from 48 to 91. The spousal caregivers are older, ranging in age from 57 to 91, while the adult child caregivers range in age from 48 to 71. Not surprisingly, the care recipients are closer in age, with care recipients of spousal caregivers ranging in age from 61 to 92 and care recipients of adult child caregivers ranging in age from 70 to 93. In terms of gender, six spousal caregivers are female and four are male; nine of the adult child caregivers are female and only one is male. Of note is that the male adult child caregiver is an only child and reported a high level of caregiver burden, while three of the four male spousal caregivers are in the low burden group.

The length of time caregiving varies across the caregivers interviewed, ranging from two months to 30 years. Only one of the adult child caregivers was still providing care for their parent, while half of the spousal caregivers were still caregiving at the time of this interview. These factors may influence the responses of the caregivers interviewed, as caregivers may represent the caregiving experience differently when they are actively engaged in caregiving as opposed to recalling what it felt like when they were caregiving.

A significant portion of the interview focused on the caregiver’s transition into the role of a caregiver. While the details of these transitions are outlined later in this chapter, this chart provides a snapshot of how these transitions transpired. For nine out of the 10 adult child caregivers, their transition into caring for their parent was a gradual process that evolved over time. For the one adult child who reported a more rapid transition, this was due to the fact that her mother had been failing for a period of time.
and had entered a nursing home. She made the decision to move her mother into her home, thus precipitating a rapid transition into the role of caregiver, even though she had seen her mother’s condition deteriorating over time. The transitions for spousal caregivers are more varied, with six reporting a gradual decline in their spouse along with a concomitant increase in the types of care they provided over time. The care recipients in these situations are likely to have Alzheimer’s or other dementias or a chronic illness. Four spousal caregivers report a more rapid transition into caregiving, typically precipitated by a stroke or traumatic brain injury experienced by their spouse.

Caregivers were chosen for this sample based on their burden scores which are reported in Table V.2 above. As found in the larger sample, high burden was found to be associated with high levels of depressive symptoms for most of the caregivers interviewed. Of note, however, is that two adult child caregivers with high burden scores reported low levels of depressive symptoms. Remember, a score of 16 and higher on the CES-D is considered to be predictive of clinical depression.

Employment is an area in which differences can be seen between the adult child and spousal caregivers interviewed. While two spousal caregivers report being employed, this was earlier in their caregiving career, and they were no longer employed at the time of this interview. In contrast, eight of the 10 adult child caregivers report being employed while they cared for their parents. Only two were retired prior to taking on the care of their parent, and two retired as a direct result of their caregiving responsibilities.

Table V.2 above also outlines characteristics of the care recipients that are important to this discussion. Ten of the care recipients are diagnosed with Alzheimer’s,
other dementias, or brain disorders, evenly split between adult child and spousal caregivers. The next largest group of diagnoses is strokes, with three being cared for by spouses and two being cared for by adult children. The other five care recipients have a range of chronic conditions including a bone disease, diabetes, Parkinson’s, and chronic obstructive pulmonary disease (COPD). The number of Activities of Daily Living (ADLs) for which the care recipients need assistance ranges from zero to 11. Surprisingly, spouses who report low levels of burden are caring for care recipients with the highest levels of need for assistance with ADLs. The level of cognitive impairment of the care recipients ranges from zero (no impairment) to three (high level of impairment), with no particular clusters by caregiver grouping.

In order to assure that the interview sample was representative of the entire population of the 418 caregivers in this study, I made comparisons across a number of factors. The results are indicated in Table V.3 below. As indicated in the table, the caregivers who agreed to be interviewed are similar to the population of all caregivers in the study in terms of age, gender, and age of the care recipient. A few notable differences are that more adult daughters than sons are in the interview sample, and more adult children are caring for their mothers than in the total study sample. Only one adult child is caring for their father. Caregivers in the interview sample have been providing care for more years, and more of the adult children interviewed are employed. Of those employed, more of the caregivers in the interview sample are employed full time. Fewer of the interviewed caregivers have other caregiving responsibilities. I found similar percentages across the two groups in term of living arrangements and whether
the caregiver found this living arrangement to be problematic. In general, the interview sample is found to be similar to the overall study sample.

Table V.3. Comparison Between Total Study Sample and Interview Sample

<table>
<thead>
<tr>
<th></th>
<th>Spousal Caregivers (n = 211)</th>
<th>Adult Child Caregivers (n = 181)</th>
<th>Spousal Interview (n = 10)</th>
<th>Adult Child Interview (n = 10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (mean)</td>
<td>74</td>
<td>56</td>
<td>71</td>
<td>57</td>
</tr>
<tr>
<td>Gender</td>
<td>Female 64%</td>
<td>Male 36%</td>
<td>Female 60%</td>
<td>Male 90%</td>
</tr>
<tr>
<td>Caring for</td>
<td>Wife 37% 37%</td>
<td>Mother 78% 22%</td>
<td>W 40%</td>
<td>M 9% 90%</td>
</tr>
<tr>
<td>Mean Age of Care Recipient</td>
<td>77 60%</td>
<td>85 78%</td>
<td>78 40%</td>
<td>89 60%</td>
</tr>
<tr>
<td>Hours/Day Providing Care</td>
<td>19.2</td>
<td>15.7</td>
<td>20.9</td>
<td>16</td>
</tr>
<tr>
<td>Years Providing care</td>
<td>6.3</td>
<td>4.7</td>
<td>7.05</td>
<td>5.47</td>
</tr>
<tr>
<td>Employment outside the Home (%)</td>
<td>11% 55%</td>
<td>53% 86%</td>
<td>0 86%</td>
<td>70 86%</td>
</tr>
<tr>
<td>If employed: Full Time (%)</td>
<td>13%</td>
<td>42%</td>
<td>10 20%</td>
<td></td>
</tr>
<tr>
<td>Other Caregiving Responsibilities (%)</td>
<td>98%</td>
<td>75%</td>
<td>90 70%</td>
<td></td>
</tr>
<tr>
<td>CG Lives with CR</td>
<td>29%</td>
<td>40%</td>
<td>30 40%</td>
<td></td>
</tr>
<tr>
<td>Living Arrangement is Difficult</td>
<td>29%</td>
<td>40%</td>
<td>30 40%</td>
<td></td>
</tr>
</tbody>
</table>

QUALITATIVE ANALYSIS

Caregiver interviews lasted anywhere from 45 minutes to two hours, depending on how much the caregiver wanted to share with me. Most seemed genuinely interested in sharing their stories with me and hopeful that my research could help other caregivers. The stories I heard were emotional, loving, and difficult; bringing several caregivers to tears during our interview. I taped each interview and had them transcribed.

My first step in the qualitative analysis process was to read through each interview in its entirety in order to get an overall sense of the results. This review helped me to gain a general overview of the contents of the interviews and a beginning sense of common themes. I took notes during this review to help me organize the data into categories and themes in the next step of the analysis. I used these notes to develop a
list of topics that emerged from the interviews and then clustered these topics into broader categories or themes. The next step was to conduct a more detailed review of the interviews, reading them a second time for common themes identified in my first review and beginning to code the data based on these themes. I highlighted specific text from each interview that I felt represented the common themes I had identified in my first read-through.

Using NVIVO, I created “nodes” or categories for the common themes that I had identified. While NVIVO calls these nodes, I will use the term “categories” for purposes of this discussion. I labeled these categories and developed a preliminary definition for the idea or concept captured. I created 22 categories with up to seven sub-categories, resulting in a total of 47 categories. I then reviewed all interviews again and began saving quotes, paragraphs, and sentence segments into appropriate categories. Following this step in the process, I reviewed the contents of each category, revising and refining my analysis once again. I deleted categories that contained few data points, consolidated categories that seemed to represent similar concepts, and created new categories for ideas that emerged during this step in the process.

At this point, I enlisted a second coder to read each of the interviews, providing another set of eyes to confirm or question my coding. Combining my analysis with the secondary coder’s review, I removed some categories, consolidated others, and created several new categories, narrowing the list of categories to 31. While this number of categories is larger than anticipated, I determined to not cut any sections at this point in my analysis in order to present a full picture of my dissertation findings and to spur future research utilizing these data.
The final step of the qualitative analysis was to interpret the meaning of these findings, particularly in relation to the stress process, the theoretical framework for this study. Both the quantitative and qualitative data were integrated during the final analysis. Findings were compared and synthesized for common, as well as divergent, results. Supporting as well as conflicting results were analyzed and reported.

Through these interviews I set out to understand how these caregivers experience their role as a caregiver. I wanted to understand difference that I found between spousal and adult child caregivers in the quantitative portion of this study. How did they experience the transition into a caregiver role? Why were they willing to be a caregiver? What were their motivations? How did finances, work, and other family responsibilities impact their caregiving? What did they find both rewarding and challenging about caregiving? What advice would they give to other caregivers? In the following sections, I try to paint a picture of the caregiving experience of these caregivers. I have changed the names of those interviewed and where they live to maintain confidentiality. I use direct quotes from the interviews as I believe that the caregivers tell their story best and that para-phrasing could lose the intent and emotional content of their words.

CAREGIVER TRANSITIONS

I asked caregivers to describe their transition into the caregiving role. Dr. Dennis McCullough (2008), in his book *My Mother, Your Mother*, describes what he calls the eight stations of late life. According to Dr. McCullough, station one is “stability” in both the caregiver and care recipient deny that anything is really wrong. The second station is “compromise” when the family admits that the older adult may be beginning to have
some problems. Station three is “crisis” when something happens which typically results in the person being hospitalized. Station four is “recovery” and is often characterized with a stay in a rehabilitation facility. McCullough calls station five “decline” in that the care recipient begins to fail more and more, and the family begins to accept that they are not going to recover. Station six he calls the “prelude to dying” when there begins to be an acceptance that the person is dying, both by the person and their caregivers. Station seven is the death of the care recipient, and station eight is grieving over their death.

I found through my interviews that this was a pretty typical progression. Families would begin to notice small changes in the older adult, but they would often dismiss them as normal forgetfulness or typical signs of aging. Ultimately, something would happen which precipitated a hospital stay leading to an admission to a rehabilitation facility. Often this hospitalization and rehabilitation stay would be precipitated by a fall, a stroke, pneumonia, or other medical crises. The family is usually hopeful of a good recovery following this first incident. But eventually the older adult continues to decline, and the family begins to accept the fact that they are failing. It's at this time that I found that the caregivers I interviewed began to realize that they were caregivers and that they needed to make changes in their lives. This is the point where many of the adult children I interviewed either moved in with their parent or had their parent move in with them. They begin to look for supports and hire people to come in to help them care for their parent or their spouse. This then leads to what Dr. McCullough calls the prelude to dying, when families begin to realize and accept that the death of their loved one is inevitable and imminent. Several of the caregivers I spoke with talked about accepting
that caregiving for an older adult is about helping that person to die. They also talked about how lucky they were to experience this stage of life with their parent or spouse. Following the death of their loved one comes a period of grieving. Many of the caregivers I interviewed noted that their caregiving experience helped them to grieve and have no regrets about how they handled the end-of-life for their loved one.

These stages were pretty typical across all of the caregivers that I interviewed, and the stories I heard generally followed this series of stages. There were some differences, however, in how adult children and spousal caregivers experienced the transition into the caregiving role. The timing of these transitions also varied, primarily based on the nature of the care recipient’s condition and how quickly caregiving demands increased. That is, for persons caring for a loved one with a chronic condition, such as Alzheimer’s Disease or COPD, the transition into the role of caregiver evolved over time. Other caregivers were thrown into the role more suddenly as the result of a catastrophic event such as a stroke or accident.

The transition into caregiving for the adult children I interviewed was primarily a gradual experience. Only one out of the 10 caregivers interviewed described a rapid transition. In this situation, she made a decision to bring her mother to live with her following a rehabilitation stay. She felt the quality of care in the facility was poor and the cost was prohibitive, so decided to bring her mother home. In fact, her mother had been failing for some time, and she had been helping to manage her care from afar, but she had to rapidly adjust to her mother living with her once she decided to move her into her home.
A common experience for the adult children in this study was that their parent was living on their own, and they started to notice small signs of decline. They would notice that their parent was becoming more forgetful or confused. Friends and neighbors would call to let them know that they were concerned about their parent. The adult child would often start to provide some type of support to their parent. This support might be help with grocery shopping, driving them to doctor’s appointments, and helping with household chores or home maintenance. This often evolved to greater concerns about their parent’s safety and, for many adult children, having their parent move in with them or moving into their parent's home. One of the adult child caregivers that I interviewed had lived with her mother her whole life and began to provide more and more care as her mother declined due to complications from diabetes and other chronic illnesses. Two of the adult child caregivers that I interviewed had brought their parent to live with them prior to them becoming frail in anticipation of their increasing needs as they aged.

Diana, an adult child caregiver, talked about moving her mother in to live with her following a series of falls. She was working at the time, and her mother was able to stay at home alone for a while. However, she eventually decided that her mother was not safe staying alone and decided to retire early, at the age of 58. She described a fairly typical transition scenario:

It’s been ten years. She lived up in Vermont, and she had her first fall and did some serious damage to her arm and some like I think her face as well. But she was living by herself, and at some point she had some other falls. But she got better. She came down and visited me, fell when she was down here, and just stayed and eventually moved in with me. So she was here by herself for six years, and, then I retired four years ago. And I've been taking care of her full-time.
Jim is an only child who had brought his mother to live with him when she was still healthy and active. They spent many years living abroad, traveling, and enjoying their life together. He described how over time she began to decline and how he transitioned into the role of full time caregiver:

At the end of 2001, she had a stroke and recovered rather well from it. It was minimal damage. She regained her ability to walk and speak and all of that. But then she gradually declined, and, I became, over time, a 24/7 caregiver for her. Our schedule revolved around doctor’s appointments and all of that. She had several incidents, where she would have some kind of a mini-stroke or whatever and would fall, and she had to go to the hospital rehab and like that. And then in 2009/2010, it got to be more and more 24/7. It really was—toilet training, toilet assistance, getting in and out of bed. She had very poor circulation below her knees, and so she was constantly getting ulcers on her feet, her heels, her toes. So we were bandaging those, taking the bandages off when she’d go to bed, putting them on when she would have to get up and go to the bathroom. So, I was getting very little sleep, and it got to be very, very draining on me.

The adult children interviewed reported that they had been caregivers for their parents from a range of two months to over 23 years. Many did not identify themselves as a caregiver until their parent was quite frail and in need of significant care. For example, Karen described the long, slow process of decline for her mother. She moved her mother into her home for the last three years of her life. Yet, when asked, she stated that she had been a caregiver for six months. She did not identify the care she had been providing to her mother for years as caregiving. As she described her mother’s decline and her own transition into the caregiving role:

Well it started out basically, like she gave up driving on her own, which was great, because I know a lot of other people have issues with that. And she would do, like she’d make dinner, and that went away. And she would do the laundry. You know, she would do different things. And you could leave her alone. I could go to work and come back and know that she was okay, and little by little by little, things stopped happening. Just little by little by little, she went from being able to take care of herself to not being able to do anything
without prompting. And then I went to, you know, changing diapers and getting her to eat a regular meal.

For many of these caregivers, their caregiving role ended with the death of their parent at home. For others, the caregiving transition included, ultimately, placement in a nursing facility. As Ellen, an adult daughter caring for her aging mother, described:

My mother lived in an elderly housing complex, an apartment, and she had Parkinson’s disease. So, at first it was, you know, I would see her probably every other day while she was in her own apartment and would take her shopping and to the hairdresser’s and prepare meals at her home. And then she was getting some confusion, so we signed her up to go to a daycare program. And she would go there Monday through Friday during the day. They would pick her up on the bus and then bring her home in the afternoon. And she went along doing that for maybe six months, possibly a little longer. And then she was getting confused on what time of the day it was, so she would go out at nighttime to wait for the bus. And the neighbors would call me worried. And, then we made the decision to have her come stay with us. And it worked well. She’s a lovely person, easy to get along with. It was just, as she got more confused, she would get frightened being alone. And I worked, and also my husband worked. Then she had incontinence, and so we started the process of getting support through the agency. Beverly would come and just if we had any concerns or any other support we could get. We did that for a time also, and then it just came to a point that we realized that it was too much. And she wasn’t, she was lonely and missed seeing people but wasn’t able to enjoy the independence of seeing old friends. So that’s when we started the process of looking for a nursing home.

There was greater variability in how spouses transitioned into the role of caregiver for their spouse. For six of the caregivers, the transition was gradual, and the care they were providing evolved over time. For four of the spousal caregivers interviewed, the transition was very quick, typically precipitated by a catastrophic event such as a stroke, fall, or brain injury.

The stages of transition for the spouses I interviewed were similar to those of the adult child caregivers, but how they experienced these transitions was quite different. This is primarily due to the fact that they were living with their spouse and were dealing
with the changes that were occurring on a daily basis. As the changes in functioning are often slow and small, many spouses were unaware of how much care they were beginning to provide. Several talked about how they ignored signs of decline or excused them as normal stages of aging. Others talked about how they just saw the care they were providing as normal things that spouses do for each other. They would take on more responsibility for cooking and cleaning, laundry, picking out clothes, helping with dressing, etc., and would think of it as just a normal shift in marital roles as they grew old together. Some noted that they never really thought of themselves as caregivers; they thought of themselves as spouses. For these spousal caregivers, caregiving was seen as a normal role expectation and part of the aging process.

Robert explained the transition as he discovered his wife had Alzheimer’s disease. He talked about how he felt he was a husband taking care of his wife and never thought of himself as a caregiver.

I guess she had it for quite a few years before we really pinpointed what it was. There were signs, but we never recognized the signs. And the doctor didn’t recognize it either unfortunately. And uh, most of it had to do with, she would do things that was out of the ordinary for her. And I think one of the things that I had a problem with is that, and I still do today, and I think about it, is she was very active mentally. So to all the sudden, bang, come up with Alzheimer’s just shocked the hell outta me. Little things would happen. I mean, when we would go to church, I would have to guide her up to go to communion because she had a tendency to go communion, and then she would want to go up to the alter itself. And I had to steer her and stuff like that. She would go shopping and buy things, and then she would come home and would never realize she bought it. So that, I would say it had to be three, four years before she actually was confined. And when she was confined, she [snaps] was just like that. She was walking and talking in December, and then January and February, January, she was no longer talking and walking. I looked at it as, I was her husband taking care of his wife. She needed to be taken care of.

Jane, caring for her husband who had suffered a debilitating stroke, described a
more rapid transition into the role of caregiver and how she felt about providing that care at home:

He had a stroke about five years ago and it was such a shock to both of us. But that’s how it started—with a stroke, his right side. He can walk, but he has no use of his right arm or hand. And so that alone causes me to do, you know, almost everything for him. And then, about a year and a half later he had a heart attack. And that really knocked him back. The doctors and his staff, his team, they bring him to a room, and they ask me what my plans are. And I didn’t know they were thinking, ‘Do you wanna put him in another rehab for a certain amount of time? Or is this, you go into a nursing home?’ Never, never occurred to me a nursing home. I just figured, ‘He’s in the hospital. He’s coming home.’

For four of the spouses I interviewed, their caregiving role ended with the death of their spouse at home. However, as with the adult child caregivers who ultimately made the decision for nursing home placement, some spouses grappled with this decision as well. Martha, caring for her husband with Alzheimer’s Disease, describes her painful decision to place her husband in a nursing home. It is important to note that her caregiving role did not end when she placed her husband in the nursing home as she visits him almost daily.

He was 43 and I was 20-years-old when we got married. We’ve been married 50 years. The last nine years he has had Alzheimer’s. We didn’t notice it at first. I went to Florida because I have health problems, and he was still working. My son called me, and he said, ‘There’s something wrong with Dad, and you need to get home.’ ‘He doesn’t seem to know what he’s doing, and I went into his refrigerator. And he has spoiled food in there that he’s eating and so forth.’ And that was the beginning of our seeing some kind of a problem. From that point it was, forgetting things, and it was gradual with him. This winter is when he got very bad. He’s been getting progressively worse, but very bad, and it became very difficult. He wound up in the hospital. And was in there for two weeks, and they told me at that time and had been telling me for the last two years that, ‘You really need to transition him into a nursing home.’ I wanted to take him home again and try. And, [crying]. And I brought him home. And within two hours, I knew I couldn’t handle him and went back to the hospital—had to call the ambulance—went back to the hospital. And from that point, he went into rehab. From rehab, he was transitioned into a dementia unit in Haverhill,
which is a wonderful, wonderful, wonderful place. I’m there every other day if not every day. He was a very good husband, good father, very happy person and thought of everybody. And everything changed, and he became very mean and very self-serving.

Each caregiver’s story was unique, but two general themes emerged. For some the transition into caregiving happened literally almost overnight. For others the transition was gradual and evolved over time. The timing of the transition was typically related to the reason for the care recipient’s decline. Alzheimer’s, other dementias, and other chronic illnesses were characterized by subtle declines and the need for more care over time. As Martha noted:

Well it was gradual. The demarcation point was probably when we got the diagnosis. …. when the diagnosis finally came he was at mid-stage Alzheimer's and it felt like I was kicked in the stomach. It was just awful. So that is the demarcation point but in a lot of ways. It's gotten better because at least I know what it is. The explanation of so much of his behavior became abundantly clear to me and then I began seeking agencies and people and ways to deal with it. That makes it sound very simple but it didn't just happen like that. But that's basically it. By the time that I suddenly realized that I am the caregiver it got better after that when I knew.

Ellen describes the gradual decline of her mother and how she transitioned into the role of caring for her mother:

So for us it was just a gradual seeing her slip and trying to fill in the pieces so she could stay as independent as possible. And then, it was just kind of a natural, and then, for being a full-time caregiver, I think it was when she wasn’t safe. I think that’s when you come to realize that you need to do more than assist them. For my mom, it was falling. She had two falls in her apartment and her confusion on not knowing whether it was day or night.

For others the transition into caregiving was sudden, the result of an accident, stroke, or other catastrophic medical event. As Jane, whose husband experienced a devastating stroke that left him completely dependent on her, described:

It was just so unexpected, you know? It’s, it’s just not his life. My whole life changed, too, ’cause I was working at the elementary school. And I got up,
you know, to get coffee ready, ‘cause he was not feeling that well. And that morning that it happened, March 20th, 2000, he just sat up in the bed, went to stand up and went down. And that was it.

STRESS PROCESS FRAMEWORK

The framework for this dissertation research is stress process theory (Pearlin 1989). This framework considers exposure to sources of stress, resources that help moderate the manifestations of stress, and the outcomes associated with exposure to these stressors. In the context of this study, caregiving is considered to be a chronic stressor. Resources available to caregivers to help mediate or moderate this stress include factors such as family and community support, supportive services, and positive rewards of caregiving. Caregiver outcomes include both physical and mental well-being. The caregiver interviews conducted as part of this story were designed to elicit information to help explain the caregiving experience within this theoretical framework. Specifically, interviews helped to elicit information from caregivers on how they experience the role of caregiving, the meanings they place on these experiences, the resources available to them, and how they cope with the stresses of caregiving.

The in-depth interviews conducted as part of the qualitative portion of this study were designed to further elucidate findings from the quantitative analyses. The quantitative analysis found that burden is both directly related to poor mental health outcomes for caregivers and mediates the relationship between caregiving demands and depressive symptoms. I also found that employment is significantly related to lower mental health distress, and increased age is significantly related to lower caregiver burden. Utilizing the stress process framework, I further explored these findings through
the qualitative data. Figure V.1 below provides a simple schematic that outlines the framework for this analysis.

Figure V.1: Stress Process Framework for Qualitative Analysis

I categorized the themes that emerged from the caregiver interviews as either stressors that increase the burden or demands placed on caregivers or resources that help caregiver cope with the demands of caregiving. The analysis also considered whether caregiver characteristics--specifically age, employment, and kinship--condition the way in which caregivers experience these stressors or utilize the resources available to them.
SUMMARY OF CAREGIVER THEMES

The qualitative portion of the study was designed to help capture the diverse nature of family relationships and allow for a deeper understanding of the unique and personal aspects of family caregiving. My hope was to gather information from caregivers to better understand how differences in caregiver characteristics, such as kinship, gender, age, and employment, condition the caregiver’s perception of their caregiver role. While my interviews focused on these specific areas, the nature of the semi-structured interview garnered a remarkably rich body of information about the caregiving experience. The richness of the data collected raised a number of interesting questions that both enrich my research model and lead to a number of additional questions in the pursuit to better understand the caregiving experience.

In conducting this qualitative analysis, I looked for common themes that emerged from these interviews. Many similarities emerged across the caregivers interviewed, which are reported in this analysis. However, what really struck me was the uniqueness of each of the caregiving dyads. No two stories were alike. Each situation was unique and each caregiver’s needs were unique. Therefore, my analysis of the commonalities across these caregivers should in no way diminish the importance of considering the unique characteristics and needs of caregiving dyads. Jim, caring for his mother, reflected on this notion of finding commonalities in the experience of caregiving, even though each caregiving situation is unique. As he described the support group he attended:

But there is commonality. And that, like I say, the group that I was with, you know, they were, everybody had a different person they were caring for, a different relationship, and yet our experiences were so common.
The extensive collection of data from the 20 caregiver interviews was analyzed for themes related to the meaning that caregivers ascribe to the experience, within the stress process framework. These themes were then grouped as either a caregiver stressor or as a coping strategy or social support that help caregivers cope with the caregiving situation. The tables below summarize these themes.

Table V.4: Summary of Caregiver Themes Related to Caregiver Stressors

<table>
<thead>
<tr>
<th>CATEGORY OR THEME</th>
<th>DEFINITION</th>
<th>NUMBER OF CAREGIVERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Challenges of Caregiving: Life Interrupted</td>
<td>Demands and challenges of caregiving</td>
<td></td>
</tr>
<tr>
<td>Role Overload</td>
<td>Caregiving is a physically and emotionally demanding job that is all-consuming.</td>
<td>12</td>
</tr>
<tr>
<td>No Time for Self</td>
<td>Loss of independence and having no time for oneself.</td>
<td>13</td>
</tr>
<tr>
<td>Isolation and Loss of Relationships</td>
<td>Family and friends no longer visit and caregiver feels lonely and isolated.</td>
<td>7</td>
</tr>
<tr>
<td>Conflicting Emotions</td>
<td>Caregivers express a wide range of emotions, both positive and negative, when describing their caregiving experience.</td>
<td>20</td>
</tr>
<tr>
<td>Inter-Personal Conflict</td>
<td>Conflict with other family members</td>
<td></td>
</tr>
<tr>
<td>Conflicts with Siblings and Children</td>
<td>Issues related to other siblings and adult children who the caregiver felt did not help out enough or whose help was not appreciated.</td>
<td>9</td>
</tr>
<tr>
<td>Parent-Child Relationship</td>
<td>Quality of parent/child relationship prior to caregiving is important in handling the role reversal of becoming a caregiver for a parent.</td>
<td>5</td>
</tr>
<tr>
<td>Spousal Relationship</td>
<td>Caregiving can add strain on a marriage when spouse is not supportive of the caregiving arrangement; yet supportive spouses are a resource to the caregiver.</td>
<td>7</td>
</tr>
<tr>
<td>Role Conflict</td>
<td>Increased burden due to multiple roles and responsibilities</td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td>Employment can add additional stress and burden to caregivers</td>
<td>10</td>
</tr>
<tr>
<td>Other Caregiving and Family Responsibilities</td>
<td>Other responsibilities such as child care and family demands that compete with caregiving demands</td>
<td>4</td>
</tr>
<tr>
<td>Decision Making Burden</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty of Making Decisions for Loved One</td>
<td>Difficulty experienced by caregiver in making decisions, especially for end of life care or nursing home placement.</td>
<td>3</td>
</tr>
<tr>
<td>Nursing Home Stigma</td>
<td>Negative conception of nursing home/facility-based care</td>
<td>10</td>
</tr>
</tbody>
</table>
Table V.5: Summary of Caregiver Themes Related to Resources and Coping Mechanisms

<table>
<thead>
<tr>
<th>CATEGORY OR THEME</th>
<th>DEFINITION</th>
<th>NUMBER OF CAREGIVERS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>RESOURCES AND COPING MECHANISMS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Re-Framing</td>
<td>Coping functions that caregivers employ to frame the meaning they ascribe to the caregiving experience</td>
<td></td>
</tr>
<tr>
<td>Caregiver Motivations</td>
<td>Reasons for being a caregiver.</td>
<td></td>
</tr>
<tr>
<td>Promise</td>
<td>Spouses spoke of their wedding vows as a commitment to take care of their spouse in sickness and in health. Children spoke of making a promise to their parent to never put them in a nursing home.</td>
<td>4 Spouses</td>
</tr>
<tr>
<td>A Love Story</td>
<td>Caregivers spoke of their deep love for the person they were caring for, whether a parent or a spouse.</td>
<td>20</td>
</tr>
<tr>
<td>Obligation/Reciprocity</td>
<td>The notion that there was a responsibility to give back to the care recipient for all they had done for the caregiver and/or the family.</td>
<td>9</td>
</tr>
<tr>
<td>Natural Caregivers</td>
<td>The notion that some people are simply cut out to be caregivers and others are not.</td>
<td>5</td>
</tr>
<tr>
<td>No Regrets</td>
<td>That in the end, they would have no regrets that they did not do everything they could for their spouse or parent.</td>
<td>7</td>
</tr>
<tr>
<td><strong>Rewards of Caregiving</strong></td>
<td>Rewards associated with caregiving.</td>
<td></td>
</tr>
<tr>
<td>Keep Them Home and Happy</td>
<td>The desire to keep their parent or spouse home and keep them comfortable and happy.</td>
<td>8</td>
</tr>
<tr>
<td>Experience a Deeper Relationship</td>
<td>Experiencing end of life with loved one brought a deeper meaning to the spousal or parent/child relationship.</td>
<td>5</td>
</tr>
<tr>
<td><strong>Importance of Care Provided</strong></td>
<td>Importance caregivers ascribe to their caregiving.</td>
<td></td>
</tr>
<tr>
<td>Dignity and Respect</td>
<td>Maintaining the dignity and respect of the care recipient. Making sure they look nice and others see them in a positive light.</td>
<td>6</td>
</tr>
<tr>
<td>Quality of Life/Quality of Care</td>
<td>That the care recipient’s needs are addressed, signs of problems are not overlooked, and the care recipient is happy and content.</td>
<td>6</td>
</tr>
<tr>
<td><strong>Coping Strategies</strong></td>
<td>Coping strategies that caregivers employ to manage or change the caregiving situation.</td>
<td></td>
</tr>
<tr>
<td>Seeking Supportive Services</td>
<td>What triggers caregivers reach out for supportive services</td>
<td>16</td>
</tr>
<tr>
<td>Modifying Behavior</td>
<td>Skills and behaviors caregivers employed to manage the day to day tasks associated with caregiving</td>
<td>20</td>
</tr>
<tr>
<td>Social Supports</td>
<td>Resources and supports that caregivers utilize to manage the caregiving situation.</td>
<td></td>
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<tr>
<td>----------------</td>
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<td></td>
</tr>
<tr>
<td><strong>Community and Family Support</strong></td>
<td>Importance of being involved in community activities and receiving support from other family members.</td>
<td></td>
</tr>
<tr>
<td>Family Support</td>
<td>Importance of support received from close family and relatives</td>
<td>7</td>
</tr>
<tr>
<td>Community Support</td>
<td>Importance of being involved in community and social activities.</td>
<td>16</td>
</tr>
<tr>
<td><strong>Decision Making Support</strong></td>
<td>Support sought to help make difficult care decisions.</td>
<td></td>
</tr>
<tr>
<td>Sought Advice of Medical Professionals</td>
<td>Relied on advice from doctors, nurses, and VNA to make decisions. This was more common with spousal caregivers.</td>
<td>7</td>
</tr>
<tr>
<td>Researched on Own</td>
<td>Researched on line or by talking to others. This was more common with adult child caregivers.</td>
<td>2</td>
</tr>
<tr>
<td>Knows Care Recipient Best</td>
<td>The sense that the caregiver knew the needs of the care recipient best and knew when problems were starting.</td>
<td>8</td>
</tr>
<tr>
<td><strong>Employment as a Source of Support</strong></td>
<td>Ways in which employment provides a source of support to caregivers.</td>
<td></td>
</tr>
<tr>
<td>Supportive and Flexible Employer</td>
<td>Employers who allowed flexibility in scheduling and time off so caregivers could manage work and caregiving responsibilities.</td>
<td>8</td>
</tr>
<tr>
<td>Support from Co-Workers</td>
<td>Co-workers and customers who were understanding and provided both moral and tangible support to the caregiver.</td>
<td>4</td>
</tr>
<tr>
<td>Retirement</td>
<td>Caregivers who retired as a result of their caregiving responsibilities.</td>
<td>4</td>
</tr>
</tbody>
</table>

**SOURCES OF STRESS AND THE MEANING ATTACHED TO THESE STRESSORS**

Using the stress process framework as a general organizing guide, I looked for themes that might help identify what makes caregiving stressful and strategies that caregivers employ to manage these stressors. Themes that emerged that I categorized as sources of caregiver stress include challenges or demands of caregiving, interpersonal conflict, role conflict, and decision-making burden. These themes are described in detail below.
Challenges of Caregiving: Life Interrupted

As noted above, caregiving is considered to be a chronic stressor. But what is it that makes caregiving so stressful? Caregivers were asked what they found most challenging about caregiving. Many of the caregivers talked about the physical and emotional demands of caregiving, the lack of time for oneself, isolation and loss of relationships, the sense of loss of their loved one, and the strain of providing physical and personal care. What emerged from these interviews was a picture of a life interrupted. Caregiving becomes an all-consuming endeavor and leaves the caregiver with little time or energy to do anything else. As Kelly, caring for her mother, lamented, “I was absolutely emotionally and physically and mentally exhausted.”

Role overload. Aneshensel et.al. (1995: 80) define role overload as “the internal experience of being overwhelmed by care-related tasks and responsibilities.” A common theme among the caregivers I interviewed was what a demanding and all-consuming job caregiving is. Comments related to the demands of caregiving were more common among adult child than spousal caregivers. Eight of the 10 adult child caregivers that I interviewed expressed concerns with how difficult and demanding caregiving is. Only four of the 10 spousal caregivers made similar comments. Jim summed it up by saying, “And you’re just in it, and you can’t see any way out of it.”

The intense demands of caregiving are reflected in comments from adult children caregivers. For many of the adult children I interviewed, they were juggling family, work, and caregiving responsibilities. They talked about how caregiving was emotionally and physically draining. As Kelly described:
It consumed my life. That’s why I think you can’t remember because you just take it on. And it just becomes part of your life, and it just evolves. And then all of the sudden you’re in it. And then you don’t know it until you’re done.

Jean worked full time and cared for both of her parents whose health was failing. She talked about the stress of getting home from work and having to care for her parents. She worried that she was not able to do any of her multiple roles well. As she explained:

And I couldn’t sit down and just have a conversation with them. It was drop my stuff, you know, run upstairs, get their meal, and then I had work to do for my first job, and get that done, and then get them ready for bed, get them pills. I, it was just, it was, that’s all there was. It was like the quality of our relationship wasn’t there because I was so exhausted. Well, I wasn’t doing anything 100%, you know? I was giving the most I could to everything—the marriage, my parents, the job, and of course I was last.

Similarly, Kelly talked about the strain of working all week and caring for her mother on weekends. She talks about the burn out from the emotional and physical toll:

I was bringing her home weekends. I was doing all the day work, you know, Monday through Friday. Then I would go down and get her on Saturday and do the Saturday and Sunday. And so I was doing it all the time. And I finally just, it was like burn out. It’s emotionally draining, not only emotionally, but physically because I didn’t have a life. I gave up my life. It became harder and harder. So, the last, the last six months were really, I was, I was shot. You have no choice. You just gotta keep gettin’ up and gettin’ going.

Jim, an only child, talked about how consuming caring for his mother became, especially since he was the sole caregiver:

People don’t realize how draining and all-encompassing it is on your whole life when you’re the sole caregiver. You, you become totally tied to the person you’re caregiving especially if there isn’t another sibling or somebody else to help.

Susan compared caregiving of her mother to caring for a baby. She talked about how exhausting it was and how she mustered the strength to continue caregiving:
Caregiving is, it’s one of the real, real tough things. You’re exhausted. You’re just exhausted. But when you just don’t think you can, ‘How am I gonna do it? Oh my God.’ You just find a way. It just comes to you. It’s like getting up with a baby. You know? You know have to do it.

Spousal caregivers made similar comments about the demands of caregiving. Several noted that others don’t understand how difficult caregiving is and that they did not realize what they were undertaking until they were immersed in the experience. Martha talked about how caregiving consumed her life. She described how she was unable to leave her husband alone and had to fit showers into the few minutes when he would be napping.

It’s difficult, and I think that, people don’t understand unless they’ve been through it. I never understood. You have to be there 24/7, and I mean it gets to the point where you can’t even, you have to plan taking a shower. If they fall asleep for two minutes, you can run into the shower fast. You can’t leave them. It’s very difficult.

Two of the husbands I interviewed talked about how demanding the job of caregiving is and how challenging they found the situation. Robert, caring for his wife with Alzheimer’s Disease, related that he had no idea how hard it would be. Tom, caring for his wife with a severe brain injury, expressed similar feelings about how he found caregiving to be difficult and all-consuming.

I never sat down to figure out the consequences, how difficult it was gonna be ‘cause I’m saying, ‘Ha,’ you know? I can do this.’ And uh, I didn’t get it. I did, but that’s because I loved her. Anyway, I still miss her. (Robert)

A caregiver has to realize one thing: it’s a total surrender to the situation you’re in. You don’t get up and sit there every morning and, every morning I cry. Every morning I sit out here saying, ‘Why?’ You know? Uh, I used to get up every morning at five o’clock and just prepare. Now I, maybe ‘cause of my age, I’m getting too old to do this, you know? (Tom)

Jane talked about how caregiving consumes her life. She talked about needing to be home most of the time and her fear of even going out on short errands. She talked
about how critical the care is that she provides and how she has trouble finding relief as she doesn’t feel that others could handle the responsibility.

But the time spent here is like 90% of the time. I’m really afraid to go and fill out his prescriptions and pick ‘em up and feeling like if he has to walk into the bathroom, and what if he falls? He’s got the First Alert button on him but still it’s not the same. You know? So, you, you’re pretty much home. Caregiving is, is critical. That person’s life is in your hands on a twenty-four hour a day, you know eight shifts in a row. Three of ‘em every day. And you know, you’re there. You’re in it, and you’re doing it. Um, and it’s a lot of responsibility. It’s a huge responsibility. And you don’t feel like anybody can just come in here and relieve you.

For some caregivers, the difficulty of providing physical and personal care to their loved ones was the greatest challenge of caregiving. This was particularly true for some adult child caregivers who had to provide very intimate types of care to their parent.

Diana talked openly about how difficult it was to clean her mother’s dirty Depends, but how she ultimately was able to handle these very intimate and difficult tasks:

I think, well I mean, certainly the physical things are hard, you know, cleaning, taking your mother’s Depends off and cleaning feces and putting her on the commode and all. That, initially I thought I could not do it and especially if she has a bout of C-Diff, it’s really, really hard. And then you sort of move just beyond that.

Ellen spoke about how hard it was to provide intimate personal care to her mother and to have to tell her mother to bathe. “I think it was the personal care. That was the most difficult for me is the showering and, you know, she wouldn't want to shower, and having to say, ‘Mom, you smell’.” Jill also expressed how hard it was to have to help her father bathe and noted how helpful it was to have help with these types of personal care, once her father received hospice services. As she noted, “The ones that came, like in the end, to give the bath, that was very helpful. I mean it's hard to wash your father.”
No time for self. Related to the notion of how demanding a job caregiving can be is the loss of independence and having no time for oneself. Both spousal and adult child caregivers talked about the disruption to their lives and how hard it was to find time to take care of their own needs. This was the most common theme that emerged through these interviews. Thirteen out of the 20 caregivers interviewed talked about how caregiving consumed their life and left them with no time for themselves. Nora, who cared for her dying husband as well as her frail mother-in-law stated, “Well, it’s a whole new experience. It’s stressful. You give up your life. You have no time of your own. You grab sleep when you can.” Marsha painted a particularly graphic picture of how she felt about caring for her husband:

Well I don’t know what those things are that attach to a whale and just stay on the whale all the time, but I think that the hardest thing is I don’t feel that I can go anywhere very much without taking him. It’s just sort of, I won’t say embarrassing to take him. I’m over that now, but it’s a nuisance. So I will leave him home for a short period of time once in a while, but I, I really feel like it’s a chain around my neck that I have to wear.

This lack of time for self was particularly difficult for adult child caregivers who talked about how hard it was to find time to take care of their own needs, perform other responsibilities, or just get a break. They talked about how their life had to be put on hold and the difficulty of balancing multiple roles. Doreen, caring for her mother who had Alzheimer’s Disease, summed it up:

That you put your life on hold, and that’s no lie. Everything that you do, or everything that you’ve done you have to take a step back and say, and modify it. Everything’s modified. Everything, literally, what you do, where you go. Just everything has to be modified, because when the day is over, it’s just you and her. You know, there is no one to come and say, ‘Okay, well I’ll help you to put her to bed.’ You know? So it’s just your, your whole life just gets put on hold for however long, you know?
Jim, who was caring for his mother, talked about the loss of independence and freedom:

Loss of independence, that was the biggest thing, no longer independent, able to do things when I wanted, what I wanted...how I wanted, and to be by myself. Um, because we were; we were always together. You have to really figure out how to manage that. It can be very difficult.

And Jill, caring for her father, talked about both the loss of time for herself and the disruption to her home:

The time involved. You don’t have free time. Our whole house was disrupted. You know, in your living room, you have a bed and try to make things easy for him. The bathroom was demolished all the time because with all the stuff he needed. And if we wanted to go anywhere, it was like an all-day thing to get ready.

Isolation and loss of relationships. Professionals working with older adults express concern about the social isolation of older adults who live alone. But little attention has been paid to the isolation of their family caregivers. Social isolation and the loss of previous relationships was a common lament among the caregivers I interviewed. This sentiment was more prevalent among spousal caregivers, particularly husbands. Three of the four male spousal caregivers talked about the loss of outside relationships and that they were hurt by this loss. Three of the adult children interviewed talked about how isolating caregiving could be. As Jean stated, “So it was very isolating. It was hard for people to understand.” This notion that others who have not experienced caregiving can’t really understand the experience was expressed in other ways throughout my interviews. In this context, it highlights why some caregivers felt that people backed away as they did not understand what the caregiver was going through
or how to respond. This was especially true for the spousal caregivers, as reflected in the following comments from spousal caregivers:

Friends really back off. They really don’t want to see him suffering, including his son. My children, they just, well they adored him, but they couldn’t bear it. And so they retreated. So I felt a lot of sense of people retreating from the situation. (Nora)

You lose your sociability. That was one of the biggest things. People would forget that you existed, and they wouldn’t come. She had family that wouldn’t come. They said later on, well they couldn’t stand to see her the way she was. But they never expressed that to me, so that irritated me. I think that’s one of the hardest things for caregivers, is that people tend to forget that they need companionship. (Robert)

In addition to the loss of outside relationships, many caregivers, particularly spousal caregivers, talked about the loss of the companionship or relationship with the loved one. This sentiment was particularly prevalent among those caring for someone with Alzheimer’s or other dementias. They talked about how they had already lost their loved one, although the person was still alive. These caregivers spoke about missing the person their spouse or parent used to be and how they had already grieved the loss of that person. Aneshensel et.al. (1995) refer to this phenomenon as the loss of intimate exchange. As Martha, caring for her husband with Alzheimer’s, so poignantly put it, “What I miss most is him. The vital intelligence helping me make decisions, that’s the hardest.”

Both spousal and adult child caregivers talked about how difficult it was to watch the person they love failing or slipping away. As Joseph related in describing his wife’s decline, “I think that’s the hardest part is to watch somebody slowly disintegrate before your eyes.” Similarly, Karen described her mother’s deteriorating condition, “Just watch her shrivel up into this person that nobody knew. I mean it looked like her, but there
weren’t nobody home. That’s, that was the hardest and not understanding.” Several spousal caregivers talked about how hard it was to lose their lifelong partner, whether through death or a more prolonged loss to dementia. Nora talked about the ongoing grieving for her husband as he slipped further into dementia:

You have to learn that you’re grieving all the time. It’s not like a normal death, because especially in his case, he was gone. So I was grieving the man I’d fallen in love with, but I still had his physical body to care give. I think that was the hardest bit.

And Janet talked about how much she missed her husband since they had done everything together as a couple:

We did everything together. That’s why I miss him so much. We skied. We snow-shoed. We hiked. We canoed. We played tennis. We went golfing. There wasn’t anything we didn’t do together, and that’s why I miss him so much.

Conflicting emotions. Caregivers expressed a wide range of emotions, both positive and negative, when describing their experience. Some of the emotions conveyed in these interviews included anger, frustration, total exhaustion, resentment, love, sadness, appreciation, fear, responsibility, and guilt. These conflicted feelings provide a snapshot into how caregivers experience the stressors related to caregiving. Jill talked about her feelings around caring for her father, “It is very hard. It is, um, it’s saddening. You know, but you have to, it’s hard, but it’s better than putting somebody away.” Diana talked about how she became increasingly resentful of her mother, “So, I realized that I was getting, grumpy, snapping at her, being resentful, all of these emotions, and yet not wanting her to be institutionalized.” Marsha talked about her anger over her husband’s situation but that she could envision her life without him:

And I was so frustrated and so angry, and that, that’s a hard thing ‘cause you get so angry that you, you just lose it. And that’s one of the things you can’t
do if they have Alzheimer’s; they could care less, or dementia. But, uh, no it, I’m, I hate that it happened. I will admit that. I absolutely hate that it happened. Um, I think that if anything happens to him, I don’t think I’m going to be one of these desolate widows. You know, ‘Oh, I can’t live without him.’ I don’t mind living with him, but I think I could live without him.

Ellen talked about her guilt over placing her mother in a nursing home when caring for her at home became too difficult:

‘Cause I was just crying all the time, thinking I’d failed Mom, that I should be able to do this. And, so it is; it’s hard. Yeah, you think you can do it all, and, ‘No, I don’t need any help.’ You know?

Susan talked about the range of emotions she felt when caring for her mother:

Understand that there’s gonna be depression there. You’re gonna be depressed because this is... Oh yeah, you’ll be crying and sad and upset and angry. And then laughing and you’ll go through all of ‘em.

Several caregivers talked about the need to step away from the situation by taking a break, letting out a scream, or venting in some way. This helped them to regroup and come back to handle the situation. Diana talked about how she coped with her feelings of frustration, “I didn’t, you know, I mean it was, it was trying. There was times when you lost your patience, but you know, just go in the other room and come back……and start again.” She went on to talk about how she struggled with her emotions related to caring for her mother:

But, and there are many times where I’m just so, so frustrated, and I think I can’t do this anymore. I have a meltdown. But I know I’m not gonna change anything about it. So, just the other day when I was talking with Hospice, and they were saying, ‘Do you still feel like you wanna have her at home?’ And I said, ‘Yeah, if it all, as long as I can physically do it.’ It’s very, very hard, say I’m getting her up in the morning, and she’s just having a real bad morning, and she can hardly bear her weight anyway, and I know it’s not her fault. But it’s, it’s really, and I always know I would never do anything, and I leave the room if I have to just to like yell or something. And then I go back in, She’s not doing it intentionally. I always feel guilty if I’m getting cranky or I’m being abrupt with her, and I try to, I, at some point when I used to really just get crazy and start yelling and have to go outside, and then finally I
decided the approach is, ‘You’ll get through it.’ You know, ‘Just take a
breath, keep going. It’ll all get done.’ And it does. I feel great that I’m doing
it. I’m tired. I feel tired that, I feel tired a lot.

Debra talked about how she would lose her temper, feel guilty, let off steam, and
then return to continue caring for her husband. As she described her range of emotions,
“I do all the work. And I get tired, and I get grumpy. And then, you know, it’s like, ‘I’m
sorry. I’m snappy.’ And you just gotta step back, or I sit in the car, let out a scream or
twice, just one of those, just breathe.”

Five of the caregivers interviewed made some reference to elder abuse,
homicide, or suicide. They talked about how hard caregiving is and how they can
understand why caregivers and care recipients contemplate ending the pain. As Martha
painfully recalled:

I was fine, probably until two years ago, and I was starting to get some
resentment, which I guess is normal. And the resentment was being
exhausted, exhausted. And, when you’re 24-hours-a-day, 7-days-a-week,
and you’re not sleeping, you know, you start to look at the person as if they
have horns and a tail. You know? It’s, and then, of course, you get your
rest, and you feel bad……..The other thing I understand, I never understood,
and I, I understand now. And, and that’s why you need to ask for help when
you do. Um, you hear about, ‘specially with the elderly people, um,
committing suicide and murder, because they can’t handle it. I understand; I
totally understand. I’m not like that, but at times you think, ‘My God, this has
gotta end somehow.’ I totally understand that, and I think that people need
more of an understanding of really what you go through.

A number of caregivers talked about the need to laugh in order to cope with the
challenges and conflicting emotions surrounding caregiving. Joseph encouraged
caregivers to maintain their sense of humor, “Laugh. You know, I mean don’t take
everything really serious, because if you do, you’re gonna end up with a heart attack or
some kind of illness because you’re just holding it in. And we would laugh, and she
would laugh.” Debra also talked about how laughter helped her to cope, “Sometimes it’s
hard. Sometimes it’s okay. You gotta laugh. We are so good at just laughing because it's like I can't keep crying; it makes my makeup run.”

The range of emotions expressed by these caregivers is indicative of the complexity of caregiving and how demanding it is, both physically and emotionally. These comments help elucidate how the stressors associated with caregiving impact caregivers well-being.

Inter-Personal Conflict

Caregiving for a loved one is an intense and demanding responsibility. It often strains even the closest of families. Many of the caregivers I interviewed shared stories of conflicts among family members. These conflicts were sometimes related to long-standing family dynamics, and sometimes they were related to differences of opinion around the care of the family member. Regardless of the origin, family conflicts were clearly an added stressor on caregivers.

Conflicts with siblings and children. Many adult children hinted at, or stated outright, that they resented their siblings or other relatives for not doing more. On the other hand, some caregivers expressed that when siblings did come to help they only added to the caregivers’ stress. Often family members who lived far away and did not understand the level of decline of the care recipient questioned the actions of the caregiver. In addition, many families experience conflict over decisions to institutionalize the care recipient or not. Three of the adult child caregivers were only children. The other seven all expressed some level of frustration with their other siblings in relation to caring for their parent.
Diana, an adult child caring for her mother, talked about her resentment of her sister who was able to live rent-free in the family home while she, Diana, cared for their mother in her own home and had to pay a mortgage:

Being the sole caregiver is really, really tiring. And you know my sister’s up in Vermont, living in the family home. We’re very close, very close. But it’s very hard to know that she’s up there living her life and in a house that’s paid for, and I’m down here paying a mortgage and caring for Mom. And, like I always say, I wouldn’t change it. But, but those are issues that, and I think you see that in families a lot: there’s one person who does it all.

While several adult child caregivers talked about wanting their siblings to help out more, they also complained that the assistance other siblings provided was not always helpful. They felt their siblings couldn’t handle the work or that they did not do it the way they (the primary caregiver sibling) would do it. Doreen discussed having her brothers and sister come to help her:

And I’d ask my brothers or my sister to come up and give me a little break, you know? And, they didn’t do well. They didn’t do well at all, you know, and she, when she put her mind to it, man, she’d do anything. I mean you know, my sister would come up and visit and everything. I had my older brother come in. I had to do something, so I said, ‘All right, well,’ you know, ‘come up and give her her meds.’ You know, and he couldn’t, he couldn’t do it. I don’t know why, but he said, ‘Well she wouldn’t take it for me.’ ‘Well you know what, then you try something different, or you give it a minute and try again.’ You know? But for the most part, it didn’t work. It was more of a disaster, because it, you get her on a schedule, and you get her, you know, used to that schedule. And then it turns around, and it just didn’t work.

Jill talked about how the help she received from her siblings only added to her burden:

Like I said, I was a little resentful sometimes, because I figured my brothers could have given me a day or two off. But it’s, one brother took him overnight, and ….. I don’t think he had a good time. So, I said, ‘Yeah, well.’ I mean they, you know, my brother that’s closest would come and visit, and I mean I never even left. So, there’s no break for me. It’s just entertaining more people.
Typically, one sibling takes on the primary responsibility as the caregiver for a parent. But this often brings on resentment of the other siblings. As Amy noted:

Being the youngest, I had a family meeting saying, ‘Well listen, we’re gonna have to start taking turns here, ‘cause it just can’t be up to me.’ Even though I was the main caregiver for my mom.

Family dynamics also impacted the support spousal caregivers received. Spouses that I interviewed talked about a range of issues including children who were not as present as they would have liked, children who disagreed about care or placement decisions, and issues with their spouse’s family. Marsha talked about the disagreements among her children regarding her husband’s care:

So, well I have two, uh, three children. So the younger one has taken care of him for four or five days at a stretch now and then. ‘I don’t know how you do it, Ma.’ Um, these two (children), ‘Well it can’t be that bad.’ ….. Our son, bless his heart, still is sort of in denial. And, he offers me all these suggestions for having the brain come back to work again, and sometimes I get so frustrated I cry because I’m doing the best I can. But uh, he will come over every now and then, and, well he used to. He’s real busy now. But he’ll take his father out to supper or something. You need breaks…..So, the two girls are okay with him going into the soldier’s home. Uh, my son says, ‘What do you mean you’re gonna put him in a home? You don’t do that to your father. You keep him in the house.’

Similarly, Martha talked about the differences among her children in accepting their father’s dementia:

I will say one thing. And this pertains to the children of the person who has it. Everyone has to reach their own level of acceptance. Three of my boys were very good in accepting and understood and so forth. The one here in Florida that flies back and forth, had the hardest time. And I think that that’s one of the resistances I had to putting him in earlier. I was trying to let him get through his own, and, he understands now. ….. when he was transitioned to a nursing home, it was, it was not a good scene with my son; he was beside himself. And um but he just couldn’t see his father in this, and so it was a very difficult time in the family. Um, there comes a point when you have to make the decisions whether they like it or not, and that’s a difficult, that’s difficult, too. Because if you do have, and they tell me it’s typical to have one in the family or sometimes even more that does not
accept. You know, but like the doctor said to me, um, ‘You know, if he took him for a week, he would understand.’ You know?

Spouses also talked about the pressures from other family members and how this added to their stress and burden. Tom made the decision to prolong his wife’s life, following a devastating brain injury. Few of his family members agreed with his decision which resulted in him being isolated and disenfranchised from his in-laws and children. As he related, “Real difficult for me because at that time, her two sons, her sister, my daughter-in-law, and her mother all said the same thing: ‘Let her go.’ And, uh, that’s probably when the animosity started because I wouldn’t let her go.” Nora had never been accepted by her husband’s family so received little support from them as he was dying. As she explained:

And his family didn’t support me at all. They didn’t approve of our relationship. They were far away. They had just taken advantage of him all of his life. And, so then, when he died, I of course had to deal with them coming here. And that was rough. They didn’t stay very long, ‘cause I didn’t make them feel very welcome. ‘Cause they never acknowledged our relationship or our marriage. So, for stupid reasons, just those stupid things that families do, being judgmental.

**Parent-child relationship.** There are many complications related to the parent-child relationship when a child takes on the role of caregiver for their parent. Many of the adult child caregivers talked about their relationship with their parent(s) prior to taking on the caregiver role. Those caregivers who talked about a close and loving parent-child relationship presented a more positive view of their caregiving role. For those caregivers who had a difficult relationship with their parent prior to the caregiving, the experience was not as positive. These dynamics are complicated by the reversal of roles experienced by adult children as they take on the role of caregiver for their parent. Ellen reflected on this role reversal, “Kind of, it’s almost kind of not reverse roles...
because you have to, you have to determine that line where they’re still your parent, and you have that respect.” Jim talked about the challenges of managing the shifting relationship with his mother:

I would say if she wasn’t my mother, we probably woulda been best friends. Having taken care of me, now it was, I was taking care of her, kind of reversal of roles. Even though she’d have to remind me sometimes, ‘Remember, I’m still your mother. Don’t talk to me like that.’ You know? And, but it, I think it, totally different dimension.

Kelly had a difficulty relationship with her mother growing up and resented that she was now forced to be a caregiver for a mother who she felt had not been a good caregiver to her as a child. As she related:

I ended up really disliking my mother, ‘cause that person was not my mother. And I resented the, the whole situation, yep, and I’m still a little bitter about it I guess. We just really never, never hit it off. And then I ended up having to take care of her, which was kind of ironic. We never got along. We never saw eye-to-eye. She didn’t take care of my needs as a kid, a young adult. And then all of the sudden I have to provide all of the care for her needs. And I really resented it a lot, and I guess I still do.

Jean talked about her struggle in managing the role reversal from daughter to caregiver. She eventually made the decision to place her mother in a nursing home so she could return to the role of daughter. As she explained:

You’re not a daughter anymore; you’re a caregiver. You can have lousy care, and I’ll be your daughter. Or I can be a really good caregiver. So, that’s what I’m enjoying about my mother now, and she’ll say, ‘Why can’t I come home?’ And I’ll say, ‘Mom, ‘cause I just couldn’t do it anymore. They change you. They bathe you.’ I give her the whole list. And when I do, she’s like, ‘Oh you poor thing. How did you ever do all that?’ And um, I said, ‘I get to come and visit you, and we play Scrabble and cards,’ and you know? So it’s a, I’m really enjoying her again, you know?

Spousal relationship. Adult children who choose to care for their parents are rarely alone, and the decision to take on the care of an aging parent impacts the lives of
their spouses and families as well. Seven of the 10 adult child caregivers I interviewed were married. Most talked about the support they received from their spouse and how this was critical to their being able to care for their parent(s). But others talked about the strain that caregiving placed on their marriage. In this way, spousal relationships can be viewed as both a stressor and a resource when considering the impact on the caregiver. For example, Jean talked about the severe strain that caregiving placed on her marriage:

The hardest was it really, really effected my marriage in a negative way. Yeah, it’s been, we’re still struggling. My husband’s an only child, and you know, just the two of us for 25 years, and then my parents moved in. And you know, so, I, we weren’t prepared. We should’ve probably had some counseling…

Supportive spouses appear to be an important ingredient to making a caregiving arrangement work. Susan, however, was warned not to take her mother in, as it would hurt her relationship with her husband. “Everybody said, ‘Don’t take her to live with you. She’ll ruin your relationship,’ because she was a feisty little person.” she stated. Ellen talked about what a help her husband was in caring for her mother. She related, “My husband, he was a huge help. Yep, he and Mom get along very well, and he would take Mom to a doctor’s appointment. They get along well, so he was a huge help.” And Kelly talked about how her husband supported her and helped her care for her mother:

So I spent probably 99% of the time down at the farm, and my husband was a gem. He just, he just did what he needed to do and pitched in when he could. And he never complained about, you know, ‘This has gotta go’ or ‘This has gotta stop.’ So I was very fortunate… was lucky that I had a good foundation of our relationship, and he was totally supportive, totally. I had his utmost 100% support, and thank God I did because I can’t imagine having to do that and not having a spouse to support you in that.
Role Conflict

Both being employed and having other caregiving and family responsibilities added to the demands of caregiving for many of the caregivers I interviewed. Previous research has indicated that working does not diminish caregiver responsibilities, but caregivers, particularly women, take on additional roles (Moen, Robison, and Fields 1994). This seemed to hold true for the caregivers in this current study.

Employment can be both a source of added stress as well as an outlet that provides some relief to caregivers. All of the adult child caregivers in the study were employed while caring for their parents, although two had retired as a direct result of their caregiving responsibilities. Two of the spousal caregivers had been employed while caring for their spouse but had stopped working prior to involvement in the caregiver program. In a very real way, working outside of the home adds additional demands on a caregiver. While working can provide an outlet and break from the demands of caregiving, it adds additional demands on the caregiver. And caregivers are rarely able to mentally disengage from their caregiver responsibilities at work. Ellen talked about how stressful it was to juggle work while worrying about her mother at home. As she explained, “I mean, ‘cause you’re working. It can be stressful. I will admit that ‘cause you’re working full-time and, you know, calling and making sure she’s safe….”

Two of the adult child caregivers and several of the spousal caregivers found it too difficult to balance both work and caregiving and so retired. Other caregivers cut back on their outside commitments. Kelly worked as a school aide and did a number of other jobs over the summer. When she took on the care of her mother she remained working at the school but had to give up her other jobs. As she noted: “So, I had to stop,
when school wasn’t going on, I used to teach riding lessons and work odd jobs. So I had to stop everything because my mom needed someone there to take care of her ‘cause she was, then, her mind was going even more.”

Several caregivers wondered how it was even possible for caregivers to work. As Nora speculated, “I don’t know how people do it. I don’t have any idea how people do it while they’re working, and they don’t have any support.”

Other caregiving responsibilities were noted by only four of the caregivers interviewed. Three caregivers reported caregiving responsibilities for children or other family members. Jean talked about the challenge of juggling work, caring for her parents, sustaining her marriage, and maintaining relationships with friends. As she explained, “I was giving the most I could to everything—the marriage, my parents, the job, and of course I was last. You know, I mean, my relationships with my girlfriends didn’t change, but it was, you know, it’s hard when you make plans, and you’re always the one that has to cancel because someone’s sick or…”

Decision Making Burden

Both spousal and adult child caregivers talked about the difficulty of making decisions for their loved one, especially decisions related to medical care, end of life care, and nursing home placement. This emerged as an issue that can add substantial stress to a caregiver. Decisions about end of life care were particularly difficult, especially for adult children. If Hospice was involved, all of the caregivers interviewed seemed more likely to turn to the Hospice staff for advice. Diana talked about her knowledge of her mother and knowing when to reach out for help. This changed, however, when Hospice became involved, and she notes that she touched base with
them on most everything:

You know when you’re with someone long enough, you know when to call the doctor or the, the nurse, or you may figure out what to do at home without really their input. But, but when you’re with Hospice, I almost always touch base with them for almost anything.

She also talked candidly about her conflicted feelings around end of life care. She appreciates the relationship she has with the medical professionals but laments being responsible for making end of life decisions for her mother.

And they were really trying to encourage me to, to make some of those decisions. But Mom has never said that she doesn’t wanna keep going. She usually says, ‘I wanna be around ‘till my next birthday,’ so, and that’s February. But she’s never, ever said, ‘I just want to die.’ And so as long as she says it, and if she can clearly state, and I say to her, ‘Do you wanna be treated? Do you wanna keep going?’ As long as she says, ‘Yeah,’ I, I feel like I have to respect that. And so I make choices around, you know, if she’s delusional and agitated, I, I touch base. But I know we’re probably gonna do some Haldol or something. But I always push for treatment if we suspect UTI or C-Diff, you know, you can generally figure it out and, I push for treatment right away. And the doctors, the people I deal with, trust me enough at this point to kind of, you know, know what to do. But, I can’t make a decision to not treat someone, say, for a UTI if they really wanna keep going. And it just feels too much like you’re saying, ‘Okay, don’t treat, and you’ll die.’ And I’m making a choice to play God. I don’t like that.

Karen talked about how hard it was to make decisions for her mother:

Everything was on me, all the decision-making, you know. What do you, what do you do when, you know, the decision-making was all on me—you know, pull the plug or not? You know, take her to the doctor or not? Is this, everything was on me.

Equally painful were decisions around placement in a nursing home. Martha related the emotional turmoil of transitioning her husband into a nursing home following a hospital admission:

It was decided for me. When I had brought him back to the hospital, and they had to transition him immediately, the only place that would take him at that time was Wingate at Andover. When they told me that they could no longer
care for him, and he needed to go, it was a whole, emotional thing all over again, having to transition him again.

A common theme throughout these interviews was a negative conception of nursing home care which made decision-making around nursing home placement more difficult for some caregivers. Many caregivers reported that their parent/spouse asked that they not be placed in a nursing home, and many caregivers promised their spouse or parent that they would never place them in a nursing home. Yet when care demands became too great and caregivers confronted decisions around nursing home placement, they faced conflicting feelings. Some caregivers also recognized that their loved one was isolated and lonely living in the community and struggled with the placement decision. The stigma caregivers felt around nursing homes placement is reflected in the following comments from Doreen:

So, when it came to the point, I’ve worked in many, many nursing homes. So I know what goes on, and I wasn’t gonna do that to her, you know? And for the most part, I mean we had a pretty good time with her, you know? There were, we made arrangements. We put up a ramp for her, and you know, I mean we did do everything that we could to make her feel at home.

This stigma regarding institutional care and promises made to loved ones not to place them in a nursing home left some caregivers feeling conflicted when faced with placement decisions. Jean, who felt obligated to care for her parents at home, struggled with the decision to move her mother to a nursing home. As she related:

It was like the quality of our relationship wasn’t there because I was so exhausted. Um, so I, I just was providing for them. I was taking care of them, and it was like you have a choice. You can have lousy care, and I'll be your daughter. Or I can be a really good caregiver. So, that’s what I’m enjoying about my mother now.

And Ellen talked about the isolation her mother was experiencing living with them:
Then it just came to a point that we realized that it was too much. And she wasn’t, she was lonely and missed seeing people but wasn’t able to enjoy the independence of seeing old friends. So that’s when we started the process of looking for a nursing home.

RESOURCES THAT MAY BUFFER THE NEGATIVE EFFECTS OF CAREGIVER-RELATED STRESS

While caregivers are exposed to similar stressors when caring for an older adult, not all caregivers experience the same levels of burden associated with those stressors. Additionally, physical and mental health outcomes vary across caregivers. Stress process theorizes that the resources available to a caregiver, both internal and external, may help to buffer the negative effects of caregiver-related stress. This study looked at a number of resources that might be available to a caregiver to help them cope with the stresses of caregiving. These resources include internal coping mechanisms, such as reframing the situation and focusing on their motivations for and rewards of caregiving, as well as external resources such as services and family and community support. Interviews with caregivers helped to elucidate how caregivers view these resources and how they might impact how caregivers experience the stressors associated with caregiving.

Pearlin and Schooler (1978) identify the protective functions of coping behaviors within the stress process framework. Coping behaviors help people to manage stressful situations and can be applied in a number of ways. Pearlin and Schooler (1978) identify coping strategies as efforts to change the stressful situation itself, efforts to reframe or change the meaning of the situation, and efforts to manage the outcome of stress once it occurs. In this section, I focus on a number of ways that the caregivers interviewed coped with the stressors of caregiving through these coping mechanisms, most
importantly through the meaning they placed on their experience as a caregiver. Caregivers talked about their motivations for caregiving, rewards they received from caregiving, and the importance they ascribe to their caregiving. They also described ways in which they worked to change the caregiving situation itself by seeking assistance, modifying their own behavior, learning new skills, preparing for their own future long-term care needs, and designing creative ways to simplify their work. Finally, I note ways in which caregivers seek and utilize social supports and resources to help them cope with the stressors of caregiving. This includes utilizing family and community supports, assistance with decision making, seeking services, and employment supports.

Coping Strategies to Frame the Meaning of the Caregiving Experience

A significant finding from the quantitative portion of this study is that perceived burden mediates the relationship between caregiving demands and depressive symptoms. The qualitative portion of this study provides additional data to help explain how caregivers perceive the stressors of caregiving and frame the meaning they ascribe to these stressors. Many of the comments made by caregivers in this study can be interpreted as efforts by caregivers to perceive the caregiving experience in a positive frame in order to manage the associated stressors. In this context, I have organized comments related to caregiver motivations, rewards of caregiving, and the importance of their work as caregivers as coping mechanisms to reframe the meaning caregivers ascribe to their caregiving experience.

Caregiver Motivations. What motivates caregivers was considered in order to help explain why some caregivers experience greater burden than others. I hypothesized that caregivers who were unhappy about being a caregiver or felt forced
or trapped in a caregiving role would feel more burdened. I also wondered if the reasons why spouses were willing to be a caregiver would differ from the reasons adult children would give. In the in-depth interviews, caregivers were asked why they were willing to provide care for their loved one. Three of the caregivers interviewed indicated that keeping their loved one at home was a financial decision, as they were not able to afford the cost of nursing home care. But, for most, the reasons were much deeper and ranged from the notion that it is “just what you do,” to a sense of obligation and reciprocity, to a deep and abiding love for the person needing care. The themes that emerged related to reasons for caregiving are:

- A promise made either through wedding vows or to a parent;
- Deep love for care recipient;
- A sense of obligation or reciprocity;
- The notion that some people are natural caregivers; and
- Having no regrets.

Both spousal and adult child caregivers talked about the notion of having made a promise to their loved one to take care of them as they grew old. For spouses, this promise was based on their wedding vows and their promise to care for each other in sickness and in health. Four of the 10 spousal caregivers talked about this promise made when they were married.

Jane, a wife who is caring for her husband following a devastating stroke noted, “We got married 17 years ago, I remember saying to myself, ‘For better or for worse, in sickness and in health, I do’.” Similarly, Marsha, caring for her husband who has an
acquired brain disorder as a result of alcoholism, explained, "Well a long, long time ago—we’ve been married 64 years—I said, ‘in sickness and in health.’"

Adult children also talked about making a promise to their parent, but these promises primarily revolved around never putting their parent in a nursing home. While most caregivers interviewed felt bound by this promise, several acknowledged that they never really thought about, or truly understood, what this commitment meant. Jim described his promise to his mother to care for her at home: “That was my promise to her, to myself, a long time ago, having seen a lot of people institutionalized.” Amy, the youngest of a large family who was caring for her aging mother, noted:

She had asked my brother, many years ago, she said, ‘I have one favor to ask of you.’ He said, ‘What’s that?’ She said, ‘Never put me in a nursing home.’ And he said, ‘Mom, you have that promise.’ He made the promise, but we made it, we wouldn’t have her be in a nursing home, none of us.

Jean moved both her mother and father in with her and her husband as their health failed. She talked about her promise to keep them at home, but not really understanding what that meant. As she explained:

And you know, you say, ‘You know, they took care of me, and it was my turn to take care of them.’ So, and I think that’s when you’re raised like that, I remember my mother saying, ‘Don’t ever put me in a nursing home. Promise me.’ And you promise, not knowing.

During these interviews, I heard many stories of deep love and devotion. I spoke with spouses who had been married for as many as 60 years who spoke about their marriage as a deep, committed, and loving relationship. Many spoke about the close companionship they felt with their spouse and how much they missed them. This was a particularly touching experience for me during these interviews. Love for the person they were caring for, whether a spouse or a parent, was a theme expressed in every
interview. It became clear that love for the care recipient does serve as a resource to help caregivers cope with the extreme challenges they face in caregiving. As Tom, caring for his wife who had experienced a severe brain injury due to lack of oxygen, stated, “I’ve had her 48 years, so you know, to me, love is giving everything you got ‘till there’s nothing left. That’s what I got.”

Debra told a touching story about falling in love with her husband when she was a teenager, marrying him when she was only 15. They have been married for 41 years. He is a disabled veteran who began experiencing a debilitating bone disease at the age of 26, and she has been providing care for almost 30 years. Despite the challenges this presents, she spoke lovingly of their relationship and reported both low burden and low depressive symptoms. As she explained:

I knew I was gonna marry him before he even went to Vietnam. I lived next to him growing up. I saw him, and I was like, ‘I’m gonna marry that guy.’ …..It was just, it went from there. I figured God knew what he was doing. I have a very sweet man. He thanks me for everything. He tells everybody. People at the VA know us because I’ll be walking down the hall, and he’ll go, ‘There’s my beautiful wife!’ And people go, ‘Oh, get a room.’ You know, it’s just, I, I feel like this is where I need to be.

Janet is an older woman who spoke about her deep love for her husband and how much she missed him. He had recently passed away, and she indicated that caring for her husband, who had suffered a stroke, was not a burden. The deep affection they felt for each other was apparent in her comments:

Yeah, he was a good man. I’ll never find another one like him. That’s for sure. They don’t make ‘em anymore like that. He always used to say, ‘Oh you’re so good to me. You’re so good.’ Well, if it was the other way around, he’d be good to me, too, you know? I feel that way.

Robert, who cared for his wife who had Alzheimer’s for over eight years, spoke of how much he loved and missed her. He spoke about how hard caregiving was and that
you need to do it because you love the person. He found ways to express his love for her each day in the little ways he cared for her. As he noted:

Caregiving is, you can’t look at it as a job because I think if you do, you burden yourself unnecessarily. You better do it because you love the person..... She’s my wife, and I love her. And because I love her, I should be taking care of her. .......Or before I stand her up, I lean over, put her arms around my neck, put her in a bear hug, and stand her up. That’s my hug for the day. She doesn’t respond, but that’s my hug.

Adult children also spoke about how much they loved their parent and why they were willing to provide this type of intense and personal care for them as they aged. As Amy expressed, “Just because I love her, and she’s just a wonderful, wonderful person.”

Love for the care recipient was expressed in every interview, even in two situations where the relationship between the caregiver and care recipient was not particularly positive. Marsha spoke about her resentment of her husband, who had been an alcoholic and now suffered from severe brain disease as a result. Despite her resentment, she spoke of her love for him:

He’s the father of my children. I don’t like what has happened to him, and I, if you can say it, I don’t like him sometimes. But I think I still love him. In all the years we’ve been married, I think I can count him saying, ‘I love you,’ on one hand. But I know he does, which helps.

Karen, a daughter who cared for her dying mother, talked about the poor relationship she had with her mother growing up. She spoke about their difficult relationship, especially during her teenage years, and her resentment of having to care for her mother. But, even in this difficult situation, she spoke about loving her mother and how she missed her.

She didn’t, she didn’t take care of my needs as a kid, a young adult. And then all of the sudden I have to provide all of the care for her needs. And I
really resented it a lot, and I guess I still do. Um, but such is life I guess. ….. But I miss the woman that used to be. I don’t miss what we had at all.

A common theme expressed by many caregivers, and particularly adult child caregivers, was the notion that there was an obligation to give back to the person who had done so much for them. Adult children talked about their sense of obligation to give back to their parents for all they did for them. Nine out of 10 of the adult children interviewed expressed this sense of obligation to give back to their parent as a reason they were willing to be a caregiver for their parent. Many noted that they were raised in a family that took care of their elders, and this was an expectation that they had for themselves. Several expressed the hope that their own children would learn from the experience and feel a sense of obligation to them when they reach this stage of their lives. Two adult children talked about how their father had taken care of their mother when she was dying, and they felt they owed it to him to do the same for him. Ellen talked about how her mother and step-father supported her and her family and that it was her turn to care of her parents:

She was always part of our life. She babysat for our oldest daughter so I could work. And she and my step-father were just always part of our life, getting together and supporting each other. I think giving back to some of what she did for us. I get all emotional. And just being there for her, just, you know, helping her, knowing that she brought, brought me up and was there, you know, when we were first married. Building the house, they were always here to help us. And you know, you say, ‘You know, they took care of me, and it was my turn to take care of them.’

Jim talked about how his family cared for their elders and he never questioned that he would take care of his mother as she aged:

Well the family always did take care of our elders. Um, my aunt, elderly aunt, she never married, and she took care of her parents, my, my dad’s parents ‘till they died. And, uh, my mom’s mom, my dad built a house for her on our property, um, so that she would be close to us. So it’s that sense within the
family that we took care of our elders. Uh, and there was just never any question in my mind... Having taken care of me, now it was, I was taking care of her, kind of reversal of roles.

Jill talked about her feelings of obligation to her dad since he took care of her mother when she was sick. As she related:

I had decided a long time ago I was gonna try, try to take care of him. When my mother was sick, he stayed home and took care of her. Mom was an amputee and diabetic and extremely high blood pressure, and she had a stroke. And so she was in really bad shape, but Dad didn't wanna put her in a home. So I figure I I owed him for as much as he did for my mom. Cause you love 'em. You gotta take care of 'em. I owed it to him.

Spouses also talked about obligation, but more in relation to giving back to their spouse because they had been a good husband/wife, had cared for the family for many years, and deserved to be well taken care of. As Jane explained:

He’s my husband, and he needs the care. And I know, up to this point so far, I’m doing a good job. I’m learning a lot. I actually have something I could do later for work if I needed to. It’s what you do. You just do that. And, you know, should it get to the point where his care is more, he needs a lot more than what I can do, then I will have to discuss what we do next.

Similarly, Martha talked about her sense of obligation to her husband since he had been such a good father and husband.

We’d been together for so long, and he had been a good father and a good husband—excellent father, being an older father. I mean, our first child was born, he was almost 45-years-old, changed diapers, did everything. And I felt that, you know, he deserved that. And so I learned a lot from him. And I think that he always took care of us and, he wanted me to stay home and raise the children and not work outside the home during those years. And so this was a giving back.

Several caregivers talked about the notion that some people are natural caregivers and others are not cut out for this role. Several noted that they saw themselves as a caregiver, someone who naturally wants to care for others. They acknowledged that not everyone is cut out for caregiving, but they felt they were, and
thus they were willing to care for their parent or spouse. In this way, they were able to place importance on their role as a caregiver and to highlight their special ability to be a caregiver. As Martha noted, “I’m that type of person anyway; I am, I am a caregiver, yeah.” Similarly Nora indicated, “It was something in my makeup. I always liked to help people with all sorts of things, you know? I get pleasure from being a hand, giving a hand to somebody.” Debra related that her husband frequently commented on her natural ability as a caregiver. As she noted:

My husband always said, ‘You know, I picture us in a big house and you going and picking up all these old people who have no place to go.’ You know, we go to the VA, and I see an old man with his sweater all cockeyed, buttoned crooked, and I wanna go up and fix his buttons.

Several caregivers mentioned that they did not think everyone was cut out to be a caregiver. Their comments reflected a sense that caregivers have unique qualities that not everyone possesses. Susan also reflected that some people may not think they are capable of caregiving until they are forced into the situation:

But you also have to consider the fact that lots of people aren’t capable of doing it. Not everybody’s cut out for it either. And you know what? I think, too, that sometimes you don’t realize you’re cut out for it until you’re forced to have to do it.

Joseph, who had cared for his wife with Alzheimer’s Disease, was now being cared for himself by his daughter. His daughter was present during my interview with Joseph and commented that some people are not able to be caregivers. Reflecting on helping her dad, Joseph, care for her mother, she stated:

Well I think people are either up for it, or they’re not, right? We knew that this was not going to be a picnic, but we took it on because it was Mom. Some people just can’t do it. I mean even, even if they have the funds to do it with. They just don’t have the mental capacity to do it. I mean it, it takes a lot.
A common theme that flowed through most of the interviews was that the
caregiver felt they would have no regrets about what they were able to do for their
parent or spouse. And, while they might have some regrets or doubts about not being
able to do enough, they did everything they possibly could. This sense that they had a
clear conscience in relation to what they were able to do for their loved one provided a
positive reinforcer for caregivers that eased some of their caregiver burden.

This theme was common to both adult child and spousal caregivers. Amy
commented, “But, you know, I look back at it, and I have no regrets, none, zero regrets
of what I did for my mom. If I could bring her back tomorrow, I’d do it all over again.”
Similarly, Kelly noted, “I don’t think I, I personally will never regret, and I don’t think my
brother would either all that, we made sacrifices, but we wouldn’t have done it any
different.” Susan captured the feelings expressed by many of the caregivers well:

You never have to think, ‘Oh I should have done that,’ or you know. At least
my conscious is clear. I think I could’ve done a better job. I could’ve started
sooner and all of that garbage, but I did what I could. You regret the fact that
you, your parents gave you so much time, and you’re gonna regret the fact
that you didn’t at least give them. I told her that beyond a doubt I know in my
heart when my mother died, I was a good daughter.”

Spousal caregivers expressed similar feelings about having no regrets that they
had done their best for their spouse, while worrying if they had done enough. Jane
observed, “I feel like if anything should happen to him, I will have no guilt and no
regrets. And I will know I did the best that I could do right up until the end of when I
couldn’t anymore.” Robert, who cared for his wife for many years lamented, “Even now I
say to myself, ‘Did I do enough?’ I question, I’ll wake up in the morning sometimes or
even in the middle of the night and think about it and wonder, you know, ‘Did I really do
enough?’”
Rewards of caregiving. While caregiving is tremendously stressful, there are also positive rewards associated with being a caregiver. These positive experiences can help caregivers to cope with the strains of caregiving and may have a buffering effect on caregiver burden. To understand this relationship, caregivers were asked what they found most rewarding about caregiving. Karen was unable to find anything rewarding about caregiving and found the whole experience to be “nightmare.” Her experience was the exception, however, as all of the other caregivers interviewed were able to identify many rewarding aspects of caregiving, regardless of how difficult the experience was for them. Rewards identified by caregivers included keeping their loved one home, maintaining quality of care and quality of life for the care recipient, and experiencing a deeper relationship or closer bond with their loved one.

For several caregivers, the ability to keep their loved one at home was the greatest reward of caregiving. Doreen talked about the rewards of caring for her mother, “That I could give her a home and not put her in a facility. That was, to me, that was more important than anything, you know?” Kelly cared for her mother with the help of her brother. She commented on how important it was for both of them to be able to keep their mother in the family home:

I think Bob and I are really proud of each other for being able to, it meant so much for her to be home. And we were able to provide that. Even though she didn’t die in her own bed, when she was aware of her surroundings, she was really at home. She’d been brought up in that house her whole life, and, so I think we feel good that we were able to keep her there.

Keeping their loved one at home was equated with also keeping them happy and comfortable and providing the best possible care. Eleven caregivers made comments related to being able to keep their loved one happy and comfortable. Janet commented
that it was important to her that her husband was happy. She stated that it was important to her “that he would die happy. I didn’t want him to be sad, and he didn’t want me to, you know, to do things that was harmful to me.” Amy talked how important it was to her that her mother was happy, “That my mom was always clean, that she was fed, and that she was happy, and happy actually being the most, you know, important to me.” Kelly expressed this desire to keep her mother happy and comfortable well by her comment:

What meant most to her was she was, she wanted to be home. So I think we were able to give her, take care of her the best we could quality-wise, you know. We made sure that she was showered every day. Her clothes were, her bed was changed, you know.

Several caregivers talked about how lucky they felt to experience this stage of life with their loved one. This was a strong sentiment among adult child caregivers. They talked about how this time gave them the opportunity to get to know their parent from a new and deeper perspective, to develop a closer bond, and to experience an amazing stage of life with them. This was particularly true for caregivers who had a positive end of life experience with their loved one. As Jim expressed, “I think a deeper appreciation of her and of myself. To know that she was being cared for.” Others talked specifically about the end of life experience with their loved one.

Just helping them, I mean it was the last years of my dad’s life. And you know, we had some special time. It was hard being a daughter and a caregiver, but I guess it was rewarding just getting them through another crisis. (Jean)

Hospice was wonderful. He just had a whole life passage. He was, it was just really something to watch, and I lost all my fear of dying after watching him. It was just an incredible experience. (Nora)
This is a unique experience, part of life and the aging process. But mostly you know, think of how, I guess think of how lucky you are that as much work as it is, that you’re getting to experience this. It’s kind of, it’s sort of lucky. (Diana)

*Importance of Care Provided.* Caregivers were asked what was most important to them about the care they were able to provide. I wondered if a positive sense of the importance of the work of caregiving would serve as resource in helping caregivers to cope with the strain of caregiving. Caregivers expressed similar ideas as when asked what they found rewarding about caregiving. A common theme across all caregivers was the desire to provide good, quality care; making sure their loved one looked good; and that their loved one could maintain their dignity and be respected for who they are and who they had been. Caregivers also expressed the importance of being able to keep their loved one at home and providing them with a good quality of life.

The most common theme expressed regarding what caregivers felt was most important about the care they provided related to maintaining the dignity and respect of the care recipient. The notion of maintaining the dignity and respect of the care recipient was mentioned by six caregivers. These caregivers were very concerned about making sure their loved ones were well cared for, looked good, and treated with respect. These comments were also reflective of the love that these caregivers felt for their spouse/parent and their concern that others continue to see them in a positive way. As Ellen remarked about her mother, “She still had her dignity and felt good about herself. That was important to me, yep.” Amy noted similar concerns when she stated, “That my mom was always clean, that she was fed, and that she was happy, and happy actually being the most, you know, important to me.” Doreen talked about how she wanted to make sure her mother looked good, like she did before her Alzheimer’s. She remarked,
I wanted to make sure that if, either me or whoever was taking care of her made sure that she looked the way she wanted to look all of her life, you know? Being, not, not losing that. Oh, most important, making sure that she, the continuity. I really was a stickler about making sure that her clothes matched, her hair was combed. You know, I even rigged up different ways to wash her hair so that, her, before, she always had matching jewelry, clothes matched; they were ironed.

Two of the spousal caregivers I interviewed talked about wanting to make sure their husbands looked good. Marsha stated, “I guess making sure that he takes a shower at least once a week, and he always changes his underwear and everything. Just, I guess making sure that he doesn’t look like a slob.” And Martha noted, “I was trying to preserve his dignity. That he was well taken care of, that he was well groomed, keeping his dignity.”

This notion of maintaining the care recipient’s dignity and respect and assuring that they look well cared for raises some interesting questions about caregiver motivations. Is the caregiver trying to maintain the image of how they see their loved one? Is the caregiver trying to maintain their image of themselves as a “good” caregiver so that others will see them in a positive light? While I am unable to answer this question from the data collected, comments from Robert shed some light on this issue. He saw himself as a husband caring for his wife, and he found other’s attributions of him as a “nice guy” irritating. While other caregivers may not be as altruistic, I certainly sensed from most of the caregivers in this study that their motivations were sincere, numerous, and deep.

And people would tell me I was a caregiver, but I, I, uh, one of the things that used to irritate me about it is, is people would say, ‘Oh you’re such a nice guy doing what you’re doing.’ I’d say, ‘I’m not a nice guy. I don’t know where you ever got the idea that I’m a nice guy.’ I said, ‘She’s my wife, and I love her. And because I love her, I should be taking care of her. But to tell me I’m a
nice guy ‘cause I’m doing it, that, you know, that’s foolish.’ It used to just irritate the daylights outta me. (Robert)

Many caregivers felt the most important aspect of the care they provided was that it was of high quality, that their loved one’s needs were being addressed, signs of problems were not overlooked, and that their loved one was happy and content. Comments related to making sure that the care recipient’s needs were taken care of were expressed by six caregivers. As Jane remarked, “The most important thing is that he’s taken care of, his needs, and that I don’t miss signs of something going wrong.” She was particularly concerned that others may not notice subtle signs that her husband was in distress, so she felt that she was best able to care for his needs. Marsha noted that she was pleased that her husband was well taken care of and content. She noted, “Well just that I know he’s taken care of decently, and he’s content. You know, I’m pleased at that. He’s very happy to sit all day long.” Nora, in talking about the rewards of caring for her husband stated:

That I did something that he enjoyed that was important to him but that he enjoyed doing, that he was comfortable, that I managed to reduce his anxiety, and that I showed him that I loved him.

Similarly, Jean, in talking about the importance of the care she provided for her parents noted:

That it was good care, you know? That it was really, it was my focus, that they were getting the proper medication, and you know, I’m just really blessed to have a doctor that, you know, I could text and would really work with me, and just work together to keep their health as good as we could.

Several caregivers talked about the lack of individual attention in rehabilitation and nursing facilities and how they could give more individualized care at home. Joseph’s daughter talked about their reasons for keeping her mother home:
I was afraid of the Maplewood thing. I mean some people can go for two weeks and come out, but she was so shaky and, and non-coherent that it just wouldn’t have been a good. It was much better getting her home, having the neighbors and my husband bring her in, and having Ann full-time.

Susan talked about her mother’s experience with facility based care, prior to her bringing her mother home:

She was in an assisted living, which was a really lovely place—one of the Atrias. But then she would fall down, and she’d have to go to the rehab place. And that place I did not like. It was, you’d get off the elevator, and there would be people obviously sedated unless they sleep all the time, just sitting in wheelchairs lined up against the wall, sleeping—watching television, but nobody was awake. And I just said that: ‘This is not for my mother. No way.’ So we just brought her here, just like that.

Coping Functions to Manage the Caregiving Experience

According to Pearlin and Schooler (1978) one of the coping functions that caregivers employ is to change the conditions of the caregiving situation that are problematic. In this context, I considered strategies that caregivers employed to access supportive services, to make modifications to their homes or routines, to modify their own behavior, and to learn new skills related to their caregiving as coping strategies intended to manage the caregiving experience. These strategies fall into two categories; seeking supportive services and modifying behavior to manage or change the caregiving situation.

*Seeking supportive services.* The availability of formal and informal caregiver support services is an important resource to help caregivers cope with caregiver burden. All of the caregivers in this study had received caregiver support services so were asked what prompted them to seek services. Most reported that they were pushed to the limit and felt they couldn’t continue without some support. Others explained that their doctor or another professional had referred them for additional services. It is
interesting to note that most of these caregivers did not seek services early in their caregiving career, but waited until they were exhausted and near collapse to ask for help. Yet when asked what advice they would give to other caregivers, as reported above, many emphatically stated to seek out help and support.

Ten of the caregivers interviewed stated that they did not pursue services on their own but were referred by their doctor or other professional. Diana and Jill talked about how their doctor referred them for services:

And then the doctor had suggested Hospice, and I think at the hospital they had. I dragged my feet on that I remember for a little while. Because when people said, ‘Hospice,’ you think, ‘oh, this is it.’ But I just wasn’t ready for it, so I thought I need to, we need to keep going with home care. And then somewhere along the line, I decided to try it and found, gosh, that it was where I thought we probably shoulda been, you know, long ago. (Diana)

Actually it, it was a doctor sending them over. I think the doctor was more, like he had told me one time, he says, ‘You have to take care of yourself, too. It’s not just your dad.’ You know? I said, ‘Well if I need a break, I’ll call.’ (Jill)

While all of the caregivers in this study had received caregiver support services, most of them came to the realization that they needed help late in their caregiving career when they felt they could not continue much longer. The trigger for asking for help was often a decline in the care recipient, a decline in the caregiver’s health, or the realization that it had become too much for the caregiver to handle alone. While late in the caregiving career, soliciting support helped these caregivers to manage the stressors of the caregiving situation and continue to provide care for their loved one.

The following statements present a snapshot of how and when caregivers approached asking for help:

When it started to interfere with my work, when it started to get to the point where, you know, she was going down, downhill. I knew that when she first moved in, I knew that things were not that great. (Doreen)
Once we got up here, it was a different story because my mother’s dementia was worse, and then my dad started to fail. So you know. It’s like I needed the help. (Jean)

I think the fact that I was falling asleep, and I knew I was sleep-deprived, and the fact that I was getting irritable and starting to snap at her. I knew I needed, I needed to get some kind of…of respite. (Jim)

I had to, because I felt like I was gonna have a nervous breakdown if I didn’t. I wasn’t ready to let him go into a nursing home yet, and he wasn’t really ready for a nursing home yet. (Martha)

So he couldn’t really be left alone, but I had to go out. One, or I’d go insane, or two, we wouldn’t have had food. So, that’s when I called ServiceLink, and there really was no solution, nobody. I couldn’t do it myself anymore. (Nora)

I sought services because I knew I needed help, okay? I realized that if I didn’t get the services, I couldn’t get out and do the shopping and stuff like that. And the only way I could do that was to get services that were available. But I also needed to learn what was available in order to do what I needed to do, and then from there, ServiceLink was a great help. (Robert)

Modifying behavior to manage or change the caregiving experience. Caregivers talked about the skills and behaviors they needed in order to cope with their caregiving experience. Some skills came naturally, while others had to be learned and developed over time. Specific skills and behaviors noted included patience, advocacy, asking for help, preparing for their own long-term care needs, and creative problem solving.

A common theme expressed by six caregivers was the need to be patient, and several noted that they learned that they had more patience than they expected. This was an emotional topic, bringing Martha to tears as she talked about what she had learned from her caregiving experience, “That probably I have more patience than I thought I did, that, you can do anything if you have to [crying]. It’s hard.” The emphasis on having patience underscores how difficult the job of caregiving is. As Amy noted:
Patience. You have to have patience, because like another thing with my mom, she started getting dementia. Patience, patience, patience, pat-, I can’t specify that anymore. You have to have patience if you’re caring for elderly.

Jane talked about how difficult caring for her husband was, how much she had learned, and how she had discovered patience:

I’ve learned, how to take care of a disabled man who needs to be catheterized, his blood pressure checked, his Coumadin level, his glucose level, the most efficient way to change Depends without getting yourself a mess as well. I’ve learned some neat tricks, and I’ve learned that I’m a lot stronger than I thought I was, a lot more capable than I thought I was, and smarter than I thought I was. And I’ve learned also that I have tanks of patience that I had no clue that I had.

In addition to being patient, caregivers noted the need to be a strong advocate for their spouse/parent. This notion was expressed by 10 caregivers. Persistence was a common theme and three caregivers specifically commented that caregivers need to “hang in there.” Adult children talked about how they gained confidence to argue with doctors and other professionals, since they knew their parent and their needs so well. The following three caregiver statements provide an important message about the need to be persistent and advocate:

And I have no problem advocating for her or getting in touch with whoever I need to, to, to make sure she has what I think she needs. And I, I’ve learned more and more how to navigate the system and what services are out there and to really advocate and to really say whatever you think whether you, you know I kind of don’t care anymore after a while whether people like you or not. You’re doing this for, for someone you wanna make sure they get the best if at all possible. So, I, I’ve learned to really, really speak up about any issues that come up. Yeah. And people know, they all know that, and then I think they, they expect it. (Diana)

But it’s just, it’s, you get to a point where you have to step up and say, ‘Hey wait a minute.’ You know? You know what’s going on; you know the
inevitable is going to happen sooner or later. So you, you have to be their spokesperson. (Doreen)

Have to say I’m a very aggressive advocate, so when, I usually got things done for them. I, probably it gave me a lot more self-confidence, um, because I had to tell people what I needed. And there was no, sometimes, no sugar-coating it, you know, to get things done, and going toe-to-toe with emergency-room doctors that were saying no. And you know, it just, I always had their best interest at heart, and it got to the point where—it might sound callous—I don’t care who I had to step over. (Jean)

A number of caregivers talked about the importance of speaking up with doctors, administrators, and other professionals. They noted that they know their loved one best, they need to make sure that they are involved in the care of their loved one, and that professionals need to learn to listen to what they have to say. Debra talked about how families know the person best and need to make sure their voice is heard. She remarked, “Be persistent. Know that the person that you’re talking about, when you’re talking to someone else, make sure that they’re listening ‘cause the family can provide a lot of information. So, don’t cut it short. I can be very persistent.” And as Jim eloquently explained:

I learned how to be patient, learned how to juggle, doctors’ appointments, pharmacy pick-ups, medications, insurance, the insurance forms and all of the paperwork involved in it…keeping track of it, following up if you think she was overbilled at the hospital for something, and doing battle with the administration, bureaucracy. Uh, but I think I learnt that it is very important for the family to be fully involved with the care of one of their loved ones, whether it be a parent or a child or a sibling. Families really need to respond and not rely upon outside services to, know at times it may not be possible.

Eight caregivers specifically noted the importance of reaching out for help, even if they had not done so themselves. Caregivers felt it was important to reach out to service providers as well as other caregivers or caregiver support groups. Many noted
that the job is too stressful to do it alone. Ellen made a plea to other caregivers to ask for help before the situation becomes too stressful:

Definitely to, to reach out, you know, contact, elderly services, you know, see what's available to help you so you're not isolated, so you're not just going through this alone, you know, if that's your comfort level. I think it, it is a tremendous help. And to reach out if you have other family members, you know, grown children, or siblings, just not try to take it all on yourself. If you feel it is too much, don't get angry and upset and short with your parent 'cause it can be very stressful if you're not sleeping and they're up in the night. If their days and nights get confused, and you get overtired, it can be stressful. So reach out to other people.

Jill also encouraged caregivers to reach out for help early, before the situation becomes too stressful:

Try to get, try to use the services that are available, really. You feel you can do it at first when you first start out, 'Oh no problem.' You know, two years in, it's like, 'Oh, God.' And then you get in such a routine of not doing what you wanna do, you know, like now I've got freedom, and I still don't go anywhere.

Jane talked about the importance of taking care of oneself and not being afraid to ask for help, even though she admits that she did not always follow this advice. She also encourages caregivers to not give in to everything their loved one wants and to take care of themselves as well.

Take care of yourself, as I don't always do that. Don't be afraid to ask for help, and take care of yourself. You have to, and don't always feel like whatever this person wants, they can have at your expense. You have to take the time for yourself. And even if they get angry with you, if you know that what you're doing is the right thing for that person, you've got to do that. You've gotta do what you think is right. And don't be afraid to ask for help, which means call a doctor's office. Call a, dial a nurse. Call anybody.

Caregivers talked about the need to reach out to others for emotional support through family, friends, or organized support groups. They talked about the importance of a good support network, the need to get a break, and the need to take care of
yourself as a caregiver. As Karen so poignantly expressed, “And if you can set up some sort of support group or, uh, remove yourself from the situation as often as you can, ’cause it’ll burn you out. It did me.” Doreen and Jim both made the case for caregivers to reach out for help:

To make sure that you have a strong support system, um, a little bit of knowledge as to what you’re gonna expect. Anybody that does, even if it’s not Alzheimer’s, even if it’s just, you know, they’re ill, and they can’t stay home anymore; they can’t, you know, get up and move around. Just make sure that you have a good support system, because that, out of everything, is the most important thing. You know? Make sure that you know, somebody needs to make a list of what, what’s available. What do you have that you can use? You know, what, what kind of, um, services do you qualify for? And that, that to me, I mean I did a lot of research online. (Doreen)

Get support. You, get caregiver support, and I do that, so, with my friends whenever I see that they’re any kind of a long-term, caregiving situation. Go to ServiceLink, or wherever you are……to see what kind of support you can get because you need it to recharge your own internal batteries in order to be a more effective and loving and caring caregiver. (Jim)

Despite the resources available for family caregivers, few people are prepared when the time arrives that a loved one begins to fail and needs greater levels of care. Few of the caregivers interviewed felt they were adequately prepared for caregiving. Jean poignantly talked about accepting and preparing for the death of her parents, “With parents, people have to realize that, you know, you’re gonna help them die, you know? So you gotta be ready for that.” Jean and Kelly talked about the importance of planning for caregiving:

To just be prepared, to just try to talk to someone who’s been through it. And if there’s a counselor out there that, you know, can specialize in this and tell you what to expect, and what you need to know about death and dying and dementia and all of that. Yep, that would be my biggest advice for people. you need to find out the services and really be prepared. And I mean, and you’ve gotta prepare your house. (Jean)
Um, when they start to see their parent deteriorate, start talking about it. Start looking for resources. Start making a plan, home-wise, like if they live by themselves, or they don’t have, look at the bathroom facilities, kitchen facilities, their bedroom facilities to make sure it would accommodate a wheelchair or walker. Check out the services like Castle Center. Just you know, just start to look around and think. (Kelly)

Caregiving also heightened the caregivers’ awareness of the need to plan for their own aging and long term care needs. Several talked about the importance of planning for their loved one as well as for themselves. Karen provided the following advice for others:

Get your…crap in order. If you have an elderly parent or even yourself, I’m working on getting our stuff in order, so my kids don’t have to go through this. What I learned is I don’t ever wanna be a caregiver, ever again.

Caregivers have to make significant adaptations to their homes and their routines. The caregivers who were interviewed talked about the creative strategies they devised to solve simple care problems. They showed tremendous ingenuity in finding ways to accommodate the care recipient’s needs in often cramped and non-accommodating circumstances. Joseph talked about adaptations he made to help his wife drink: “Oh, for example, when taking orange juice, it got a point where she had difficulty sipping. So I’d find that I could use a straw, put my thumb over the end of it, and bring the straw over, and give her her orange juice.” Jane talked about how she and her husband would work together to come up with ways to make the physical tasks of caregiving easier on both of them:

And we have figured out he has suggestions, and I have ideas. And we redo the way that we do things. We come up with better ways. We have systems that will help us, you know, to make it less physically demanding. You know, but you work around these things. You find a way around. And, you know, you just do it.
Janet was particularly creative in designing ways to help her husband continue doing what he enjoyed and easing the physical demands of caregiving on her. As she described:

I had a board made to hold his cards, and we’d play cribbage. So to me it was, and I made him nightgowns that tied in the back. I’d had a pattern there that I’d took apart, and I made him several. And he enjoyed those ‘cause he wasn’t tangled up in them like pajamas.

One of the more ingenious arrangements was described by Susan who figured out a way to give her mother a shower in the kitchen as their first floor bathroom could not accommodate her:

But we would take her in the wheelchair over to the sink, and we had a garden hose from outside with the sprayer on it. And we’d hook it up to the faucet and put her in a thing that was, it would go under a washing machine (a cement tub).

Social Supports

Pearlin et.al. (1981) identify two types of mediating resources within the stress process framework; social supports and coping mechanisms. I have discussed coping mechanisms at length above. Social supports are considered to be the individuals, organizations, and supportive services that are available to help support the caregiver in managing the stressors of the situation. In this context, I considered comments related to utilizing community and family supports, decision making supports, and support from employment under the rubric of social supports.

Community and family support. The importance of community and family support is well documented in the caregiver literature (Clyburn et al. 2000; Goode et al. 1998; Weisser, Chernew, and Hirth 2003). I wondered how community and family support might impact caregiver burden and whether these supports vary across adult child and
spousal caregivers. As noted earlier, family conflict can serve as an additional stressor for caregivers. On the other hand, positive support from family members can be an important resource to help moderate the impact of caregiving. Caregivers were asked about the level of family and community support that they enjoyed.

Caregivers described varying levels of involvement and support from other family members, but those who had strong connections to family, friends, and other community members described a much more positive outlook in regard to their caregiving. Seven of the 20 caregivers interviewed talked about the importance of the support they received from other family members, and this did not seem to differ across spousal and adult child caregivers. Amy talked about the help she received from her siblings, “Yeah, absolutely, because I’m, like it was Tuesday, ’cause when I was working at the restaurant, Tuesday was my day with my boyfriend. And either my nephew would come over, or my sister would come over.”

Jane talked about how the support she receives from her daughter and son-in-law is helpful:

But my daughter Linda is fabulous. She comes over. She cuts his hair, and she comes over anytime. Her husband shovels for me, shovels me out. But I tend to, to do it before he gets here unless it’s a big storm. He gets the pool ready in the summertime…does all of that, and he’s awfully good-natured about it. You know, it’s not a chore. And he’s a big help, and she’s a big help.

And Martha talked about the support she received from her four sons:

We have four sons—the youngest one is a college football coach, took a year off to be with his father. And I couldn’t have gotten through the winter without him. And it was also good for him, because being a coach, he’s away most of the time and didn’t have that contact in the last few years with his father that he should have. And he’s the youngest and was very close to his father. So it was good for him, and it helped me.
Other caregivers talked about how they felt more support from family members would have been helpful, but felt that other family members were not able to help for a variety of reasons. As Ellen noted:

I think my mother was still in her own home. And my daughter would occasionally go over and pick up some groceries for, for Mom. But then she moved to North Carolina, so. And my other daughter lives over in Rochester, New Hampshire and works full-time. But that would be a Godsend if you had family, you know, so you, if you had more than just yourself.

And Karen talked about the support she received from her husband and sons:

I really felt like I was hanging on my own. My husband was very, he's supportive in what he did to help, you know, physically. But as far as asking if, he didn't have any input. There was no, I mean I'd ask the boys, but they didn't, you know, they didn't know. I didn't have, I didn't have any support other than, you know, what I could get from ServiceLink.

As important as family support is to a caregiver, is the need for other community and social supports. I asked caregivers about the kinds of connections they had to community organizations, volunteer activities, church, social events, friends, and neighbors. Some caregivers noted that they did not have time for outside activities and talked about how isolating caregiving can be, while others talked about how they worked to maintain their outside interests and contacts. Several caregivers lived in small communities and talked about the support they received through their community connections. Caregivers with a broad range of connections in their community talked about how these supports benefitted both them and their care receiving spouse or parent. Diana talked about the support she receives from friends and neighbors:

And I have some friends that stop by just to, that always come in and say, 'Hi,' to her and touch base. So she has some other contacts, and that's nice, too. I get out on a walk every day, and I enjoy that. I have a neighbor, my neighbors are real good, and one of 'em's retired across the street. And I see, talk with him every day and his dog. And another neighbor down the street, I usually stop and chat with. So I don't feel real isolated. I have a
friend, I have a couple of friends who stop by, people who I hear from that I worked with periodically who I’ll reconnect with after she’s gone. Usually around Christmas, I have a party and, and invite a bunch of, mostly people I used to work with that I’m still kind of close to. And that’s just real fun. But as far as just going out and, and spending some time going to the movies or whatever, it doesn’t really happen.

Doreen lives in a small, rural community and talked about the importance of the support she received from community members:

We live in a small community, lots of support. We made sure she went to church every Sunday. She enjoyed that……. And I was lucky ‘cause living in a small community and luckily my niece and nephew were high-school age. And people would take her out for drives. Um, like I said, some people would take her to church. If we went out for breakfast, we’d take her along, have breakfast. Mom was never left alone that whole time, and I’m just, we were blessed…to have people like that in our lives. We were just blessed. Oh it was a big help because, it broke up her day. It gave her, mentally I think it kept her stimulated. Having people come and socialize with her was nice because there was other interactions than us. It gave me a little reprieve ‘cause a lot of times if we took her to like church, during coffee hour or, people could entertain her. And then I could go off and chat with people and not have to be right there. Um, social events, the same thing: people would come up and sit beside her, and then I could go off.

Ellen also lived in a small community and talked about the help she received from church and community members was beneficial to both herself and her mother:

Yes, we’re active in our church here, and our pastor would come and visit Mom and has seen her when she’s in the nursing home. That’s a big thing I think I would recommend for other caregivers. The more people you talk to, that are supportive of this, and if your parent has friends that they can keep in contact with and visit, I think that helps. ‘Cause sometimes it is depressing and sad, you know, as you get older. And if you can keep your spirits up and, it’s a big help.

Similarly, Jean talked about how her close knit neighborhood helped her find services and get a break from her caregiving:

But the difference was once we got up here, all the neighbors, once they found out I was taking care of my parents, ‘Oh, you’ve gotta call so-and-so. You’ve gotta call…..’ They hooked me up with all the services, so, and I can’t say enough about Visiting Nurse and Hospice and everything. They were
just amazing. The neighborhood’s very tight. We have a lot of parties here. Um, a lot of people are retired, so, it made it easy.

Jim talked about the importance of his staying involved in activities but lamented that he was always worrying about his mother when he was out. This anxiety lessened his ability to get out and get a mental break from caregiving.

I would do some things. I was in a Bible study group at church. I studied Chinese. So I’d go off to class and be away for two hours or two-and-a-half, three hours at a time, but I’d -, in the back of my mind, ‘I hope she doesn’t fall,’ uh, because of her falls. So it was hard.

The spousal caregivers I interviewed did not report being as active and involved as the adult child caregivers. This is likely due to the fact that most spousal caregivers were older and less active in their communities, regardless of their caregiving. Several did talk about how it became more and more difficult to take their spouse out, and they began to stop activities that they had been involved in prior to the beginning of their caregiving. Those who did remain involved in community and social activities noted the value of these activities. Marsha talked about how her quilting group was a good outlet for her. However, she reflected that she and her husband had few friends as a couple and therefore did not have many visitors once he became homebound. As she explained, “I belong to a quilting guild, and I quilt. That is a lifesaver. Unfortunately I didn’t realize how few couples we had as friends, you know? I’m more gregarious than he is. So we don’t have very much company come here.” Herman, caring for his wife who had suffered a stroke, talked about the value of visits from her women friends:

One thing I noticed about these women that come in here, they talk with her. Women talk, you know, different things. There’s a radio going a lot of the time and the television. Oprah’s on in the afternoon, and they discuss that. And they talk about, and that’s good, because that gives her female companion.
Another reason that spousal caregivers gave for lack of outside activities was that these outings often became too difficult to manage. Several talked about how difficult going out became and how they eventually stopped taking their loved one places. Joseph talked about how he tried to continue to take his wife to church, but it ultimately became too difficult for him:

Church-going became more and more difficult. At first we would both go, and she would receive communion and so forth. And she enjoyed meeting people there and all that. And then it came to the point where that was not practical any longer. It was difficult to get her into church. I think it was important in that it was another outlet for her. We had people that came in occasionally for visits and so forth, which were always good.

**Decision Making Support.** In general, decision making, especially around complicated health care issues, is an area that adds additional strain on family caregivers. While decision making can be considered a stressor, in term of the stress process framework, the way in which caregivers make decisions and the information available to them can be viewed as a resource that may moderate the stress of decision making. Decision making is an area where differences were found in how spousal and adult child caregivers make decisions for their loved ones. Spousal caregivers were more likely to state that they rely on doctors, nurses, and other health care professionals for advice. Adult children were more likely to rely on their own knowledge of their parents’ needs as well as researching on the internet and asking others in similar circumstances.

Both spousal and adult child caregivers talked about their reliance on medical professionals for advice. However, this tendency was more common among spousal caregivers, who were more likely to rely on medical professionals for advice and accept recommendations for placement or care more readily than adult children. Marsha talked
about her reliance on her husband’s doctors to determine what to do, “So I called his
doctors. If I don’t know, and if I’m not very comfortable with what I’m
thinking I’m gonna do, then I will call the doctor’s office and do what they say.” Joseph
noted that he was coached by his wife’s doctors but relied on his knowledge of her
needs to decide what she needed:

> Well, we were coached by regular visits to her doctor, and uh, we naturally
knew pretty much what was needed. Uh, if she needed pain pills or a snack
or something like that, it was natural. It wasn’t, we just continued to try to live
our lives as it was, but it was disintegrating little by little.

While only mentioned by three adult child caregivers, the notion of using on-line
resources and talking with friends and associates was an important difference between
how spousal and adult child caregivers made decisions. They noted how helpful it was
to find information on line or from other caregivers. No spousal caregivers mentioned
doing research on their own or talking to friends and associates to get advice. As Ellen
reported:

> Just research, just talking to other people, finding what was available. Um,
when she was home alone, I can’t remember who, someone told me about
the daycare program in Jaffrey. And that’s where Mom was living. So I think
just networking and talking to other people was a big help.

A theme expressed by eight of the caregivers was that they knew their spouse or
parent better than anyone else, including the medical professionals, and they knew
when a problem was brewing. This sense that they knew their loved one best helped
them to make difficult decisions regarding their care. Several talked about their strong
advocacy when medical professionals did not listen to them. As Amy related:

> So I called the nurse over, and I said, ‘Listen, my mother’s supposed to be on
two-and-a-half liters of oxygen, not to exceed three. Please turn it down.’
And she said, ‘No.’ I said, ‘No?’ And I said, ‘Either you turn it down, or I’m
gonna. It’s just that plain and simple.’ She said, ‘I’ll call security.’ I said,
‘Call the National Guard. I don’t care who you call. You’re not gonna burn my mother’s lungs.’ She went over and asked the doctor, and he went, ‘Oh yeah.’ He goes, ‘Yeah, it’s right here on the paper that it can’t exceed that.’ You know, I was really disturbed by that.

Employment as a source of support. An interesting finding in the quantitative portion of this study is that caregivers who were employed experienced statistically significant lower levels of depressive symptoms. This was the case, even though they also reported slightly higher levels of caregiver burden than non-employed caregivers, although not at a statistically significant level. Thus, while employment was an added burden to caregivers, it also had a positive impact in relation to mental well-being. This section of the qualitative study is intended to help provide some insight to help explain these findings and to help explain how employment might impact burden and mental health outcomes.

Eight of the 10 adult child caregivers were employed while caring for their parent; only two of the 10 spousal caregivers had been employed while providing care. Two of the adult child caregivers chose to take early retirement, primarily due to the demands of caregiving, and both of the spousal caregivers stopped working as a result of their caregiving demands. While caregivers talked about the increased demands placed on their time juggling work, family, and caregiving responsibilities, many also noted that they had very understanding employers and co-workers and had some flexibility regarding their caregiving. They talked about how lucky they felt to have jobs that allowed them this flexibility, and they did not take advantage of it.

None of the spousal caregivers were employed at the time of this interview. Six of them noted that they were not employed during any of their caregiving years and felt that it would have been impossible to be employed and be a caregiver.
One explanation as to why caregivers who are employed may fare better in terms of mental health outcomes is that employment can serve as an outlet and source of outside support for the caregiver. The caregivers in this study talked about the positive relationships they had at work and the support they received from co-workers, particularly in relation to their work load. This may provide some insights into why caregivers who are employed reported lower levels of depressive symptoms. The experience of the employed caregivers in this study certainly points to the need for supportive and flexible work environments and support from co-workers if caregivers are going to be able to balance work and caregiving demands.

Supportive and flexible employers were important to the well-being of caregivers who were employed. All of the caregivers who were employed talked about ways in which their employers were supportive of their caregiving demands and how this helped them manage both employment and caregiving. Ellen discussed how her employer was willing to give her a half day off every week to take care of her mother's needs:

It was stressful. I mean, 'cause you're working. It can be stressful. I will admit that 'cause you're working full-time and, you know, calling and making sure she's safe. I took off, I was able, my job was full-time, but I was able to get one half a day off a week just for errands. And it was pretty much to take care of Mom.

Doreen talked about how appreciative she was that her employer allowed her to take the entire month of December off when her mother was struggling with medication changes.

I took the month of December out of work and stayed home with her until I could get her medication. I worked for some people that were very, very understanding, and thank God for that. Because every time I turned around,
I had to leave. And um, that’s why I took December off, because they were calling me every day, literally every day.

And Jean talked about how both her employer and customers were supportive of her situation and flexible in working with her:

I’m a sales rep. And I travel, you know, all over the place. And I’d come home, and my second job would start the minute I’d walk through the door. Home Health aides were great. You know, because of them, I was able to still work. If it wasn’t for them, I would’ve had to do something different. I was on the road. My territory’s from Manchester to Waterville, Maine, so you know, thank God, I can set my own schedule. And my customers knew what the situation was. So, you know, if I needed to stay home and take care of them, I did.

Amy worked at the family restaurant and talked about the flexibility this allowed her in caring for her mother. She also talked about how her mother’s ability to spend time at the restaurant provided a social outlet for her mother.

It was a family business, so, it didn’t impact it at all. So, along with working at the restaurant, I was there 24/7 for my mom. And the restaurant was only two-and-a-half miles from the house. So if an issue came up, that really wasn’t a problem. And I could just go down to the house and, you know, get whatever she had needed…. and she went to the restaurant quite often. You know, she sat at the first table, and everybody called her, ‘Mom.’ You know, she was definitely the matriarch.

Caregivers who were employed talked about the support they received from co-workers. Several talked about how connections with co-workers helped them to find home care workers. Specifically, Kelly, who worked in a school, was able to hire the teen and college-aged children of her co-workers to provide weekend and summer care for her mother. Kelly was particularly skilled at asking for help and utilizing her connections to find a pool of people to help provide care for her mother. She also talked about the flexibility that working at the local school offered her:

I was very fortunate to have, work with a teacher that, if I came in late, wasn’t annoyed by it because she, I had told her, you know, the situation. And so if
Nana was having a hard morning, it took the stress out because I wasn’t worried about being late to school. I was lucky at my school location with the principal and so forth was aware of it also, so they knew that it wasn’t that I was being negligent and that I worked hard all day.

Susan also talked about the support she received from her co-workers:

And there are many, many people that would help you. I’m astounded at the people that would help you. People I work with would say, ‘You know, if you need a night out, I can come.’

While work provided an outlet and source of support for caregivers in this study, both of the spousal caregivers who were employed at the beginning of their caregiving experience and two of the adult child caregivers found that they had to retire from work as a result of caregiving demands. As Diana explained:

And she was in her 80s. And I was still working then. I knew there were, there were too many times when I would call, and she wouldn’t hear the phone. And I wouldn’t know what was going on. And I did come home to find her on the floor one time and the ambulance driving in, and, so it just became so risky that I took early retirement.

SUMMARY

My original intent was to answer the question:

*How do meanings ascribed to the caregiving experience help explain how different caregiver statuses, such as kinship, age, and employment, condition whether objective demands of caregiving are perceived as burdensome?*

But the richness of the data collected through the qualitative interviews led me to explore a number of additional avenues to better understand the caregiving experience in the context of the stress process framework. These findings are described in detail in this chapter and are summarized here.

I interviewed twenty caregivers for this portion of my dissertation research. Caregivers were chosen based on kinship and burden scores reported during the first assessment survey. I interviewed five spousal and five adult child caregivers with high
burden scores (more than one standard deviation above the mean for all caregivers) and five spousal and five adult child caregivers who reported low burden scores (more than one standard deviation below the mean). Caregivers interviewed represent a fairly diverse sample of the 418 caregivers in the larger study. Through the qualitative analysis, I look for variances that might help explain differences found between spousal and adult child caregivers. I also focus on how varied meanings and experiences of caregiving can help us understand why some caregivers are more burdened than others. Utilizing the stress process framework, I analyze the qualitative data in light of how caregivers talk about the stresses of caregiving as well as the internal and external resources they employ to cope with these stressors.

The transition into the caregiving role either happens suddenly or gradually evolves over time. Sudden transitions into caregiving are often precipitated by a catastrophic incident such as a stroke or an accident. For other caregivers, the transition into caregiving is gradual, with caregiving demands increasing as the care recipient’s health or condition continues to decline. This is often the case when the care recipient has dementia or other chronic conditions such as COPD or diabetes. The speed of the transition is also related to kinship status and living arrangement. For spouses who live together, the transition is often gradual as the caregiver slowly takes on more care responsibilities. For adult children, caregiving may be more sudden and be precipitated by moving in with their parent or their parent moving in with them. In general, with the caregivers I interviewed, I found that spouses were more likely to experience a gradual transition into caregiving.
Caregiving Stressors

Caregiving is a demanding and stressful experience, and the caregivers in this study paint a vivid picture of a demanding and all-consuming job that leaves them little time for themselves or their families. While both spousal and adult child caregivers talked about the demands of caregiving, a number of differences emerged in how they experience these demands. Many talked about the physical demands of providing intense levels of personal care as well as the emotional toll of providing this type of care to a parent or spouse. Adult children found providing intimate personal care for a parent to be particularly difficult. A common lament was that caregivers had no time for themselves, and some felt they could not even leave their loved one alone to go out to pick up medicine or buy groceries. This was a greater issue for adult children who are often juggling multiple roles such as parent, spouse, and worker in addition to their caregiving responsibilities. Caregivers also talked about how lonely and isolating their life became. Many caregivers, especially the male spouses, talked about how friends and family drifted away and how hard this is for them. Caregivers also talked about how difficult it is to lose the person they love, especially when the person has dementia and can no longer interact with them as they had before. This was particularly difficult for spousal caregivers who were losing their life partner. Overall, these caregivers painted a picture of a life interrupted. Caregiving becomes all-consuming, and the caregiver’s world becomes focused on the needs of the care recipient.

All of the caregivers interviewed expressed a wide range of emotions, both positive and negative, when talking about the care recipient as well as the caregiving experience. Emotions that were expressed by caregivers in these interviews included:
anger, frustration, total exhaustion, resentment, love, appreciation, fear, responsibility, and guilt. Most talked about their deep love and devotion for the care recipient, but also how frustrated they could become at how difficult or demanding they could be. This would then result in feelings of guilt for being upset or angry with their loved one. Five of the caregivers made some reference to elder abuse, homicide, or suicide. They talked about how hard caregiving is and how they can understand why caregivers and care recipients contemplate ending the pain.

Family dynamics often added additional strain on caregivers. Adult children talked about their frustrations with siblings who were either not present or were not helpful when they were. Several expressed resentment at being the primary caregiver for their parent while their siblings carried on their lives uninterrupted. Managing the reversal of roles from child to caregiver was difficult for many adult child caregivers, especially if their prior relationship with their parent was turbulent. Spousal caregivers talked about difficulties with their children who were often too busy with their own families to help or who didn’t understand the full impact of their parent’s decline and would question decisions made about care or placement.

**Resources and Coping Mechanisms**

Within the context of the stress process framework, Pearlin and Schooler (1978) describe coping strategies as efforts to change the stressful situation itself, efforts to reframe or change the meaning of the situation, and efforts to manage the outcome of stress once it occurs. Pearlin et al. (1981) also identify social supports as a moderating resource in the stress process framework. Analysis of the caregiver interviews in this study identified a number of coping strategies and social supports utilized by caregivers
to manage the caregiving experience. As examples of ways that caregivers change the meaning of the caregiving situation, they talked about their motivations for caregiving, rewards they received from caregiving, and the importance they ascribe to their caregiving. They also described ways in which they worked to change the caregiving situation itself by seeking assistance, modifying their own behavior, learning new skills, seeking assistance, preparing for their own future long-term care needs, and designing creative ways to simplify their work. Finally, caregivers sought and utilized social supports and resources to help them cope with the stressors of caregiving. This includes utilizing family and community supports, assistance with decision making, seeking services, and employment supports.

Caregivers shared a number of ways in which they were able to manage the stressors of caregiving by positively framing the caregiving experience and accessing supportive resources. Factors that I considered as internal coping strategies to help caregivers manage the stressors of caregiving included their motivations for caregiving, the rewards they experience, and the importance they place on the care they provide. External resources that were identified as coping mechanisms include support received from family, friends, and community members; decision making support; formal caregiver support services; and employment.

Caregivers’ motivations for caregiving were varied and provided some insights into ways that caregivers define their caregiving role, why they are willing to be a caregiver, and how they experience that role. Reasons for being a caregiver included having made a promise to their loved one, love for the care recipient, a sense of obligation or reciprocity, being a natural caregiver, and having no regrets. Caregivers
identified a number of common rewards associated with caregiving including having no regrets, keeping their loved one at home, and experiencing a deeper relationship with their loved one. Caregivers also talked about the importance of the care that they were able to provide. Six noted that it was important to make sure that their loved one looked nice so that others would see them in a positive way and would treat them with dignity and respect. Six caregivers also talked about making sure that the care recipient received good, quality care and that signs of problems were not overlooked. Many talked about how they know their loved one best and know when something is amiss.

Despite the demands of caregiving, caregivers were able to reframe the situation in a way that helped them feel good that they could take care of their loved ones needs, keep them happy and comfortable, and maintain their quality of life. This provides the caregivers with a positive sense of mastery, being needed, and following through on commitments to their loved one.

Seven of the caregivers interviewed talked specifically about the importance of being involved in community activities and receiving support from community members and other family relations. Adult child caregivers were more likely to have maintained their involvement in community activities. They also noted the importance of support from their spouse. Several of the spousal caregivers related that they were no longer able to participate in activities they enjoyed prior to becoming caregivers. Some talked about trying to reengage in these activities once they were no longer a caregiver. Those caregivers who related that they had lost contact with family and friends and were no longer able to attend community activities such as church indicated that this was troublesome to them and that they missed this outside connection. These comments
reinforce the importance for caregivers in maintaining community and family connections.

Decision making, especially around complicated health care issues, is an area that adds additional strain on family caregivers. While decision making can be considered a stressor, in terms of the stress process framework, the way in which caregivers make decisions and the information available to them can be viewed as a resource that may moderate the stress of decision making. Spousal caregivers were more likely to state that they relied on doctors, nurses, and other professionals for advice. Adult child caregivers reported that they do their own research, either on line or by talking with friends and others going through similar experiences and how helpful they found this resource. This phenomenon may be specific to the current cohort of older, spousal caregivers who are not as adept at using technology and have always relied on the professional experts for medical advice.

*Caregiver Characteristics that Impact Stress, Burden and Well-Being*

Kinship, employment, and age were all found to be associated with caregiver outcomes in the quantitative portion of this study. While multiple regression analyses did not find that kinship was predictive of caregiver burden or mental health well-being, many significant differences were found when comparing means between spouses and adult children on a number of the key variables under consideration in this study. Additionally, employment was found to be related to lower depressive symptoms, and increased age was found to be related to lower caregiver burden and depressive symptoms. Both employment and age are highly correlated with kinship; that is, adult child caregivers are more likely to be employed and are younger than spousal
caregivers. Therefore, I focused much of my qualitative analysis on differences between spousal and adult child caregivers. A number of interesting differences were expressed during these interviews that help to elucidate how kinship impacts the experience of caregiving. Table V.6 provides a comparative analysis of differences and similarities found across the identified themes based on kinship.

<table>
<thead>
<tr>
<th>Category or Theme</th>
<th>Adult Child</th>
<th>Spousal</th>
<th>Both</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transition</td>
<td>Primarily gradual</td>
<td>Gradual or sudden based on care recipient’s condition</td>
<td>Demand of personal care</td>
</tr>
<tr>
<td>Caregiving Demands</td>
<td>Intimate care of parent particularly problematic</td>
<td>Behavior problems seen as more problematic</td>
<td>Demand of personal care</td>
</tr>
<tr>
<td>No Time for Self</td>
<td>Competing demands of caregiving, family, work, other responsibilities</td>
<td>Focus on spouse’s needs over their own</td>
<td></td>
</tr>
<tr>
<td>Isolation and Loss of Relationship</td>
<td>No time for other family and friends</td>
<td>Family and friends no longer visit</td>
<td>Others don’t understand</td>
</tr>
<tr>
<td>Conflicting Emotions</td>
<td></td>
<td></td>
<td>Range of emotions, both positive and negative</td>
</tr>
<tr>
<td>Family Dynamics</td>
<td>Parent/child role reversal</td>
<td>Feelings that children do not help enough or don’t understand</td>
<td></td>
</tr>
<tr>
<td>Decision Making</td>
<td>Research on own; online or talk with friends</td>
<td>Rely more on professionals for advice</td>
<td>Knows caregiver best</td>
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<tr>
<td>Nursing Home</td>
<td></td>
<td></td>
<td>Negative conception of facility based care</td>
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<tr>
<td>Promise</td>
<td>To not place in nursing home</td>
<td>Wedding vows: “In sickness and in health”</td>
<td></td>
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<tr>
<td>A Love Story</td>
<td>Love for a parent</td>
<td>Love for a spouse</td>
<td></td>
</tr>
<tr>
<td>Obligation/Reciprocity</td>
<td>Sense of obligation to parent for all they did in raising them</td>
<td>Sense of obligation to spouse for their years as spouse, parent, provider, etc</td>
<td></td>
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<tr>
<td>Natural Caregivers</td>
<td></td>
<td></td>
<td>Sense that some people are natural caregivers and other are not</td>
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<tr>
<td>No Regrets</td>
<td></td>
<td></td>
<td>Have no regrets that they had done everything they could</td>
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<tr>
<td>Keep them Home and Happy</td>
<td></td>
<td></td>
<td>Keep loved one at home and make sure they are comfortable and happy</td>
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<tr>
<td>Experience a Deeper Relationship</td>
<td>Get to know parent on a different level and</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Category</td>
<td>Description</td>
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<td>---------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td></td>
<td></td>
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<tr>
<td>Dignity and Respect</td>
<td>Keep loved one clean and looking good</td>
<td></td>
<td></td>
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<tr>
<td>Quality of Life/Care</td>
<td>Provide high quality of life and care</td>
<td></td>
<td></td>
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<tr>
<td>Family Support</td>
<td>Importance of receiving support from family and relatives</td>
<td></td>
<td></td>
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<tr>
<td>Community and Social Support</td>
<td>Importance of involvement in community activities as often</td>
<td></td>
<td></td>
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<tr>
<td>Seek Services</td>
<td>Professional referred to services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td>Did not seek services until near collapse</td>
<td></td>
<td></td>
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<tr>
<td>Sage Advice</td>
<td>Be prepared to help your parent die</td>
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<td></td>
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<tr>
<td></td>
<td>Plan for your own long term care needs</td>
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<td></td>
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<tr>
<td></td>
<td>Patience</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Persistence</td>
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<tr>
<td></td>
<td>Pursue Assistance</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Problem Solve</td>
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</table>

A number of differences were found in how children and spousal caregivers enter the caregiving role, their reasons for caregiving, how they experience family dynamics, their employment status, and decision making. I found that caregivers experience the transition into caregiving differently based on their relationship with the care recipient as well as the care recipient’s condition that precipitated the need for care. It was more typical that adult child caregivers transitioned into the role of caregiving gradually, as their parent began to fail and needed more care, regardless of their parent’s precipitating medical condition. Many caregivers, particularly spousal caregivers, did not identify as a caregiver until the care they were providing became more intense. However, these differences in transition timing are often more perceptual as child caregivers see themselves as caregivers earlier in the process of decline; therefore they see the transition as more gradual. Spouses tend to view their caregiving role as simply being a supportive spouse until something catastrophic happens that leaves their
spouse very impaired; therefore the transition to caregiving is experienced as being more sudden.

I found differences in the motivations for being a caregiver expressed by adult child and spousal caregivers. While both groups felt a sense of obligation or reciprocity, there were different senses of obligation between adult child and spousal caregivers. Spouses talked about the long term commitment they had made when they got married and that they were honoring their vow “in sickness and in health.” They also talked about how they owed it to their spouse who had been a good father/mother and provider. Many also noted that their spouse would do the same for them. Adult children, on the other hand, spoke more of a sense of obligation to give back to a parent who had done so much for them. Many referenced the “promise” they had made to their parent that they would never put them in a nursing home. In these ways, adult children and spousal caregivers experienced this sense of obligation or reciprocity differently.

Role conflict is another area where differences between adult child and spousal caregivers were seen. For many of the spouses, caring for their spouse was just something that you do and was seen as part of their responsibility as a spouse. And, for most of the spouses interviewed, the transition into the caregiving role happened at an expected time in the life course. This was not true for all spouses, however, as several of the spouses I interviewed became caregivers early in life as the result of their spouse suffering a stroke or debilitating condition. However, for both spousal and adult child caregivers, entering the caregiving role is unexpected even though it is expectable.

Family dynamics were problematic for many of the caregivers I interviewed. For spouses, these conflicts were in relation to their children or other family members. For
adult children, conflicts arose with other siblings when the primary caregiver felt that their siblings were not helping enough or that their assistance was not helpful. And finally, adult child and spousal caregivers approached decision making differently. Spousal caregivers were more likely to rely on professional and medical advice, while adult children reported that they often research what is available online or talk with friends who have similar experiences.

For most of the adult children I interviewed, caregiving was not something they were prepared for or expected. They talked about the disruption to their lives and the difficulty of managing work, children, and other responsibilities along with caregiving. Adult children also talked about the role reversal of becoming a caregiver for their parent and how difficult this was to manage. In these ways, the role of caregiving was experienced in a more problematic way for adult child caregivers than for spousal caregivers.

Employment was found to have a positive effect on mental health outcomes for caregivers in the larger quantitative portion of this study. Interviews with caregivers helped to elucidate how employment can serve as a moderating factor. While all 10 adult child caregivers who were interviewed were employed at the beginning of their caregiving experience, only two spousal caregivers were employed. At the time of my interviews, none of the spousal caregivers were employed, and two of the adult child caregivers had retired as a direct result of their caregiving responsibilities.

While employment and caregiving are competing roles, placing more demands on the caregiver, employment also provides additional sources of support and an outlet for the caregiver. Employment changes the context of caregiving, helping caregivers to
feel less isolated. The flexibility and support of employers was important to all of the caregivers interviewed. They noted that, with the support of their employer and co-workers, they were able to adjust their schedules to meet the demands of caregiving while maintaining their employment responsibilities. These are important understandings in relation to the quantitative finding that employment is directly related to lower depressive symptoms.

Sage Advice

Caregivers were very open and prolific in providing advice for other caregivers. I grouped their advice into five categories that I call the “Five P’s.” These are Patience, Persistence, Pursuing Assistance, Preparing, and Problem Solving. Caregivers talked about the need to be patient when caring for a person who is frail or disabled, and many remarked that they found they had more patience than they imagined. The caregivers interviewed talked about the importance of being persistent and becoming a strong advocate for their loved one. They advise that caregivers need to learn to navigate a complex system of care and services, and to be a strong advocate. Some talked about the specific skills they had learned in providing complex medical care such as catheterization, wound care, foot care, diabetes management, etc.

While most of these caregivers waited until they were near collapse to seek services, they advised other caregivers to seek assistance early on in their caregiving experience. Many of the caregivers also advised people entering the caregiver role to be prepared. Being prepared included making physical modifications to your home, being prepared emotionally, researching what services are available, and being prepared to help your loved one with end of life care decisions. They also talked about
the need to prepare for their own long-term care needs. Finally, many caregivers talked about creative and ingenious ways that they solved everyday care problems and advised other caregivers to be creative in thinking about how to manage the day-to-day challenges of caregiving. Overall, these caregivers provided a wealth of sage advice that can help other caregivers as well as inform policymakers.

The analysis of the in-depth caregiver interviews provides important data to better understand the processes, attitudes, and experiences of caregivers to help explain the associations found among caregiver and care recipient characteristics, caregiver burden, and caregiver outcomes in the quantitative portion of this study.
CHAPTER VI

DISCUSSION AND CONCLUSIONS

This dissertation utilizes a mixed methods research design, including both structured social survey data and semi-structured interview data, to research the complex experience of family caregivers. The goal of this research is to assess the relationship among the objective demands of caregiving, caregiver’s subjective appraisal of burden, and physical and mental health outcomes; whether burden mediates these relationships; and whether and how caregiver characteristics have a direct effect on or moderate these relationships. Finally, through the analysis of qualitative interviews with 20 caregivers, I study how meanings ascribed to the caregiving experience help explain how caregiver statuses condition whether objective demands of caregiving are perceived as burdensome. The qualitative analysis also provides insights into how and why caregiving is experienced as a stressful life event and how caregivers utilize coping strategies and resources to manage the caregiving experience. A mixed methods design is incorporated due to the complexity of family caregiving relationships. Mancini and Blieszner (1989) argue that research on family caregivers is enhanced through the inclusion of qualitative approaches in addition to the structured social survey.

From the extensive body of literature on caregiver stress and burden (George and Gwyther 1986; Pearlin, Mullan, Semple, and Skaff 1990; Pillemer and Suitor 1996; Skaff and Pearlin 1992; Zarit, Orr, and Zarit 1985; Draper, Poulos, Poulos, and Ehrlich
1996, Etters et al. 2008), we know that long-term caregiving is a chronic stressor that impacts both mental and physical health outcomes for caregivers. The findings from my research study confirm the important links among long term caregiving, caregiver burden, and caregiver outcomes. Additionally, a number of findings emerge from my study that I believe contribute important new knowledge to inform existing theories of caregiver burden. These findings are summarized in this chapter and include: the particularly strong association between caregiver burden and depressive symptoms; that caregiver’s subjective appraisal of burden mediates the relationship between caregiver demands and depressive symptoms; the relationship between age and caregiver burden; the relationship between employment and caregiver depressive symptoms; how social statuses such as kinship, age and employment impact caregiver outcomes; how caregiver statuses impact the caregiver’s experience of the caregiver role; and how the meaning that caregivers ascribe to their experience help them to manage the stressors of caregiving.

SIGNIFICANCE

Age has historically been an important concept in sociological study, and it is as salient today as at any point in history due to the unprecedented aging of the population. The first of the almost 77 million baby boomers turned 65 in 2011. The aging of the baby boomer generation creates a dual strain on the current long-term care system. Many baby boomers are currently providing care to aging family members and facing their own future long-term care needs. Caregiving impacts most everyone in some way and caregiver supports need to be a core component of any long-term care system. While the public long-term care system has historically relied on facility-based
care, the lion’s share of long-term care services is provided by informal family
caregivers (Alexihi 2006; Thompson 2004). The study of informal caregiving is critically
important to better understand how to support the growing number of informal family
caregivers.

Stress process theory (Pearlin 1989) is critical to the analysis of caregiving and
caregiver well-being. This study utilizes the stress process framework to examine the
experience of caregivers caring for aging family members. It provides new insights
about the impact of long-term caregiving on caregivers and the importance of
supporting informal, unpaid family caregivers. This research is unique in that it studied a
relatively heterogeneous group of caregivers caring for older relatives who have a
variety of disabling conditions rather than focusing on a specific disease or impairment.
The study was multi-dimensional, assessing multiple factors related to the caregiving
dyad, rather than assessing a single dimension or focusing on one side of the
caregiving relationship.

ANALYSIS OF FINDINGS

The first phase of this research project analyzes survey data from 418 caregiver
and care recipient dyads, receiving services from the NH Family Caregiver Support
Program. Research questions considered the relationships among the objective
demands of caregiving, caregivers’ subjective appraisal of burden, and physical and
mental health outcomes and whether, or which, caregiver characteristics moderated
these relationships. The second phase of this research project consists of qualitative
analysis of interviews with 20 caregivers who had participated in the first phase of this
study. The rich body of data collected from these interviews not only helps to provide
insights into the quantitative findings but led me to explore a wide range of issues related to the caregiving experience.

*Caregiver and Care Recipient Characteristics*

Both the caregivers and care receivers in this study are primarily female, married, and older. Most caregivers in the study have been caregiving for an extended period of time, with an average of five and a half years. In order to determine how typical the caregivers in this study are, I compare them with a national sample of caregivers of older adults, compiled by Mack, Thompson, and Friedman (2005) at the Georgetown Health Policy Institute, utilizing data from the 1999 National Long Term Care Survey and its Informal Caregivers Supplement. In comparison to the national sample represented in the Health Policy Institute’s data profile, caregivers in this study provide more hours of care (17.6 hours per day as opposed to four in the national sample); more are spouses (51% as opposed to 40%); the same percent are adult children (44% for both samples); more are women (70.3% as compared to 64%); and caregivers in this study are slightly older than the national sample (mean age of 65 as opposed to 62.7). Eighty-seven percent of caregivers in this study live with the care recipient as opposed to 66% in the national sample. Twenty-four percent of caregivers in this study report other caregiving responsibilities as opposed to 10% in the national sample. Employment rates of caregivers in both this study and the national sample are 32%, however 50% of the employed caregivers in this study work full time as opposed to 78% in the national sample. In general, I conclude that the caregivers in this study are relatively similar to the national sample of caregivers in terms of age, employment, and kinship--key caregiver characteristics that are a focus of my study. The caregivers
in this study provide a good cross section of the demographics of caregivers of older adults, as compared to the national sample, except that they appear to have greater demands as a result of their caregiving. That is, they provided more hours of care and were more likely to live with their care recipient and have other caregiving responsibilities.

The caregivers in this study present with high levels of caregiver burden and depressive symptoms. Over three-quarters of the caregivers report mild to severe levels of burden on the ZBI and almost 42% report clinical levels of depressive symptoms. In a meta-analysis of 228 caregiver studies, Pinquart and Sorenson (2003) found that participants in these caregiver studies had an average burden level of 29.9 on the ZBI and an average score on the CESD of 11.5. Participants in my study obtained an average burden score of 33.21 and an average score on the CESD of 14.61. In comparison, participants in this study report higher burden and depressive symptoms than has been reported, on average, in other studies of caregivers of older adults.

A number of other comparisons of caregiver characteristics between caregivers in this study and those reported in Pinquart and Sorenson’s meta-analysis can be made. Caregivers in this study are older (65 years old as compared to 59.5 in the meta-analysis), have been providing care for a longer period of time (66 months as opposed to 53.9 in the meta-analysis), are more likely to live with the care recipient (87% as opposed to 66%), are less likely to be employed (32% as opposed to 50%), and provide more hours of care (123 hours per week as opposed to 35). Caregivers in this study are relatively similar to the meta-analysis subjects in that they are primarily female (70.3% as opposed to 73%) and represent similar percentages of spouses (51% as opposed to
45.8%) and adult children (44% as opposed to 43.8%). The care recipients in this study are older than the meta-analysis sample (81 years old as opposed to 71 years old) and a slightly smaller percent are female (56.5% as opposed to 61.4%).

Caregivers in this study are caring for family members with high levels of functional, behavioral, and cognitive needs. Care recipients average 3.56 activities of daily living (personal care) and 7.61 instrumental activities of daily living (cooking, housekeeping, transportation) requiring assistance from a caregiver. Behavioral problems are related to memory (average of 4.68 behaviors per week), followed by depression (average of 3.69 behaviors per week), and then disruptive behaviors (average of 2.49 behaviors per week). Care recipients exhibit mild to moderate cognitive impairment on average, with over 30% assessed as having severe cognitive impairment. In these ways, the caregiving dyads that participated in this study are not necessarily typical of the general population of caregivers of older adults but are reflective of the population of caregivers who seek or are referred to services. I believe they represent an important sector of caregivers in terms of considering public policy implications of caregiving and service needs.

Quantitative Findings

A key focus of this study was on the relationship between the objective demands of caregiving, caregiver’s subjective appraisal of burden, and physical and mental health outcomes for caregivers and whether caregiver’s subjective appraisal of burden mediates these relationships. Correlation and regression analyses indicated that the objective demands of caregiving alone do not account for the physical or mental health outcomes experienced by caregivers. However, when the caregiver’s subjective
appraisal of burden is considered, statistically significant relationships are found between burden and caregiver outcomes. These findings indicate that caregiver outcomes are most directly related to how the caregiver perceives and reacts to the demands of caregiving and not to the physical demands of caregiving, per se. This is consistent with the literature on stress theory that indicates that a caregiver’s subjective appraisal of stress has a significant impact on caregiver outcomes and can help explain differences found in caregiving outcomes (Aneshensel et al. 1995; Zarit, Reever, and Bach-Peterson 1980; Pearlin et al., 1990; Son 2007). This finding is also consistent with the results of other caregiver studies which indicate that one of the most enduring findings in caregiver research is that stressors have a surprisingly modest association with outcomes (Zarit 2005).

I did, however, find that the frequency of depressive and disruptive behaviors in the care recipient is predictive of caregiver depressive symptoms. This is consistent with previous research findings that reported that behavior problems in the care recipient were the only care recipient characteristic that was consistently linked with caregiver physical and mental well-being (Schulz et al. 1995); as well as Pinquart and Sorenson’s (2003) finding that behavior problems in the care recipient were strongly related to caregiver well-being. In a more recent study, Suk-Young Kang (2008) also found that the care recipient’s disruptive behavior was predictive of caregiver depressive symptoms.

Of particular interest to me were differences found between adult child and spousal caregivers in this study, and I wondered if kinship was an explanatory factor in caregiver outcomes. Analysis of differences in means found that adult child caregivers
in my study report statistically higher levels of depressive symptoms and caregiver burden as compared to spousal caregivers. Adult child caregivers are younger, care for older care recipients, provide fewer hours of care, and have been caregiving for a shorter period of time. They are also more likely to be employed and to have other caregiving responsibilities. They are less likely to incur out of pocket expenses, but more likely to find these expenses to be problematic, although this latter difference is not found to be statistically significant. Finally, they are less likely to live with the care recipient, but more likely to find their living arrangement to be problematic. Of note, there are few differences found among measures of care recipient functioning among the two groups, so the level of care required by the care recipient does not seem to be an explanatory factor. These findings led to further multivariate analyses to determine if these relationships would remain significant when controlling for other caregiver characteristics. The findings from these regression analyses did not support my hypothesis that kinship would moderate the relationship between objective demands of caregiving and caregiver burden and between caregiver burden and depressive symptoms. However, I was still intrigued by the differences found between spousal and adult child caregivers and expanded my inquiry in this area through the in-depth caregiver interviews.

The OLS regression analyses also tested for the moderating effects of caregiver employment and age on the association between caregiver burden and depressive symptoms and the association between caregiving demands and caregiver burden. The findings from these regression analyses did not support my hypothesis that age and employment would moderate the relationship between objective demands of caregiving
and caregiver burden and between caregiver burden and depressive symptoms but did find direct relationships between employment and depressive symptoms and age and burden. Employment is found to have a direct effect on caregiver depressive symptoms in that caregivers who are employed experience lower levels of depressive symptoms. Age is found to have a direct effect on caregiver burden in that older caregivers experience lower levels of burden. These relationships are explored further through the in-depth caregiver interviews and are discussed in more detail later in this chapter.

Qualitative Findings

Themes that emerged from analysis of the qualitative interviews are organized in relation to the stress process framework. I categorized themes that emerged from the 20 caregiver interviews either as demands that create stress for caregivers or as coping strategies or resources that help caregivers to manage these stressors. In general, the picture that surfaced as a result of these interviews is that caregiving is a demanding and stressful experience that leaves caregivers with little time for themselves or their families. However, there are many rewards associated with caregiving, and caregivers express a number of internal and external resources that can help them cope with the stresses of caregiving.

Themes emerged related to how physically and emotionally demanding caregiving is as well as areas that caregivers find difficult to manage. I categorized these themes as stressors. Caregivers talked about the physical demands of providing high levels of intimate, personal care as well as the emotional toll of providing this type of care to a parent or spouse. All of the caregivers interviewed expressed a wide range of emotions related to caregiving, both positive and negative. Caregivers also talked
about how lonely and isolating their life as a caregiver became. Family dynamics is another area that was raised as adding additional strain on caregivers. In summary, caregiving becomes all-consuming, and the caregiver’s world becomes focused on the needs of the care recipient.

On the flip side, caregivers shared a number of ways in which they experience positive reinforcement from caregiving. These factors were categorized as coping strategies and resources that help caregivers manage the stressors related to caregiving. Ways in which caregivers are able to positively frame their feelings about caregiving are reflected in their motivations for caregiving, rewards they receive from caregiving, and the importance they ascribe to their caregiving. Pinquart and Sorenson (2003) call these positive experiences “uplifts of caregiving” and note that they may help reduce levels of caregiver burden and depression. “Uplifts” that they identify include feeling useful, appreciating the closeness with the care recipient, and pride in being able to handle crises. I found similar ideas expressed by the caregivers during my in-depth interviews. These “uplifts” provide caregivers with a positive sense of the value of the work they are doing, the importance of the care they are providing to their loved one, and a sense of mastery in managing complex medical and personal care.

Caregivers’ motivations for caregiving are varied and provide some insights into ways that caregivers define their caregiving role, why they are willing to be a caregiver, and how they experience that role. Reasons for being a caregiver include having made a promise to their loved one, love for the care recipient, a sense of obligation or reciprocity, being a natural caregiver, and having no regrets.
Both adult child and spousal caregivers were able to express a number of rewards that they experience as a result of caregiving and, in general, spoke positively about the experience. Major themes include being able to keep their loved one home and keeping them healthy and happy. A number of caregivers also talked about their appreciation of being able to experience this unique stage of life with their parent or spouse. When asked about the importance of the care they provided, caregivers talked about the importance of maintaining the dignity and respect of their loved one and providing for a good quality of life. These comments reflect how caregivers are able to frame the meaning they derive from caregiving to help them feel their work is important, that they have unique skills as a caregiver, and that they are making a difference in the life of the care recipient.

Caregivers also described ways in which they worked to change the caregiving situation itself by seeking assistance, modifying their own behavior, learning new skills, seeking assistance, preparing for their own future long-term care needs, and designing creative ways to simplify their work. Caregivers are also able to cope with the stressors of caregiving by seeking and utilizing social supports and resources including utilizing family and community supports, getting assistance with decision making, seeking supportive services, and having supportive employers. While many caregivers stressed the importance of strong community and family support, some noted that they no longer had time to engage in activities that they enjoyed prior to becoming a caregiver.

Decision making, especially around complicated health care issues, is an area that adds additional strain on family caregivers. While decision making can be considered a stressor, in terms of the stress process framework, the way in which
caregivers make decisions and the information available to them can be viewed as a resource that may help moderate the stress of decision making. Spousal caregivers are more likely to state that they rely on doctors, nurses, and other professionals for advice. Adult child caregivers report that they do their own research, either online or by talking with friends and others going through similar experiences and how helpful they find this resource.

In summary, caregiving can be a rewarding and positive experience, but it is demanding, all-consuming, and difficult. Caregivers give up much of themselves to take on the care of an aging parent or spouse. They may have to leave employment, abandon outside relationships, miss social and community events, and forego any personal free time. The caregivers I interviewed paint a clear picture of a life interrupted by the demands of caregiving. They also provide great insight into strategies they employ to cope with the stressors of caregiving.

TRIANGULATION OF QUANTITATIVE AND QUALITATIVE FINDINGS

The mixed methods design of this study was intentionally constructed to collect both quantitative and qualitative data and to integrate the analysis to better understand the processes by which caregivers experience their caregiving role. Quantitative findings that I tried to elucidate through the qualitative interviews are reviewed here. Burden is found to be significantly related to caregiving well-being and, in fact, mediates the relationship between caregiving demands and caregiver well-being. Interviews helped to identify how caregivers experience caregiving as burdensome and how their framing of the meaning they attach to the caregiving experience buffers the negative impacts of caregiving. While kinship is not found to be significant in the regression
analyses, a number of significant differences are found between spousal and adult child caregivers. I further explored the context in which adult child and spousal caregivers experience their role as caregivers through the qualitative analysis. Other significant findings of the quantitative analysis are that employment is directly related to lower depressive symptoms and that increased age is directly related to lower caregiver burden. In this section, I triangulate the quantitative and qualitative data in an attempt to better understand these findings.

*Life Interrupted: The Demands of Caregiving*

As the relationship between burden and caregiver depressive symptoms is the most consistent finding in the quantitative portion of this study, the in-depth caregiver interviews provide an opportunity to further explore how caregivers experience this burden. Etters et al. (2008), in their meta-analysis of the caregiver literature, identify a variety of factors that have been found to be related to how caregivers perceive and cope with the stressors of caregiving and the outcomes they experience. These include, but are not limited to: gender, age, caregiver relationship, living arrangements, amount of formal and informal support available, caregiver health, social participation, length of time caregiving, and care recipient characteristics. The themes that emerge from the interviews with caregivers in my study corroborate many of these caregiving stressors. Caregivers talked about the physical demands of providing intense levels of personal care as well as the emotional toll of providing this type of care to a parent or spouse. Caregivers also talked about how lonely and isolating their life became as their caregiving career progressed. Many caregivers, especially the male spouses, talked about how friends and family drift away and how hard this is for them. Caregivers also
talked about how difficult it is to lose the person they love, especially when the person
has dementia and can no longer interact with them as they had before. Caregiving
becomes all-consuming, and the caregiver’s world becomes focused on the needs of
the care recipient. As Kelly talked about caring for her mother, “It consumed my life…..
And it just becomes part of your life, and it just evolves. And then all of a sudden you’re
in it. And then you don’t know it until you’re done.”

All of the caregivers interviewed expressed a wide range of emotions, both
positive and negative, when talking about the care recipient as well as the caregiving
experience. DeFrias et al. (2005) note the importance of assessing both the positive
and negative aspects of caregiving and the comments from caregivers in this study
support that caregiving evokes a range of feelings. Emotions that were expressed by
caregivers in these interviews include: anger, frustration, total exhaustion, resentment,
love, appreciation, fear, responsibility, and guilt. Most talked about their deep love and
devotion for the care recipient, but also how frustrated they can become at how difficult
or demanding they could be. In talking about how challenging they find caregiving, five
caregivers referenced elder abuse, homicide, or suicide and how they now understand
why caregivers and care recipients contemplate ending the pain. The emotional toll of
caregiving is clearly a major stressor for many of the caregivers in this study.

Family dynamics are noted as a dimension that adds additional strain on
caregivers. Adult children talked about their frustrations with siblings who were either
not present or were not helpful when they were. Managing the reversal of roles from
child to caregiver of a parent is difficult for many adult child caregivers, especially if their
prior relationship with their parent was turbulent. Spousal caregivers talked about
difficulties with their children who are often too busy with their own families to help or who don’t understand the full impact of their parent’s decline and will question decisions made about care or placement. These findings are similar to those of Suk-Young Kang (2006) who found that family disagreement was a predictor of emotional strain for both spousal and adult child caregivers.

The picture that emerges from these interviews is of a life interrupted by the demands of caregiving. While much of the focus is on the care recipient as their condition worsens and their need for care increases, the caregiver’s life changes in significant ways. As Jane, caring for her husband who had suffered a stroke, so aptly put it, “It was just so unexpected, you know? It’s just not his life. My whole life changed too.” Caregivers describe a life totally focused on the care recipient’s needs. They talk about the lack of sleep, having to squeeze showers in while the care recipient naps, and not being able to leave to even do simple errands. Those who did go out talked about their constant worry that something would happen while they were out. As Doreen, caring for her mother with Alzheimer’s Disease, lamented, “that you put your life on hold, and that’s no lie.”

*Creating a Positive Frame: Coping with the Stressors of Caregiving*

At the outset of my study, I questioned why some caregivers, when exposed to the same demands of caregiving, experience negative mental and physical health outcomes, and others do not. While my study does not unequivocally answer this question, it does provide some insights into this question. As noted previously, quantitative findings indicated that subjective appraisals of burden mediate the relationship between objective demands of caregiving and depressive symptoms.
Qualitative data obtained in the caregiver interviews provides further explanation of how these caregivers ascribe meaning to their caregiving experience by providing a positive frame within which to manage their stress, giving them a sense of mastery and importance, and helping them to cope with this stressful life event.

Noonan and Tennstedt (1996) found, through their interviews of 48 caregivers, that caregivers both search for and find meaning in caregiving. They found that caregivers "make the best" of the situation and reported caregiver themes related to gratification and satisfaction with the caregiving role, a sense of responsibility or reciprocity, the friendship and company that caregiving provided, and a commitment to doing what needs to be done. Similar themes are expressed by caregivers in the current study and are categorized based on Pearlin and Schooler's (1978) structure of coping as either efforts to change the meaning of the caregiving experience or efforts to manage or change the caregiving situation. Efforts to positively frame or change the meaning of the caregiving experience include caregiver’s motivations for caregiving, rewards they receive from caregiving, and the importance they ascribe to their caregiving. Themes that emerged related to changing or framing the meaning of the caregiving experience include: a sense of family obligation often related to a promise made either through wedding vows or to a parent; deep love for and commitment to the care recipient; the notion that some people are natural caregivers; having no regrets that the caregiver did everything they could for their loved one; a sense of mastery and pride in providing high quality care, a good quality of life, maintaining their loved one’s dignity; and experiencing a deeper relationship with the care recipient. Efforts to change the caregiving situation itself include seeking assistance, modifying their own
behavior, learning new skills, preparing for their own future long-term care needs, and designing creative ways to simplify their work. Additionally, caregivers sought out and utilized social supports and resources to help them cope with the stressors of caregiving. This includes utilizing family and community supports, assistance with decision making, seeking services, and employment supports.

**Kinship Matters: Differences between Spousal and Adult Child Caregivers**

Kinship, employment, and age are all found to be associated with caregiver outcomes in the quantitative portion of this study. While multiple regression analyses did not find that kinship is predictive of caregiver burden or mental health well-being, many significant differences are found when comparing means between spouses and adult children on a number of the key variables under consideration in this study. Additionally, employment is found to be related to lower mental health distress and increased age is found to be related to lower caregiver burden. Both employment and age are highly correlated with kinship; that is, adult child caregivers are more likely to be employed and are younger than spousal caregivers. Therefore, I focused much of my qualitative analysis on differences between spousal and adult child caregivers. A number of interesting differences were expressed during these interviews that help to elucidate how kinship impacts the experience of caregiving.

Kinship has been the subject of many caregiver studies and the findings have varied. Some studies have found that spousal caregivers experience more burden and psychological distress than adult child caregivers (Miller et.al. 1991; Cator 1983; Zarit, Todd, and Zarit 1986). Other studies found that adult children fared more poorly than spousal caregivers (Johnson and Catalano 1983; Harper and Lund 1990). Still others
found little differences in outcomes between spousal and adult child caregivers (Chumbler et al. 2001; Gort et al. 2007). Some researchers have argued that it is the closeness of the filial bond (Etters et al. 2008) or age (Fitting et al. 1986) that impacts the caregiver experience rather than kinship. Analysis of the qualitative interviews with caregivers provides some insights into how kinship influences the context of caregiving and impacts caregiver outcomes.

Through the qualitative interviews I discovered a number of differences in how children and spousal caregivers enter the caregiving role, their reasons for caregiving, how they experience family dynamics, their employment status, and decision making. These differences may help describe the context in which adult children and spousal caregivers experience their caregiver role and provide some insights into differences in outcomes. Briefly, I found that caregivers experience the transition into caregiving differently based on their relationship with the care recipient as well as the care recipient’s condition that precipitated the need for care. The reasons for becoming a caregiver also vary, although a majority of the caregivers I interviewed note a sense of obligation or reciprocity, whether to a spouse or a parent. Many reference a “promise” made to the care recipient, but for spouses this promise refers to their wedding vows and for adult children it is a promise to not place their parent in a nursing home. Adult children relate feelings of role conflict in becoming a caregiver for a parent while employed and/or caring for children or other family members. Family dynamics are problematic for many of the caregivers I interviewed. For spouses, these conflicts are in relation to their children or other family members. For adult children, conflicts arose with other siblings when the primary caregiver felt that their siblings were not helping enough.
or that their assistance was not helpful. Employment status is an area of considerable difference among adult child and spousal caregivers. At the time of my interviews, no spousal caregivers were employed, while eight of the 10 adult child caregivers were. The other two adult child caregivers reported that they retired early as a result of their caregiving demands. And finally, adult child and spousal caregivers approach decision making differently. Spousal caregivers are more likely to rely on professional and medical advice, while adult children report that they often research what is available online or talk with friends who have similar experiences.

For most of the adult children I interviewed, caregiving is not something they were prepared for or expected. They talked about the disruption to their lives and the difficulty of managing work, children, and other responsibilities along with caregiving. Adult children also talked about the role reversal of becoming a caregiver for their parent and how difficult this was to manage. Spousal caregivers were more accepting of their role of caregiver and saw it as part of their marital obligation. They talked about the promise they made to their spouse during their wedding vows to care for them in sickness or in health. While taking on the role of caregiver was not as disruptive to the lives of the spousal caregivers in this study, it was an unexpected role change for both spousal and adult child caregivers. In these ways, the context within which spousal and adult child caregivers enter the role of caregiving varies and is experienced in a more problematic way by adult child caregivers. Elaine Brody (2010:5) talked about growing old as “unexpected, even though expectable.” It seems this is also true of caregiving, whether you are an adult child or spouse; entering the caregiving role is unexpected even though it is expectable.
Employment: Role Strain or Role Enhancement

Employment is found to have a positive effect on mental health outcomes for caregivers in the larger quantitative portion of this study. Interviews with caregivers help to understand how employment can serve as a source of support for caregivers. While all 10 adult child caregivers who were interviewed were employed at the beginning of their caregiving experience, only two spousal caregivers were employed. At the time of my interviews, none of the spousal caregivers were employed, and two of the adult child caregivers had retired as a direct result of to their caregiving responsibilities.

Reid and Hardy (1999) note that there are two perspectives relative to role theory, role strain, and role enhancement. Role strain theory suggests that multiple roles can add to burden and negatively impact mental and physical well-being (Pearlin 1989; Young and Kahana 1989). Role enhancement theory argues that multiple roles can improve well-being (Brody, Litvin, Hoffman, and Kleban 1992; Moen, Robison, and Dempster-McClain 1995; Stephens and Franks 1995; Stoller and Pugliesi 1989) Reid and Hardy suggest that employment may provide greater economic, social, and emotional resources as well as an outlet and break from caregiving responsibilities.

This study found that employment is predictive of lower depressive symptoms for caregivers. While employment and caregiving are competing roles, placing more demands on the caregiver, employment also provides additional sources of support and an outlet for the caregiver. Employment changes the context of caregiving, helping caregivers to feel less isolated. Interviews indicate that the caregivers who were employed received a variety of positive outcomes from employment. The flexibility and support of employers was important to all of the caregivers interviewed. They noted
that, with the support of their employer and co-workers, they were able to adjust their schedules to meet the demands of caregiving while maintaining their employment responsibilities. One caregiver related that she was able to find summer and weekend help by hiring the grown children of her co-workers. Thus, she was able to find additional support and resources through her employment. Results from my study are similar to findings reported by Scharlach (1994), that employed caregivers found a sense of accomplishment, opportunities for social relationships, and a break from caregiving through their employment. My findings seem to provide support for the role enhancement perspective as employment provides the caregivers in this study with economic resources, flexibility in order to fulfill their caregiving responsibilities, and support from their co-workers. It is important to note that while caregivers in this study report flexibility at work, not all caregivers may have the benefit of such flexible employment arrangements. Caregivers with less flexible work arrangements may find it impossible to continue in employment.

**Age as a Social Status of Caregivers**

The quantitative analysis conducted as part of this study found that age is directly related to caregiver burden in that older caregivers report lower levels of burden. While there has not been a lot written about the relationship of age to caregiver burden, the findings are mixed. Kim et al. (2012) found that older caregivers reported higher levels of burden than younger caregivers. In contrast, Hayden and Heller (1997) found that younger caregivers of adults with intellectual and developmental disabilities experienced more burden than older caregivers. There is some evidence that age may have an impact on the caregiver experience and that younger spousal caregivers may have
similar experiences as adult child caregivers. Fitting, et al. 1986 found that younger spousal caregivers were lonelier and more resentful of their role than the older caregivers in the study.

The results of my analysis and interviews shed some light on why age may be related to caregiver burden in that older caregivers are less likely to be employed or have other caregiving responsibilities. They are also more likely to be a spouse and feel that caregiving is a more anticipated or expected part of life as opposed to younger caregivers whose lives may be more disrupted when taking on the caregiving role for a parent. This hypothesis is supported by the work of Conde-Sala et al. (2010). They found in their study of 251 caregiving dyads that spouses viewed caregiving as a normal stage of their married life while adult child caregivers viewed it as a disruption to their lives. However, these explanations are more speculative than based on clear and convincing evidence. The relationship between age and caregiver burden deserves further study.

POLICY AND PRACTICE IMPLICATIONS

Informal, unpaid, family caregivers are the under-recognized cornerstone of the long-term care system in the United States. Approximately 78 - 80% of all care provided at home is provided by family and friends (Thompson 2004) and, more importantly, 36% of long-term costs are offset by informal caregiving (Lyons, Schneider, and Desmond 2005). Yet these caregivers are often over-looked by policy makers when considering issues related to long-term care and are rarely considered to be part of the long-term care system.
The long-term care system in the United States has not kept pace with the changes necessitated by an aging population. It is predicated on historical and political beliefs about the nature of old age and has developed as a welfare program for the old. Public programs for both institutional and home and community based long-term care are available only to those who are poor enough to qualify for Medicaid. Families are expected to be the primary providers of care, and public programs are designed to provide supports that supplement family caregiving or provide more extensive care when families can no longer provide care or when no family is available (Achenbaum and Carr 2014). The current long-term care system is focused on rebalancing towards a greater reliance on home and community based services. This shift, combined with changes in health care delivery with shorter hospital stays, places families at the center of this systems change as they are expected to provide greater levels of in-home care to their aging family members.

The long-term care system lacks a coherent vision, which has resulted in a decentralized system, multiple funding streams with little coordination of care, fractured community support systems that are difficult to navigate, no universal funding strategy, a heavy reliance on informal family caregivers, and shortages in the workforce to provide the medical and direct care services needed to support people to live in the community. Within the larger context of long-term care policy, family caregiving should be supported through a coherent set of policy and programs that strengthen this critical foundation of the long term care system. Schuster (2014:4) calls for “public policies that support family caregivers with meaningful financial, social and physical help for the challenges we all face as our society ages.”
My study adds important knowledge about the experience of family caregiving that can help inform public policy. Every caregiver has an important story to tell, and it is incumbent on policy makers and service providers to listen to these stories so that policies and programs are designed to meet the needs of individual caregivers, not a political agenda. Key findings from my study that should inform public policy and program development include the important relationship between employment and caregivers’ mental well-being, the need for supportive and flexible workplace policies to support caregivers who are employed, the need for better information about available services and supports, the need to encourage caregivers to seek services early in their caregiving career, the need to provide education and support for caregivers to both understand the care needs of their loved one and to be strong advocates, and the individual nature of each caregiving dyad.

Investments in supports for family caregivers will reap large payoffs for state and federal budgets by delaying unnecessary and costly institutionalization. Funding for these critical supports should be included in both state and federal budgets. The federal government must also act to reauthorize the Older Americans Act, an important source of funds for caregiver support programs. Social Security credit for workers who must leave the workforce to care for an aging parent or spouse is an important consideration. The Social Security Caregiver Credit Act of 2014 allows for individuals who serve as caregivers of dependent relatives to be deemed wages for up to five years of caregiving service. If passed, this bill would provide increased retirement security for millions of Americans, mostly women, who must leave the workforce to care for a dependent relative. In addition, income tax credits for dependent care of an aging parent or spouse,
similar to the child and dependent care tax credit, would help caregivers manage the added financial burdens of caregiving.

Our population is aging, and so is our workforce. How will we support an aging workforce, many of whom are caring for an aging parent? Findings from my study indicate that employment can provide important resources and supports to informal family caregivers and increase mental health well-being. It is important that employers are supportive and flexible in supporting these employees. Scharlach (1994) reported that informal caregivers found workplace practices that allow them flexibility in their schedules to meet caregiving responsibilities to be most helpful. Public policy and workplace practices need to support an aging workforce. Just as we need family friendly policies for parents of young children, we need family friendly policies that support family caregivers of older adults. In fact, Snelling (2014) notes that more employees are concerned about caring for their aging parents than caring for children at home. She argues that employers must do more to support the 15% of the workforce that are caregivers. Incentives for businesses to implement family friendly policies; such as paid time off to care for a family member, caregiver education programs, and flexible work schedules should be established.

Caregivers in this study stressed the importance of access to information about the care needs of their loved one and the availability of services. Most had to navigate the confusing and fractured long-term care system on their own. Easy access to clear and understandable information, education, and training is critical for family caregivers who are often responsible for providing complex levels of medical and personal care. This information needs to be accessible to older caregivers who may not be as
technologically savvy as their younger counterparts, as well as to the new generation of caregivers who are adept at using the internet to find resources. The Aging and Disability Resource Center Network is an important resource for caregivers and funding should be increased to support this vital network.

Caregivers also stressed the importance of being a strong advocate for their loved one. Many talked about how they know the needs of their loved one best and they often had to be very assertive to get medical professionals to listen to them. Caregiver support programs should include coaching for caregivers on how to reach out for help and to advocate for the needs of their loved one as well as their own needs. Parents of children with developmental disabilities have a number of programs and resources that teach them about their rights and how to advocate for their child’s needs. There is little available for caregivers and families of older adults to teach them how to advocate for their needs. This is not only a disservice to individual caregivers, but has resulted in a weak advocacy network for aging services in general. Programs need to consider how to transfer the knowledge and skills developed in the developmental disability field to the field of aging.

The interviews conducted for this study underscore the fact that every caregiving dyad is unique, and while many commonalities were found among caregivers, no two situations were the same. Programs developed to support caregivers, and the person they are caring for must be individualized and designed so that they can respond to the unique needs and goals of individual caregivers. Successful approaches should be person-centered in order to support informed decision making, creative problem solving, and strategies for engaging supports and negotiating service agreements that are
individually designed to meet the unique needs of the individual and their caregiver (Cotton and Fox 2011).

Finally, caregivers are the cornerstone of the long term care system, and they need to be recognized as such. Currently, there are no formal mechanisms in most health care systems to recognize a patient’s caregiver and include them in care planning, particularly related to discharge planning and after-care education. Legislation should be passed in every state to allow a patient to designate a caregiver upon entry to a hospital and mandate that hospitals instruct the caregiver relative to their loved one’s after-care.

While this study provides important new knowledge to the existing literature related to caregiving, it also raises a number of new issues that were not able to be addressed through this study and should be considered in future research. While this study analyzed the care recipient’s functional status, it did not address the functional status of the caregiver. As many older caregivers may have functional and cognitive limitations themselves, how might this affect the caregiving relationship? Another area that begs for further research is whether there are differences in burden and strain at different stages in the caregiving career. While this study did assess the length of time caregiving, it did not assess caregiver outcomes at different stages of caregiving. It seems likely that burden and strain would change over time as the caregiving experience evolves.

Finally, the economic impact of caregiving was not a focus of this study, but is a critically important issue when considering the social consequences of caregiving and policy implications. There have been a number of studies that look at the economic
consequences of caregiving for an aging parent. These consequences include lost wages, lost pension benefits, and lost social security retirement credits. The MetLife Study of Caregiving Costs to Working Caregivers (2011) estimates that the individual cost impact for men and women over the age of 50 who care for an aging parent is $303,880. This average is slightly higher for women and slightly lower for men. Across all older caregivers of aging parents, the estimated financial impact is nearly $3 trillion.

LIMITATIONS

A number of limitations must be noted regarding the nature of this study. The sample in this study is not a random sample. Participants were drawn from caregivers who presented to the SLRC for services. In addition, there is no control group for comparison purposes. As there may be clear differences between caregivers who seek help and those who don’t, caution is advised in generalizing results to the total population of caregivers. However, from a public policy perspective, I believe the caregivers who participated in this study are exactly the population of caregivers that should be considered when designing public programs to support family caregivers.

Many sections of the assessment survey rely on self-report of finances, health, burden, depressive symptoms, and feelings about caregiving. For a multitude of reasons, including embarrassment, privacy concerns, and sense of duty caregivers may not always be perfectly honest in reporting on these items.

The time frame between the initial and follow-up assessment interviews is short, and six months is a fraction of the time that most of the program’s caregivers have been providing for their care recipients. It is also a very short time within which to measure change. However, the team that designed the research study felt that too much time
between assessments would make it difficult to determine if any changes were as a
result of the interventions or other factors.

Despite these limitations, this study offers a number of design features that help
strengthen the validity of the findings. The study involves a relatively large sample of
caregiver dyads, as compared to other similar studies. It is also somewhat unique in the
depth of information available on both the caregiver and care recipient. This allows for
rich analysis of relationships within the caregiver dyad. The sample also represents a
heterogeneous group of caregivers rather than focusing on a smaller, population
specific sub-set of caregivers.

A significant strength of this study is that it employs both quantitative and
qualitative methods. Quantitative analysis alone cannot adequately describe or explain
the depth and breadth of the caregiving experience. The mixed methods design of this
study allows for a deeper exploration of the caregiving experience to help support and
explain the quantitative findings and to more fully describe the meaning these
caregivers attribute to the experience. The findings will be a significant addition to the
body of knowledge currently available related to family caregiving.

CONCLUSION

The US, along with most developing countries, is facing an unprecedented aging
of the population. Life expectancy is increasing and, with it, a growing number of people
living with chronic illnesses and dementias. Funding for long-term care services has
never been adequate and will not be able to keep pace with the growing need. Informal
caregivers are the back bone of the long-term care system and provide vital support to
vulnerable elders and persons with disabilities that prevent or delay institutionalization.
From both a social and fiscal policy perspective, it is critical that policy makers prioritize funds to support these informal family caregivers.

Caregiving is a demanding and all-consuming role. While there are many rewards of caregiving, there are also numerous challenges, and caregivers experience conflicting emotions throughout their caregiving experience, including anger, frustration, total exhaustion, resentment, love, appreciation, fear, responsibility, and guilt. Caregiving can often leave a caregiver feeling isolated and alone with little time to take care of their own needs. Programs designed to support family caregivers must listen carefully to the voice of caregivers and assure that services are individualized to meet the unique needs of each caregiver. Programs must consider the individual context in which caregivers enter their role as a caregiver. Programs must be varied to meet the unique needs of individual caregivers to help them balance the often competing demands presented by caregiving, employment, and other family responsibilities.

Family caregivers are unpaid and often unprepared when they take on the caregiver role. They need access to good information, training, and support in order to provide good care to their loved one and sustain their own well-being. It is important that caregivers are not only prepared to care for their loved one, but that they begin to prepare for their own long-term care needs. Ultimately, caregiving for an older adult is about helping them to die. Caregivers rarely enter the role with that understanding and are often faced with difficult and emotional end of life decisions. Health care and other professionals need to more openly and candidly talk about end of life issues with family caregivers of older adults.
My study adds important new findings to the body of caregiver literature that already exists by adding the caregiver voice to the understanding of the caregiving experience. While there is wide body of research on caregiving, there is a need for continued research into this important area, especially in light of the aging of the population and the increased reliance on family caregiving for older adults.
LIST OF REFERENCES


Alecxih, Lisa. 2006. “Long Term Care in the United States.” Presentation to AoA Staff.


Gallicchio, Lisa, Nauman Siddiqi, Patricia Langenberg, and Mona Baumgarten. 2002. “Gender Differences in Burden and Depression among Informal Caregivers of


Policy Briefs:


AARP Public Policy Institute. 2009. “Long-Term Care in New Hampshire”.


http://www.cdc.gov/brfss/index.htm  (2/10/2013)


APPENDIX A
INITIAL ASSESSMENT

DATE ____________________

Section 1: Initial Intake Questionnaire for the Family Caregiver

Caregiver Name______________________________ I prefer to be addressed as:__________________

Address:_________________________________________________________________________

Mailing address (if different from the address above):
__________________________________________________________________________
__________________________________________________________________________

Daytime phone:_______________ Alt phone:______________ Email:_____________________

What is the best method to contact you? □ Daytime phone □ Alt phone □ Email

Care Receiver Name____________________________

Address:_________________________________________________________________________

Phone:________________

Mailing address (if different from the address above):
__________________________________________________________________________

Care Receiver’s Emergency Contact

Primary contact person’s name______________________________

Relationship to the care receiver________________________________________

Address__________________________________________ Phone: __________

Secondary contact person’s name______________________________

Relationship to the care receiver________________________________________

Address__________________________________________ Phone: __________
CAREGIVER INFORMATION

Gender: □ Male □ Female  Date of Birth:__________________________

Marital status: □ Single □ Married □ Divorced □ Widowed □ Domestic partner

Read this statement to the caregiver: You may choose to not answer the next 2 questions. This information will not be used to determine eligibility, nor will it affect the services you receive.

Ethnic origin: □ Hispanic or Latino □ Yes □ No

Race: □ African American or Black □ American Indian or Alaskan Native
□ Asian □ Native Hawaiian or Other Pacific
□ White (Alone) non-Hispanic □ White (Alone) Hispanic
□ A person reporting 2 or more races □ Other

How are you related to the care receiver? (I am their…….)

□ Wife  □ Husband  □ Partner  □ Daughter  □ Daughter-In-Law
□ Son  □ Son-In-Law  □ Nephew  □ Niece
□ Granddaughter  □ Grandson  □ Sister  □ Sister-In-Law  □ Brother
□ Other Relative  □ Brother-In-Law  □ Friend/Neighbor

Length of time you have been a caregiver for this person: _______________ (In years and months)

Primary language spoken at home: _______________ Do you need an interpreter? □ Yes □ No

Who is your emergency contact?
________________________________________________________________________

CARE RECIPIENT INFORMATION

Gender: □ Male □ Female  Date of Birth:__________________________

Marital status: □ Single □ Married □ Divorced □ Widowed □ Domestic partner

Living Arrangements

Does the care receiver live alone? □ Yes □ No

Do you live with the care receiver? □ Yes □ No, approximate distance between residences:

Does the care receiver live in your home? □ Yes □ No

Do you live with the care receiver in their home? □ Yes □ No
Who else lives with care receiver?
Name ____________________________ Relationship ____________________________
______________________________________________________________________________

How many hours per day do you usually spend providing care to the care receiver?
______________________________

Do you have any other caregiving responsibilities? (i.e. children, other adults, etc.)
______________________________________________________________________________

Section II: In Home Evaluation
Financial/Legal
Is caregiver currently employed? □ Yes □ No If yes, full or part time?
__________________________________________

Are there medications; supplies or treatments that either you and/or the care receiver should have, but cannot afford to buy? □ Yes □ No
If yes, explain
______________________________________________________________________________

Do you (caregiver) participate in covering expenses or pay out of pocket or help support care recipient financially? □ Yes □ No
If yes, does this cause any problems for you? □ Yes □ No
Explain:
______________________________________________________________________________

In the next year, what new expenses will be necessary for caregiving (renovations, moving, wheel chair)? __________________________________________

________________________________________

Read statement to caregiver: Providing the information below is optional and is not required to determine eligibility. Only your responses without your personal identifying information will be shared. The U.S. Administration on Aging requires the collection of this information to gain a better understanding of the situations and needs of family caregivers nationwide.

Care Recipient Income (gross) and resources (estimate):
Indicate: ___ Weekly ___ Monthly ___ Yearly
<table>
<thead>
<tr>
<th>Social Security (SSDI/SSI/SSA)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pension/Annuities</td>
</tr>
<tr>
<td>Veterans</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

**Balance:**

<table>
<thead>
<tr>
<th>Checking</th>
<th>Mutual Fund</th>
</tr>
</thead>
<tbody>
<tr>
<td>Saving</td>
<td>Trust</td>
</tr>
<tr>
<td>Annuity</td>
<td>Patient Account</td>
</tr>
<tr>
<td>Life Insurance</td>
<td>Stock/Bonds</td>
</tr>
<tr>
<td>IRA401K</td>
<td>Other (prepaid burial contract)</td>
</tr>
</tbody>
</table>

**Approximate Total Resources** $__________________________

**Care GIVER Income:**
How much TOTAL income did you and your family receive in 2008, not just from wages or salaries but from ALL sources -- that is, before taxes and other deductions were made? Was it...

(READ CATEGORIES, and circle answer)

**ANNUAL INCOME**

1. Less than $20,000
2. $20,001 - $40,000,
3. $40,001 - $60,000
4. Over $60,000

97 REFUSED
98 Doesn’t Know
99 Not Applicable

**Planning Ahead**
Check any of the following that apply

- Does care recipient have a legal guardian? [ ] Yes  [ ] No
- Does care recipient have a special power of attorney for health-care decision making? [ ] Yes  [ ] No
Does care recipient have a living will?  □ Yes  □ No
Does care recipient have EMS/DNR directives?  □ Yes  □ No
Does care recipient have a funeral plan?  □ Yes  □ No
Does care recipient have a burial plan?  □ Yes  □ No

Does care recipient need assistance developing any of the above documents/plans that you have responded “no” to?  □ Yes  □ No

________________________________________________________
________________________________________________________

**Caregiving Experiences**

We have discussed possible difficulties related to your caregiving experience. Frequently there are many positive aspects of caregiving. Please tell me:

What is the most rewarding thing for you about providing care to the care receiver?  __________
________________________________________________________
________________________________________________________
________________________________________________________

What qualities and personal strengths do you bring to your caregiving role?  __________
________________________________________________________
________________________________________________________
________________________________________________________

How are other family members involved (in caring for the care receiver)?  __________
________________________________________________________
________________________________________________________
________________________________________________________

Does your living or housing arrangements cause any difficulties?  □ Yes  □ No  
Explain:
________________________________________________________
________________________________________________________

Does the fact that you live in a (rural, small town, suburban, urban) area create any problems for you with regard to your caring role?  □ Yes  □ No  
Explain:
________________________________________________________
________________________________________________________

Do you attend a support group?  □ Yes  □ No  
If no, why not? If yes, is it helpful?  ______
Do you feel you have a good understanding of your care receiver’s condition? ________

_______________________________________________________________________

_______________________________________________________________________

Describe your relationship with your care receiver’s primary care provider? _________

_______________________________________________________________________

_______________________________________________________________________

Will there be a change or temporary situation in the near future that will impact care?
☐ Yes ☐ No   If Yes, what will they be? _________________________________

Do you have any concerns about safety for your care receiver? ☐ Yes    ☐ No

Explain:
_______________________________________________________________________

_______________________________________________________________________

Are you (caregiver) at risk for abuse, neglect, self-neglect, or exploitation? ☐ Yes    ☐ No

If Yes, by whom?
_______________________________________________________________________

Is the person you care for at risk of abuse neglect, self-neglect, or exploitation by another
family member or friend? ☐ Yes    ☐ No   If Yes, by whom?
_______________________________________________________________________

What is the chance that the care receiver will be institutionalized or placed in a nursing home
within the next three to six months?

☐ Not at all likely   ☐ Somewhat likely   ☐ Very likely   ☐ Almost certain

Interviewer overall thoughts/observations: _______________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
Instructions to Interviewer:
The following questions are part of a standardized assessment. Please read each statement aloud and allow the caregiver to reflect on each statement and respond to each by choosing one of the five answer choices. The statements in the questionnaires are standardized and changes to the wording are NOT recommended. This ensures consistency in information gathering and reporting. If the caregiver does not understand any particular statement, please DO NOT interpret or explain the statement, but rather allow the caregiver to respond to the statement based on his or her best guess or understanding.

Please do not leave any question unanswered. Total scores are invalid if the questionnaire is incomplete.

Read to Caregiver: The following is a list of statements that reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers. Your answer choices are in section 1 of the response guide (give response guide to caregiver)

<table>
<thead>
<tr>
<th>Questionnaire 1</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you feel that your relative asks for more help than he/she needs?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. Do you feel that because of the time that you spend with your relative that you don’t have enough time for yourself?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. Do you feel embarrassed over your relative’s behavior?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5. Do you feel angry when you are around your relative?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>7. Are you afraid of what the future holds for your relative?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>8. Do you feel your relative is dependent on you?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>9. Do you feel strained when you are around your relative?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>10. Do you feel your health has suffered because of your involvement with your relative?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>11. Do you feel that you don’t have as much privacy as you would like because of your relative?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>12. Do you feel that your social life has suffered because you are caring for your relative?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>13. Do you feel uncomfortable about having friends over because you are caring for your relative?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Questionnaire 1</td>
<td>Never</td>
<td>Rarely</td>
<td>Sometimes</td>
<td>Quite Frequent</td>
<td>Nearly Always</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------------</td>
<td>-------</td>
<td>--------</td>
<td>-----------</td>
<td>----------------</td>
<td>---------------</td>
</tr>
<tr>
<td>15. Do you feel that you don’t have enough money to care for your relative in addition to the rest of your expenses?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>16. Do you feel that you will be unable to take care of your relative much longer?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>17. Do you feel you have lost control of your life since your relative’s illness?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>18. Do you wish you could just leave the care of your relative to someone else?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>19. Do you feel uncertain about what you do for your relative?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>20. Do you feel you should be doing more for your relative?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>21. Do you feel you could be doing more for your relative?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>22. Overall, do you feel burdened caring for your relative?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Your Health and Well-Being

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. *Thank you for completing this survey!*

For each of the following questions, please mark an [ ] in the one box that best describes your answer.

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

<table>
<thead>
<tr>
<th>Excellent</th>
<th>Very good</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
</tbody>
</table>

2. **The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**

   Yes, limited a lot
   Yes, limited a little
   No, not limited at all

   a. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf .................................................. [ ] [ ] [ ]

   b. **Climbing several flights of stairs** .................................................. [ ] [ ] [ ]
3. **During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
<td>▼</td>
</tr>
</tbody>
</table>

   ▶ Accomplished less than you would like ....................

   ▶ Were limited in the kind of work or other activities ..................................................

4. **During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
<td>▼</td>
</tr>
</tbody>
</table>

   ▶ Accomplished less than you would like ....................

   ▶ Did work or other activities less carefully than usual ..............................................................

5. **During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little bit</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
</tbody>
</table>

   □ 1 □ 2 □ 3 □ 4 □ 5
6. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>A good bit of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
</tbody>
</table>

   a. Have you felt calm and peaceful? ........................................... □1 □2 □3 □4 □5 □6

   b. Did you have a lot of energy? ............................................... □1 □2 □3 □4 □5 □6

   c. Have you felt downhearted and blue? ..................................... □1 □2 □3 □4 □5 □6

7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
<tr>
<td>□1</td>
<td>□2</td>
<td>□3</td>
<td>□4</td>
<td>□5</td>
</tr>
</tbody>
</table>
## Questionnaire 3

**During the Past Week**

<table>
<thead>
<tr>
<th></th>
<th>Rarely or none of the time – ( \leq 1 ) day</th>
<th>Some or a little of the time – 1-2 days</th>
<th>Occasionally or a moderate amount of time – 3-4 days</th>
<th>Most or all of the time – 5-7 days</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I was bothered by things that usually don’t bother me.</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>2. I did not feel like eating; my appetite was poor.</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>3. I felt that I could not shake off the blues even with help from my family or friends.</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>4. I felt I was just as good as other people.</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>5. I had trouble keeping my mind on what I was doing.</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>6. I felt depressed.</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>7. I felt that everything I did was an effort.</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>8. I felt hopeful about the future.</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>9. I thought my life had been a failure.</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>10. I felt fearful.</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>11. My sleep was restless.</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>12. I was happy.</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>13. I talked less than usual.</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>15. People were unfriendly.</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>16. I enjoyed life.</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>17. I had crying spells.</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>18. I felt sad.</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
<td>☒</td>
</tr>
</tbody>
</table>
Read to the caregiver: The last few questions deal with some of the common problems the care receivers experience. Please indicate if any of these problems have occurred during the past week. If so, how much has this bothered or upset you when it happened? Please use the choices on Section 3 to respond to these questions.

<table>
<thead>
<tr>
<th>Questionnaire 4</th>
<th>Has it occurred in past week?</th>
<th>Reaction, if yes (how much it bothered you)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Asking the same question over and over</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>2. Trouble remembering recent events (i.e. items in newspaper or TV)</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>3. Trouble remembering significant past events</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>4. Losing or misplacing things</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>5. Forgetting what day it is</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>6. Starting, but not finishing, things</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>7. Difficulty concentrating on a task</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>8. Destroying property</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>9. Doing things that embarrass you</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>
**Questionnaire 4**

Please answer all the questions for both frequency and reaction.

Has it occurred in past week?  
0 = No  1 = Yes  

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>10. Waking you or other family members up at night</td>
<td></td>
</tr>
<tr>
<td>11. Talking loudly and rapidly</td>
<td></td>
</tr>
<tr>
<td>12. Appears anxious or worried</td>
<td></td>
</tr>
<tr>
<td>13. Engaging in behavior that is potentially dangerous to self or others</td>
<td></td>
</tr>
<tr>
<td>14. Threats to hurt oneself</td>
<td></td>
</tr>
<tr>
<td>15. Threats to hurt others</td>
<td></td>
</tr>
<tr>
<td>16. Aggressive to others verbally</td>
<td></td>
</tr>
<tr>
<td>17. Appears sad or depressed</td>
<td></td>
</tr>
<tr>
<td>18. Expressing feelings of hopelessness or sadness about the future</td>
<td></td>
</tr>
<tr>
<td>19. Crying and tearfulness</td>
<td></td>
</tr>
<tr>
<td>20. Commenting about death of self or others</td>
<td></td>
</tr>
<tr>
<td>21. Talking about feeling lonely</td>
<td></td>
</tr>
<tr>
<td>22. Comments about feeling worthless or being a burden to others</td>
<td></td>
</tr>
<tr>
<td>23. Comments about feeling like a failure, or about not having any worthwhile accomplishments in life</td>
<td></td>
</tr>
<tr>
<td>24. Arguing, irritability, and/or complaining</td>
<td></td>
</tr>
</tbody>
</table>
### Section III: The Physical and Mental Status of the Care Recipient

**Instrumental Activities of Daily Living**

1. **Independent:** can accomplish with or without assistive devices—No help needed.
2. **Assistance or done with help:** Individual involved in activity, but help (including supervision, reminders, and/or physical “hands-on” help) was needed.
3. **Dependent or done by others:** Full performance of the activity is done by others.

### Instrumental Activities of Daily Living

<table>
<thead>
<tr>
<th>Activity</th>
<th>1. Ind.</th>
<th>2. Assist.</th>
<th>3. Dep.</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Meal Preparation: Care recipient can prepare breakfast and light meals</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Main Meal Preparation: Prepared or received main meal. Meals on Wheels _____ times per week.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Telephone: Can use telephone as necessary, e.g., able to contact people in an emergency.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. Light Housework: can do light housework such as washing dishes, dusting (on daily basis), making own bed.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. Managing Finances: Care recipient can manage own finances, including banking, handling checkbook, paying bills.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f. Medication: Can take medication on time with correct dose</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Transportation

<table>
<thead>
<tr>
<th>Mode of Transportation</th>
<th>1. Ind.</th>
<th>2. Assist.</th>
<th>3. Dep.</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Individual <strong>needs arrangement</strong> for transportation to medical, dental appointments, necessary engagements, or other activities.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Individual <strong>needs transportation</strong> to medical, dental appointments, necessary engagements, or other activities.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Individual <strong>needs escort</strong> to medical, dental appointments, necessary engagements, or other activities.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Extent of Help with Instrumental and Personal Activities

Indicate the extent of help the care recipient has received from family, friends, and neighbors to complete activities of daily living.

<table>
<thead>
<tr>
<th>Activity</th>
<th>1. Ind.</th>
<th>2. Assist.</th>
<th>3. Dep.</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Sum of time across five weekdays: _____ Hours</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Sum of time across two weekend days: _____ Hours</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. How many hours each day left alone: _____ Hours</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Has the care recipient been hospitalized or seen in the Emergency Room in the last month? |
|-----------------------------------------------|---------|
| a.                                            |         |
| □ Yes                                          |         |
| □ No                                           |         |
b. Do any health care providers come into the home on a regular basis to provide services such as a registered nurse, occupational therapist or physical therapist?  

☐ Yes  

☐ No  

If yes, please specify the health provider: ________________________________

### Activities of Daily Living

<table>
<thead>
<tr>
<th></th>
<th>0. Independent</th>
<th>1. Supervision</th>
<th>2. Limited Assistance</th>
<th>3. Extensive Assistance</th>
<th>4. Total Dependence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bed Mobility: How individual moves to and from lying position, turns side to side, and positions body while in bed</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Transfers: How individual moves between surfaces, to/from: bed, chair, wheelchair, standing position</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Locomotion: How individual moves between locations in his/her room and other areas on same floor. If in wheelchair, self-sufficiency once in chair</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Primary mode of locomotion:</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>☐ No assistive device</td>
<td>☐ Cane</td>
<td>☐ Walker/Crutch</td>
<td>☐ Scooter</td>
<td>☐ Wheelchair</td>
<td></td>
</tr>
<tr>
<td>Walking: How individual walks</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Dressing: How individual puts on, fastens, and takes off all items of street clothing, including donning/removing prosthesis</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Eating: How individual eats and drinks (regardless of skill)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Toilet Use: How individual uses the toilet room (or commode, bedpan, urinal); transfers on/off toilet, cleanses, changes pad, manages ostomy or catheter, adjusts clothes</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Personal Hygiene: How individual maintains personal hygiene, including combing hair, brushing teeth, shaving, applying makeup, washing/drying face, hands, and perineum.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Bathing: How individual takes full-body bath/shower, sponge bath, and transfers in/out of tub/shower.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Continence:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>urinary</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>bowel</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Continent - Complete control

<table>
<thead>
<tr>
<th>Continent</th>
<th>Response</th>
<th>CORRECT</th>
<th>INCORRECT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Usually continent - Incontinent episodes once a week or less</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasionally incontinent- 2 or more times a week but not daily</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequently incontinent— incontinent daily, some control present</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incontinent— incontinent all (or almost all) of the time</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### This set of questions needs to be asked of the care RECIPIENT

**Short Portable Mental Status Questionnaire**

Instructions: Ask questions 1-10 in this list and record whether questions are correct or incorrect. Ask question 4A only if patient does not have a telephone.

<table>
<thead>
<tr>
<th>Question</th>
<th>RESPONSE</th>
<th>CORRECT</th>
<th>INCORRECT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What is the date today? (Month, Date, Year)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. What day of the week is it?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. What is the name of this place?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. What is your telephone number?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4A. What is your street address? <em>(Ask only if recipient does not have a telephone)</em></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. How old are you?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. When were you born?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Who is President of the United States now?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Who was President just before him?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. What was your mother’s maiden name?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Subtract 3 from 20 and keep subtracting from each new number, all the way down.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Interviewer: Mark appropriate range

Care recipient’s level of education

<table>
<thead>
<tr>
<th>Grade School or Less</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beyond Grade School to completed High School</td>
</tr>
<tr>
<td>Education beyond High School</td>
</tr>
</tbody>
</table>

Supports and Services

Is anyone available to provide respite (relief) when you are unable to provide care? ☐ Yes ☐ No

If yes, is such assistance available on short notice? ☐ Yes ☐ No

Explain who is available: ____________________________________________________________

Have you received respite or supplemental services through the NH Family Caregiver Support Program in the past? ☐ Yes ☐ No

If yes, services received ___________________________________________________________

Who else helps out? Please list other informal (non-paid) supports below (alternate phrasing: Who else in your family or community is interested in the well-being of the care recipient?)

<table>
<thead>
<tr>
<th>First Name</th>
<th>Relationship to Caregiver</th>
<th>Where do they live?</th>
<th>Help they provide</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Ask of Care GIVER) What are your goals?

______________________________________________________________________________

______________________________________________________________________________

(Ask of Care RECEIVER or ask caregiver on behalf of care receiver) What are your goals?

______________________________________________________________________________

______________________________________________________________________________
Do you need in-home care or assistance (such as training for special tasks you do, homemaker services, support for emergencies, PT/OT, help in organizing services or training support)? 

Do you need Respite Care (either in the home, out of the home, overnight, Senior Center, Adult Day Program or Senior Companion program)? 

Do you need help in reviewing Long Term Care options (such as assistance in considering options, help with choosing or admitting to a facility, housing services, or understanding LTC insurance)? 

Do you or your care receiver need other services (such as meals on wheels, transportation, equipment/home modifications, medications, financial assistance, legal assistance, counseling or support groups)? 

What additional resources do you think you would benefit from? Comments 

Would you like information any topics? □ Yes □ No
Explain: 

Have you looked at other sources for help? □ Yes □ No
Explain: 

Do you have any comments or recommendations concerning the interview or specific questions?
**Questionnaire 1**

<table>
<thead>
<tr>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
</tr>
<tr>
<td>Rarely</td>
</tr>
<tr>
<td>Sometimes</td>
</tr>
<tr>
<td>Quite Frequently</td>
</tr>
<tr>
<td>Nearly Always</td>
</tr>
</tbody>
</table>

**Questionnaire 3**

- Rarely or none of the time (less than 1 day)
- Some or a little of the time (1-2 days)
- Occasionally or a moderate amount of time (3-4 days)
- Most or all of the time (5-7 days)

**Questionnaire 4**

<table>
<thead>
<tr>
<th>Reaction Ratings:</th>
<th>If yes, has it occurred in the past week:</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Not at all</td>
</tr>
<tr>
<td>Yes</td>
<td>A little</td>
</tr>
<tr>
<td></td>
<td>Moderately</td>
</tr>
<tr>
<td></td>
<td>Very much</td>
</tr>
<tr>
<td></td>
<td>Extremely</td>
</tr>
</tbody>
</table>
Transitions In Caregiving
Follow-Up Interview
Semi-Structured Interview Questions

Thank you for meeting with me today. This interview will take about an hour of your time. I appreciate your willingness to speak with me.

The questions I am going to ask you are related to your experiences caregiving for your (husband/wife/mother/father). Your responses will be totally confidential and will have no impact on any services you receive through the NHFCSP. However, your input will have an important role in increasing our understanding of the caregiving experience and helping other caregivers.

1. Tell me about your experience as you transitioned into a caregiving role for your (care recipient)?

2. What are the reasons that you are willing to be a caregiver for your (care recipient)?

3. What do you find most rewarding about caregiving?

4. What is most important to you about the care that you give? How do you think this influences the care you give?

5. How do you decide what kind of care your (care recipient) needs?

6. What helps you in deciding how to give or what types of care to provide for your (mother, father, wife, husband)?

7. What types of support do you provide to your (care recipient)?

8. How do you feel about providing this type of care or support?

9. Are you employed?
   If employed:
   a. What do you do?
   b. How many hours do you work?
   c. Do you find that you have work commitments after hours?
   d. In what ways has caregiving impacted your employment?
e. In what ways has your employment affected your ability to provide care to your (care recipient)?

10. Have you experienced any financial difficulties due to your caregiving responsibilities?
   a. If yes, please elaborate.

11. How many children do you have?

   If a spousal caregiver has children:
   a. Are any of your children living close by?
   b. Do you see them often?
   c. About how often?
   d. Do they help you in any way?
   e. Are you reluctant to ask them for help?

   If an adult child caregiver has children:
   a. How old are your children?
   b. Does caregiving for your parent affect your ability to care for your children? How?
   c. Does caring for your children affect your caregiving for your parent? How?

12. Are you involved in any church, senior center, bingo, volunteer groups, etc.?
   a. How often do you generally go to ___?

13. Is (care recipient) involved in any church, senior center, bingo, volunteer groups, etc.?
   a. How often does he/she generally go to …?
   b. How does he/she get there?

14. How often do you get together with anyone from your neighborhood for a visit, either in your home or in theirs for a meal or a visit, or to watch a TV program together in the evening, play cards, etc?
   ____ Every day
   ____ At least once a week
   ____ Every few weeks
   ____ Less than once a month
   ____ Rarely/never

15. What do you gain from being involved in these activities? How does your involvement help you cope with your caregiving responsibilities?

16. Do you have other family or friends that are able to help you?
   a. If yes, Who?
   b. How do they help you?
17. In general, if you needed someone to help you out, such as giving you a ride to the doctors, picking up some groceries, or helping you with (care recipient), how many people could you call on to help you out?
   a. Do you wish you had more people who could help you?

18. What services have you received through the NH Family Caregiver Support Program?
   _____ Respite
   _____ Funds for things I need
   _____ Caregiver Support Group
   _____ Powerful Tools for Caregivers Class
   _____ One on one support from the ServiceLink Caregiver Specialist
   _____ Information and referral services from ServiceLink

19. Which services have been most beneficial in helping you care for your (care recipient)?
   a. Why?

20. Which services were least helpful to you in caring for your (care recipient)?
   a. Why?

21. Are there other services that you think would be helpful in supporting you to care for (care recipient)?
   a. What are they?

22. What prompted you to seek services?

23. What have you learned over the past year as a result of your caregiving?

24. What do you think makes it so hard to be a caregiver?

25. What advice would you give other caregivers?

26. Are there any other questions or issues I should ask caregivers about their experience that you think are important to include?

27. What have I not asked you about that you think is important for others to know about what it is like to be a caregiver?
APPENDIX C
IRB APPROVAL LETTERS
University of New Hampshire
Research Integrity Services, Service Building
51 College Road, Durham, NH 03824-3585
Fax: 603-862-3564

06-Aug-2013

Fox, Susan W
Institute on Disability
56 Old Suncook Rd, Suite 2
Concord, NH 03301

IRB #: 5795
Study: Kinship Matters
Approval Date: 06-Aug-2013

The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved the protocol for your study as Expedited as described in Title 45, Code of Federal Regulations (CFR), Part 46, Subsection 110.

Approval is granted to conduct your study as described in your protocol for one year from the approval date above. At the end of the approval period, you will be asked to submit a report with regard to the involvement of human subjects in this study. If your study is still active, you may request an extension of IRB approval.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the attached document, Responsibilities of Directors of Research Studies Involving Human Subjects. (This document is also available at http://unh.edu/research/irb-application-resources.) Please read this document carefully before commencing your work involving human subjects.

If you have questions or concerns about your study or this approval, please feel free to contact me at 603-862-2003 or Julie.simpson@unh.edu. Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB,

Julie F. Simpson
Director

cc: File
    Turner, Heather
University of New Hampshire

Research Integrity Services, Service Building
51 College Road, Durham, NH 03824-3585
Fax: 603-862-3564

14-Jul-2014

Fox, Susan W
Institute on Disability
10 West Edge Dr
Durham, NH 03824

IRB #: 5795
Study: Kinship Matters
Review Level: Expedited
Approval Expiration Date: 06-Aug-2015

The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved your request for time extension for this study. Approval for this study expires on the date indicated above. At the end of the approval period you will be asked to submit a report with regard to the involvement of human subjects. If your study is still active, you may apply for extension of IRB approval through this office.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the document, Responsibilities of Directors of Research Studies Involving Human Subjects. This document is available at http://unh.edu/research/irb-application-resources or from me.

If you have questions or concerns about your study or this approval, please feel free to contact me at 603-862-2003 or Julie.simpson@unh.edu. Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB,

[Signature]
Julie F. Simpson
Director

cc: File
Turner, Heather
APPENDIX D
CONSENT FORM

CONSENT TO PARTICIPATE IN RESEARCH

KINSHIP MATTERS RESEARCH PROJECT

Principal Investigator:  Susan Fox, Institute on Disability, PhD Candidate in Sociology

The University of New Hampshire’s Institutional Review Board for the Protection of Human Subjects in Research has approved the use of human subjects in this study.

WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this research is to better understand caregiver’s experiences and the things that make caring for a relative who is ill or disabled more or less difficult. 20 caregivers of older adults will be interviewed as a part of this study. In addition, data from the original Transitions in Caregiving Study, of which you were a participant, will be analyzed as part of this study. This study is being conducted to fulfill the PhD requirements of Susan Fox.

WHAT DOES YOUR PARTICIPATION IN THIS STUDY INVOLVE?

If you agree to participate in the study, you will be interviewed by the researcher (Susan Fox) and asked a series of questions about your experience as a caregiver for your family member or friend. The questions ask about what it has been like for you to be a caregiver, the types of care you have provided, what supports you have received, and how caregiving has impacted your daily life. Participating in the interview will take about 2 hours or less. With your consent, this interview will be taped and transcribed. Once transcribed, the tape will be erased. If you do not want the interview to be taped, the researcher (Susan Fox) will take notes during the interview. The interview can take place in a location of your choice, such as the ServiceLink office, your home, a public location, etc.

WHAT ARE THE POSSIBLE RISKS OF PARTICIPATING IN THIS STUDY?

The potential risks of participating in this study are very small. Your participation will not change your services in any way. Some of the questions that are asked may make you uncomfortable and you may refuse to answer any questions at any time during the interview.

WHAT ARE THE POSSIBLE BENEFITS OF PARTICIPATING IN THIS STUDY?

Other benefits may be experienced by you and others like you. We hope to gather information that may help people in the future. The benefits of participation include furthering the understanding of the experiences of caregivers, what services and supports are most beneficial, and identifying the challenges that exist so that solutions can be developed to ensure that all caregivers have access to the high quality services supports they need to continue to care for their loved one at home. Information collected from this project may be used to inform program and
policy makers about the importance of programs such as this. This could potentially lead to program improvements, expansion of programs such as this one, and/or increased funding for such programs.

**IF YOU CHOOSE TO PARTICIPATE IN THIS STUDY, WILL IT COST YOU ANYTHING?**

There are no costs associated with your participation in this study.

**WILL YOU RECEIVE ANY COMPENSATION FOR PARTICIPATING IN THIS STUDY?**

You will be offered a $25 gift card in appreciation for your participation.

**DO YOU HAVE TO TAKE PART IN THIS STUDY?**

Your consent to participate in this research is entirely voluntary, and your refusal to participate will not affect your participation in the NH Family Caregiver Support Program, or any benefits associated with this program.

**CAN YOU WITHDRAW FROM THIS STUDY?**

If you consent to participate, you may discontinue your participation at any time without any effect on your participation in the NH Family Caregiver Support Program, or any benefits associated with this program. If there are certain questions that you do not wish to answer, you may refuse to do so at any time. If you chose to withdraw from the study, you may revoke your approval for the use of your information. You may do this by contacting the researcher in writing: Susan Fox, Institute on Disability, 56 Old Suncook Rd, Suite 2, Concord, NH 03301 or by e-mail at sue.fox@unh.edu.

**HOW WILL THE CONFIDENTIALITY OF YOUR RECORDS BE PROTECTED?**

The researcher (Susan Fox) will maintain the confidentiality of all data and records associated with your participation in this research. Your name, address and telephone number will be collected so that we may contact you for any follow up to clarify your responses, if needed, but will not be kept with the interview information that you provide. No personally identifiable information will be linked to any of the data collected. The interview forms will be coded with numbers that are assigned to each participant and the master code list will be kept in a locked file cabinet. All data will be reported in the aggregate so no data will be individually identifiable. Completed interviews will be stored in locked cabinets that can be accessed only by the researcher (Susan Fox) and the project staff. Electronic data files will be stored in folders/drives only accessible to the project staff on password protected computers. Project staff who may have access to this data include Melissa Mandrell, Kim Phillips, Vidya Sundar, and a contracted transcriber. Dr. Heather Turner, who is the chair of Susan Fox’s dissertation committee, will also have access to the data. In addition, other committee members may access this data. These members include Dr. Sally Ward, Dr. Sharyn Potter, Dr. Andrew Smith, and Dr. Raelene Shippee-Rice.
Information (not including personally identifiable information) collected from the interviews may be shared with other researchers at UNH and may be used to support ongoing research at the Institute on Disability/UNH. UNH/IOD researchers will ensure that confidentiality is maintained at all times. The data and results of this study will be published in Susan Fox’s dissertation. In addition, the results may be utilized in presentations, reports, and journal articles. No personally identifiable information will be reported in any of these publications or presentations.

You should understand, however, there are rare instances when the investigator is required to share personally-identifiable information (e.g., according to policy, contract, or regulation). For example, in response to a complaint about the research, officials at the University of New Hampshire, and/or regulatory and oversight government agencies may access research data. You also should understand that the investigator is required by law to report certain information to government and/or law enforcement officials (e.g., elder abuse, neglect, or exploitation; threatened violence against self or others; communicable diseases. In addition, there is no guarantee that the information cannot be obtained by legal process or court order.

WHOM TO CONTACT IF YOU HAVE QUESTIONS ABOUT THIS STUDY?

If you have any questions or concerns pertaining to the research you can call Susan Fox at the Institute on Disability, (603) 228-2085 x24 or email at sue.fox@unh.edu and be given the opportunity to discuss them.

If you have questions about your rights as a research subject you can contact Dr. Julie Simpson in UNH Research Integrity Services, 603-862-2003 or Julie.simpson@unh.edu to discuss them.

Consent

I have read the above information about the Kinship Matters Research Study and have been given an opportunity to ask questions. I have read and fully understand the purpose of this research project and the risks and benefits it presents to me as stated above. I agree to participate in this study. I have been given a signed copy of this consent document for my records.

__________________________________  _____________  
Caregiver Signature     Date

__________________________________
Caregiver Printed Name
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<th>(1) ADL</th>
<th>(2) Mental Status</th>
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<th>(4) Depression</th>
<th>(5) Disrupt Function</th>
<th>(6) Burden</th>
<th>(7) Memory Reaction</th>
<th>(8) Depression Reaction</th>
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<th>(11) MCS</th>
<th>(12) PCS</th>
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APPENDIX F: Factor Analysis of Zarit Burden Inventory

Factor Analysis on ZBI: 22 items, Principal Component Analysis, Varimax Rotation, Factor Loadings

<table>
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<tr>
<th>ZBI Items</th>
<th>Personal Impact</th>
<th>Relational Impact</th>
<th>Future Anxiety</th>
<th>Guilt</th>
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<tr>
<td>2. Do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?</td>
<td>0.7271</td>
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<td>3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?</td>
<td>0.7456</td>
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<td>6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?</td>
<td>0.4363</td>
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<td>8. Do you feel your relative is dependent on you?</td>
<td>0.6672</td>
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<td>9. Do you feel strained when you are around your relative?</td>
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<td>10. Do you feel your health has suffered because of your involvement with your relative?</td>
<td>6103</td>
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<td>11. Do you feel that you don’t have as much privacy as you would like because of your relative?</td>
<td>4857</td>
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<td>12. Do you feel that your social life has suffered because you are caring for your relative?</td>
<td>6351</td>
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<td>14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?</td>
<td>0.5159</td>
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<td>17. Do you feel you have lost control of your life since your relative’s illness?</td>
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<td>22. Overall, how burdened do you feel in caring for your relative?</td>
<td>0.5891</td>
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<td>1. Do you feel that your relative asks for more help than he/she needs?</td>
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<td>4. Do you feel embarrassed over your relative’s behavior?</td>
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<td>13. Do you feel uncomfortable about having friends over because of your relative?</td>
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<td>5. Do you feel angry when you are around your relative?</td>
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<td>7. Are you afraid what the future holds for your relative?</td>
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<td>15. Do you feel that you don’t have enough money to take care of your relative in addition to the rest of your expenses?</td>
<td>0.5219</td>
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<td>16. Do you feel that you will be unable to take care of your relative much longer?</td>
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<td>18. Do you wish you could leave the care of your relative to someone else?</td>
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<td>19. Do you feel uncertain about what to do about your relative?</td>
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<td>20. Do you feel you should be doing more for your relative?</td>
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<td>21. Do you feel you could do a better job in caring for your relative?</td>
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