Adult grandchildren providing care to frail elderly grandparents

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Adult Grandchildren Providing Care to Frail Elderly Grandparents

by

Tamara L. Smith

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ABSTRACT

A larger proportion of adult grandchildren today have grandparents still alive than in any previous historical era. An older grandchild implies an older grandparent -- and, as chronic illnesses increase with age, these grandparents are likely to be ill. Little attention has been given to the dynamics of the grandchild-grandparent relationship in the face of illness of the grandparent, although demographic shifts indicate that most grandchildren and their grandparents will share a period of time during which the grandparent is suffering from a chronic illness. This dissertation examines adult grandchildren who provide regular assistance to a grandparent with health limitations. Data collected for this dissertation is derived from qualitative semi-structured interviews with 35 grandchildren who are caring for an ill grandparent with at least one ADL impairment. Six areas of inquiry are examined: (1) how the dynamics of the existing grandparent/grandchild relationship affects caregiving processes of grandchildren; (2) how caregiving for a grandparent changes the grandchild/grandparent relationship; (3) why/under what circumstances adult grandchildren provide care for their grandparents; (4) negative effects of providing this care, (5) the positive effects of providing this care, and (6) the available supports and needs of these adult grandchild caregivers. Findings have implications for intergenerational family caregivers, the work and life trajectories for grandchildren providing care, the policies and programs aimed for supporting these grandchildren, and the need for more research on this caregiving population.
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Introduction

Family dynamics have shifted in the United States. Our population has a longer life span. This demographic shift has resulted in a more salient and varied role for grandparents and grandchildren in contemporary families (Uhlenberg and Kirby 1998; Szinovacz 1998). Grandparenthood and grandchildhood are social roles that are enjoyed by relatives for a much longer duration than in previous historical times. While grandparents as a group are heterogeneous, grandparents today are more likely to have a personal relationship with their grandchildren and are more likely to enjoy the role of grandparenthood in a companionate relationship than ever before (Cherlin and Furstenburg 1986; Uhlenberg 2009). Grandchildren are also likely to have closer ties to grandparents today than in previous historical times, largely because grandparents are living longer. Today, a larger proportion of adult grandchildren have grandparents still alive than in any previous historical era. An older grandchild implies an older grandparent -- and, as chronic illnesses increase with age, these grandparents are likely to be ill. Little attention has been given to the dynamics of the grandchild-grandparent relationship in the face of illness of the grandparent, although demographic shifts indicate that most grandchildren and their grandparents will share a period of time during which the grandparent is suffering from a chronic illness. This research will examine adult grandchildren who provide regular assistance to a grandparent with health limitations.

Adult grandchildren have been all but overlooked in caregiving research, although demographic and caregiving trends suggest that adult grandchildren are filling society’s need for additional informal caregivers. The United States has undergone a demographic
transition. According to U.S. Census data, the elderly population (65+) reached 34.5 million people in 1999, almost 13% of the overall population (Hobbs and Stoop 2002). This growth is expected to continue in the future. Between 2010 and 2030, the Baby Boom generation (those born between 1946 and 1964) will be reaching the age of 65, subsequently increasing the proportion of the population over the age of 65 to approximately 20% of the population (Administration on Aging 2009). While people are living longer lives, often this longevity is coupled with increasing chronic illness. By 1994, more than half of the elderly population reported at least one disability, and one-third of these people had severe disabilities. These numbers increase with age: almost three-fourths of those 80 and older reported at least one disability (Fowles and Greenberg 2002). Only 4.3% of the elderly population lives in nursing homes (Fowles and Greenberg 2002) -- the majority lives either alone or with spouses or families in the community, relying on filial support if they are ill. In 2009, 38% of older Americans reported at least one disability. For those over 80, this number was 56% (Administration on Aging 2009).

These figures represent only one part of the demographic shift in the U.S. population; fertility levels also determine how able current and future generations will be, as a nation, to care for our elders as they increase in numbers and proportion. The combination of low mortality and low or controlled fertility has created a shift in the population pyramid of the country. There are more generations alive at one time, and fewer people within each generation. As a result, we have a higher proportion of our
population aged 65 and older than ever before, with fewer people in each subsequent generation. This verticalization of the family has resulted in fewer relatives within each family generation to help care for the elderly.

The responsibility of providing care to the frail elderly largely falls to the family. Most elderly persons are living independently in the community. The support given by family and friends is imperative to maintain this independence. Between 5.8 million and 7 million people (family, friends and neighbors) provide care to persons 65 or older who need assistance with everyday activities (Spector et. al. 2000; Health and Human Services 1998). The Family Caregiver Alliance (2003) estimates that between 59 and 75% of caregivers for the elderly are women. Additionally, 22% of caregivers today are under the age of 35 (Dellman-Jenkins, Blankemeyer and Pinkard, 2000). No research to date has captured how many of these caregivers are actually adult grandchildren; this generation as a focus of study is only beginning to receive consideration in caregiving paradigms. Caregiving literature that has addressed grandchildren has focused on intergenerational family dynamics. These family studies in general examine grandchildren who are under the age of 18 (e.g., Adamson, Feinauer, Lund and Caserta 1992; Celdran, Triado and Villar 2009). Studies are just starting to examine the experiences of adult grandchildren when a grandparent is ill (Ruiz and Silverstein 2007; Boon, Shaw and MacKinnon 2008, Frahauf and Orel 2008). Intergenerational studies typically focus on the adult child and grandparental generations, minimizing or ignoring the role that grandchildren occupy in these families (e.g. Bengston, Schaie and Burton
Most of the research on grandchildren focuses on households where parents are the primary caregivers of an elderly relative, and grandchildren are considered “children.” These articles suggest ways that the family can unite and "work together" in order to ease some of the caregiving hardships faced by the primary caregiver, most likely the adult daughter (e.g., Adamson, Feinauer, Lund and Caserta 1992). The focus of literature has not been on facilitating ways to ease strains associated with secondary caregiving, which is the role that many grandchildren fill. In addition, many of the articles posing as "family caregiving" articles deal only with the middle and older generations, completely ignoring grandchildren altogether (Pruchno 1994).

There are more elderly people in the United States today receiving assistance from families and friends due to chronic illness than in any previous historical era. Increased life expectancy, population growth, and immigration are all resulting in a larger older population. The need for providing assistance to the elderly has become a pressing social concern. Terminology surrounding caregiving is ambiguous. There are no set parameters on how sick a person must be to be a care recipient. One determinant of how ‘frail’ an elderly person is the amount of activities of daily living (ADLs) that they are either unable to perform or need assistance to perform.

In the same realm, a caregiver may be a person who provides twenty-four hour care or a caregiver may be the neighbor who helps with errands. Important distinctions exist in the definitions of “support.” The difference between informal and formal
supports needs to be addressed. Informal support for the elderly refers to assistance from
unpaid non-professionals, mainly family members, providing care to elderly relatives or
friends. Formal support refers to paid, organized care such as homecare, adult day care,
nursing home care, or respite care. It is essential to consider the sources of, and need for,
informal caregivers. We are experiencing a worker-shortage of formal care workers,
which will only continue as the Baby Boom generation continues to age. In addition, the
cost and availability of formal sources of care are prohibitive. It is imperative that
informal caregiving models look beyond the traditional spouse and adult child caregivers
when seeking solutions to our informal caregiver shortage. This research explores adult
grandchildren as informal caregivers to their grandparents. The grandparents in these
dyads must be experiencing at least one ADL limitation.

Caregiving has been a research topic for at least the last two decades, and most of
this research has focused on adult children caring for their elderly parents. The reality is
that we have fewer adult children today available to care for their parents than in past
generations. Caregiving does not occur within a vacuum; who helps, or takes over for,
adult children in a caregiving role has not been fully examined. With fewer family
members available to help, adult grandchildren may be acting as primary or secondary
caregivers to their frail elderly grandparents.

There is a distinction between primary caregivers and secondary caregivers
providing support. When an elderly person is frail, the person who handles the majority
of the care for them is considered to be their "primary caregiver." Secondary caregivers
are those individuals that either assist the primary caregiver, or fill in for the primary caregiver for short times. Adult children, neighbors, and adult grandchildren are all important sources of secondary caregivers. To date, there has been no literature exploring the tasks and duties of grandchildren who act either as primary caregivers or secondary caregivers. This research will explore the role of adult grandchildren in both of these caregiving contexts.

As a result of the lack of studies focusing on adult grandchildren and frail grandparents, both the grandparenting and caregiving literature has failed to address the changing dynamics within this relationship. Stresses and burdens associated with grandchildren who are caregiving are also unknown. This research is a qualitative study of adult grandchildren who provide at least two days a week of help to their grandparents who are frail. This research seeks to determine (1) how the dynamics of the existing grandparent/grandchild relationship affects caregiving processes of grandchildren; (2) how caregiving for a grandparent changes the grandchild/grandparent relationship; (3) why/under what circumstances adult grandchildren provide care for their grandparents; (4) negative effects of providing this care, (5) the positive effects of providing this care, and (6) the available supports and needs of these adult grandchild caregivers. The rationale for these research questions will be derived from the general themes in grandparent/grandchild and caregiver literature. Examining grandchildren who are actively engaged with grandparents who are ill will fill a gap in both of these two bodies of literature. Grandparent-grandchild dyads that contain frail grandparents have been
excluded from research on grandparents and grandchildren, and adult grandchildren have been excluded from research on caregiving.

Chapter 1 provides an overview of the grandparent-grandchild literature. The overall encompassing roles of grandparenthood are discussed. Next, variations in grandparenting are examined in detail. Grandparent age, grandchild age, grandparent gender, maternal and paternal grandparental lineage, grandchild gender, the relationship between grandparents and parents and problems within the middle generation all mediate the grandparent-grandchild relationship, and these differences are discussed. Other determinants of grandparent-grandchild closeness are reviewed, including proximity, grandparental divorce, race, farm families, and education. The chapter concludes with an examination of how the current literature fails to account for the relationship between adult grandchildren and frail elderly grandparents. What we do know about how grandchild-grandparent relationships grow over the life course will provide a background and justification for why adult grandchildren may have a vested interest in caring for their grandparents upon illness.

Chapter 2 provides an overview of the informal caregiving literature. This existing literature helped to guide the qualitative interviews that were conducted with grandchildren helping frail elderly grandparents. This chapter begins with an overview of the history of how caregiving became a sociological concept. Next, why people provide care, and under what circumstances they provide this care, is examined. Notions of reciprocity, feelings of responsibility and gender are discussed. Negative aspects of
caregiving, including caring for more than one generation, secondary role strains, financial and legal issues, and stress and burden associated with caregiving are reviewed. Positive effects of providing care for an older relative, including feeling good about helping, increased self-efficacy, enhanced sense of purpose, meaningfulness, closeness with the care recipient, and generational reciprocity are discussed. The available supports and needs of caregivers are defined next. Social networks and social supports of caregivers are detailed. The use of formal supports is examined, and the function of support groups for caregivers is examined.

Chapter 3 focuses on research methodology. This chapter first discusses the sample size and recruitment strategies. The protection of confidentiality of human subjects, compensation, and format of interviews are then laid out. A justification of the interview guide, and the procedures for data management and analysis follow. This chapter concludes with a description of the sample used for the study.

Chapter 4 provides insight to the reasons why grandchildren provide care to a grandparent. Specifically, this chapter explores the push and pull factors for why grandchildren provide care, including feelings of reciprocity, locational proximity, and feelings of responsibility. Next, gender dynamics among grandchildren and how these affect the caregiving dynamics are examined. Sibling order and the types of care that children performed are discussed.

Chapter 5 examines the grandchild/grandparent relationship and caregiving. First, the chapter provides insight to how the existing dynamics of the grandchild/grandparent
relationship affected the grandchild’s decision to provide care to that grandparent. Second, a myriad of intergenerational dynamics and how they affected the grandchild’s role as a caregiver are discussed. Caregiving in conjunction with a parent, caring for the grandparent because of the parent’s refusal to provide this care, and becoming the caregiver because of the death of the middle-generation parent are all areas that are discussed. The ways in which the grandchild/grandparent relationship changed as a result of caregiving are also discussed within this chapter. The role reversal that occurs when the grandchild is providing the care, the decision making that is left to the grandchild, the intimate space barriers, and the navigation around the fears of the grandparent feeling that they are a burden are all summarized within this chapter.

Chapter 6 examines both the negative and positive effects of providing care to a grandparent. Negative aspects of the care that were focused on include secondary role strains (work, friendships and family relationships), financial strains brought on by caregiving, and the manifestation of stress and burden associated with caregiving. The positive effects of caregiving which this chapter discusses include the strengthening of relationships with grandparents because of providing assistance, the ability to get to know grandparents better because of spending so much time together, bringing meaning to grandparents’ final days, giving back to the grandparent, and learning more about the death and dying process. The ways that the caregiving process provided internal meaning to grandchildren are also detailed, including gaining a sense of purpose from caregiving,
gaining increased self esteem as a result of this relationship, and improving parenting skills as a result of providing care to a grandparent.

Chapter 7 analyzes the available supports and the needs of adult grandchildren who care for a grandparent. Specifically, this chapter looks at who adult grandchildren rely on for support, including siblings, friends, parents, and the grandparents themselves. Formal supports utilized by adult grandchildren who are providing care to a grandparent are examined. The chapter concludes with the role of support groups in the lives of these grandchildren, and specifically how underutilized they are among this cohort.

Chapter 8 provides a summary of this research project. The general themes extracted from the study are reviewed, and the implications of these findings for the field of sociology, the caregiving literature and the intergenerational literature are discussed. Limitations of the research, including the sample composition, the interviewing methodology, and the confines of the existing literature are considered. Future directions for research involving the examination of grandchildren who provide care to grandparents is laid out, with suggestions and insight for additional studies on this subject.
Chapter One: An Overview of the Grandchild-Grandparent Literature

Changing demographic trends and family structures in the United States have brought increased attention to the roles of extended family members. Decreasing fertility and mortality rates have caused a drastic change in family structure, with an increased number of generations alive at any one time, and a fewer number of people within each successive family generation (Hodgson 1992; Pruchno and Johnson 1996). These changes have increased the opportunity for individuals to fill both the grandchild and the grandparent role in one's lifetime.

This chapter aims to first, review the existing literature on grandparent-grandchild relationships. The literature on the grandparent-grandchild relationship has taken several directions. First, grandparenting styles have been defined and evaluated. Several studies have explored types of grandparenting styles, and which grandparents are more likely to embody certain styles. Variations in the grandparent-grandchild relationship have been the focus of several studies. These sources of variation will be discussed in this chapter. Gender has been examined from different perspectives including the gender of the grandparent, the gender lineage of the grandparent-grandchild dyad, and the grandchild’s gender. These findings will be discussed here. Other factors that affect the grandparent-grandchild relationship have also been researched. These include the quality of the relationship between the grandparent and parent generation, problems of the middle generation, divorce, and other demographic factors. These variations will be discussed in
this chapter. The absence of literature involving frail grandparents and their grandchildren will be discussed. The implications for this study will be discussed.

Increasing numbers of grandchildren will grow to adulthood with at least one living grandparent (Hodgson 1992, Uhlenberg 2009). It has only been within the later half of this century that increase in life expectancy has meant that a sizeable number of people will live to be grandparents (Aldous 1995). The demographics of the intergenerational American family have been thoroughly researched, although from many different angles. Researchers agree that the likelihood of one surviving into grandparenthood, and the duration of grandparenthood, has increased this century (Cherlin and Furstenberg, 1986; Hagestad and Neugarten 1985; Uhlenberg 2009). Because of dramatic increases in longevity over the past century, it has become more likely that a grandparent will not only survive but live long enough to have long-term relationships with adult grandchildren (Giarrusso, Feng, Silverstein and Bengston 2001; Davey, Salva, Janke & Anderson 2009). Grandparenthood today is seldom a temporary role transition; with increased longevity among the older generation, it is more likely that a grandparent will enjoy this role for several decades rather than only several years (Roberto and Stroes 1992, Szinovacz 1998). The trend towards smaller families and the lessening possibility of women having young children at the same time as their older children starting families has allowed individuals to focus their energies more freely on being grandparents (Wiscott and Kopera-Frye 2000). Research on aging has begun to
The "New" American Grandparent

It is assumed that the vast majority of families today enjoy the peripheral support of grandparents, with the possibility of direct support from that generation if necessary. The role of the grandparent has been described in many studies. This perceived role has been the standpoint from which many of our assumptions about what a grandparent should be have begun. In Neugarten and Weinstein's 1964 classic study, five grandparenting styles emerged. These styles included: the formal grandparent, the fun seeker, the distant figure, the surrogate parent, and the reservoir of family wisdom. All of these roles assume that the grandparent is physically well enough to engage in a variety of roles. Wood and Robertson (1976) proposed a model of grandparenting based on social and personal characteristics of the role. The four roles they identified were: 1) Apportioned; 2) Symbolic; 3) Individualized; and 4) Remote. This study focused on women, and also assumed that the grandparent was healthy enough to be an active role participant. Kivnick (1982,1983) identified five roles, or rather, meanings, of grandparenthood for a group of interviewed grandparents. Meanings of grandparenthood included: 1) Centrality; 2) Valued Elder; 3) Immortality through Clan; 4) Re-involvement with Personal Past; and 5) Indulgence. These identified roles refine previous research, because they focus on the meaning of the role of grandparenthood to individuals rather
than only on the type of relationship a grandparent may actually have with a grandchild. However, again these roles still assume that the grandparent is cognizant and healthy.

Thus, the overall pattern in grandparent literature today ignores those grandparents who do not fill these traditional roles due to their own frailty. Cherlin and Furstenberg's book, *The New American Grandparent*, is a prime example of this. According to the authors, grandparents today ascribe to one of several styles of grandparenting: the remote relationship, with very little contact between grandparents and grandchildren; the companionate relationship, involving easygoing, friendly contacts; and the involved relationship, involving grandparents taking on an authoritative role in the raising of grandchildren (Cherlin and Furstenberg 1986). Cherlin and Furstenberg also indicate that there is a "grandparent career" in which the grandparent shifts the amount of time and energy spent on the grandparent role throughout the grandchild's life. It suggests that grandparents use ploys such as guilt and bribery with grandchildren to create a sense of obligation on the part of the grandchild. It is important to note that this study samples only healthy grandparents, who are mobile and active. Their sample consisted of individuals available to participate in group interviews at senior service centers. This only included those healthily enough to actively be at the center and cognizant enough to maintain a group interview. As a result, the roles that Cherlin and Furstenburg observe, which are widely used in aging and family research even today, are based on a healthy model of the grandparent.
Variations in Grandparenting

Today, we are beginning to see a wider breadth of research concerning role variations between grandparents and their grandchildren. The grandchild-grandparent relationship differs according to the gender of the grandparent, the gender of the grandchild, the relationship between the grandparent and the middle-generation parent, and the life circumstances of the parent generation, the age of the grandparent, the age of the grandchild. These different situations all impact the relationship dynamics between grandparents and grandchildren.

Grandparent Gender

The salience of the grandparent role varies between men and women (Spitze and Ward 1998; Henderson, Hayslip, Sanders & Louden 2009). For women, the role of being a grandparent often provides more importance in later life, and the grandmother is also more prone to the stresses associated with being a grandparent. Studies have shown that women’s more active roles as kin-keepers results in stronger intergenerational linkages through the female line (Hagestad 1986; King and Elder 1997, Thiele and Whelan 2008). Studies show that grandmothers are closer to their grandchildren than are grandfathers (King and Elder 1995, 1997; Ruiz and Silverstein 2007). Grandchildren participate in activities with their grandmothers to a greater extent than with their grandfathers (Roberto and Stroes 1992).

In contrast, men are often considered the “forgotten family members” in research (Spitze and Ward 1991). Often, research only focuses on women, and traditional gender
roles assume that the importance of the grandparenting role would be less significant for grandfathers. While it has been found that grandparents differ in the types of activities that they do with children, the importance of this role for grandfathers is perceived as important as it is for women (Spitze and Ward 1998; Cherlin and Furstenburg 1986).

**Maternal and Paternal Grandparent Lineage**

Stronger ties are often reported between maternal grandparents and their grandchildren (Aldous 1995; Chan and Elder 2000; King 2003; Roberto and Stroes 1992; Henderson, Hayslip, Sanders & Louden 2009). Relations with maternal grandparents are described as closer and more important than relations with paternal grandparents (Dubas 2001). To the extent that mothers are more active in promoting ties to their own parents, maternal grandmothers will enjoy stronger ties to their grandchildren, and research demonstrates a clear matrilineal advantage in grandparent-grandchild relations (Chan and Elder 2000; King 2003). When both grandmothers are still living, grandchildren more frequently choose their maternal grandmother as the grandparent with whom they have the emotionally closest relationship (Hodgson 1992).

**Grandchild Gender**

In support of women as kin keepers, granddaughters report feeling closer to grandparents than grandsons do. In addition, granddaughters rate the relationship with grandmothers as more important than do grandsons (Dubas 2001). Most research has examined which grandchild the grandparent feels closest to, rather than which grandparent the grandchild feels closest to.
The parent generation serves as an important mediating link between grandchildren and grandparents, either facilitating or hindering interaction and the quality of their relationship. The quality of the relationship between the grandchild and grandparent is affected by the quality of the parent-grandparent relationship (Goodman and Silverstein 2001). Positive feelings and attitudes between grandparents and parents are likely to be experienced by children as are negative ones (King and Elder 1995). A positive grandparent-parent relationship is strongly predictive of a positive grandparent-grandchild relationship because of the parent’s role in facilitating relationships between grandparents and grandchildren (King and Elder 1995; Thompson and Walker 1987). Concurrently, a poor grandparent-parent relation can hinder grandparent-grandchild relations (King and Elder 1995; Whitbek, Hoyt and Huck 1993). Grandchildren who perceive the relationship between their parents and grandparents as close report higher levels of contact (Hodgson 1992). These effects may last a lifetime. The amount of contact a parent allows grandchildren to have with their grandparents during childhood directly affects the type of relationship they develop and later maintain (Roberto and Stroes 1992).

The strength of the bond between grandchildren and their own parents also dictates the closeness they feel with their grandparents. Children who are close to their parents are significantly closer to each of their grandparents as well, when compared to
grandchildren who are less close to their parents (Rossi and Rossi 1990; King and Elder 1995).

Studies examining types of intergenerational triads have reflected the effects of the intergenerational nature of the grandparent/grandchild relationship. Goodman and Silverstein (2001) examined different types of intergenerational triads: connected (where the grandparent, parent, and grandchild are all cohesive); grandmother-linked (where the grandmother has a relationship with their child, and the grandmother has a relationship to their grandchild, but there is no involvement between the parent and grandchild generation); grandchild-linked (where the grandchild has a relationship with their parent, and the grandchild has a relationship with their grandparent, but there is no involvement between the grandparent and the adult child generation); isolated (where the grandparent has a relationship with the grandchild with no involvement of the middle generation) and disconnected (where the grandparent, parent, and grandchild are all non-involved). Grandmothers who had strong ties to both generations had greater life satisfaction than grandmothers in most other triads (Goodman and Silverstein 2001, Goodman 2007).

Problems in the Middle Generation

Most grandparents live independent of their adult children or grandchildren (Szinovacz 1998). An ease in the interaction between grandparents and grandchildren depends on the independence of these generations. The nature of the grandparent-grandchild relationship changes when grandparents are called on to offer more support to grandchildren because of problems that the middle child generation encounters. Most
research has focused on the needs of grandparents who are raising grandchildren because of the needs of the parent generation.

When children and grandchildren do live with grandparents, it is usually due to the needs of the middle generation, rather than the needs of grandparents. Research has found that most often, in intergenerational households, the direction of assistance is downward; that is, the grandparents are assisting younger generations (Fuller-Thompson, Minkler, and Driver 1997; 7; Greenberg and Becker 1988; Ploeg et al. 2004). In the majority of cases, it is the younger generation "returning to the nest" which creates an intergenerational household. Most grandparents are caring for their grandchildren in conjunction with the middle generation also living with them. Approximately 7 percent of grandchildren are currently co-residing with a grandparent (Szinovacz 1998; Fuller-Thompson and Minkler 2001). Reasons for co-residence most often include life-altering events for the middle generation, including single-motherhood, divorce, or inability to parent. Most research has focused on the changes in relationship dynamics between grandparents and grandchildren following divorce of the middle generation.

There are significant differences in the interaction of grandparents and grandchildren following the divorce of the middle parent generation. In the case of parental divorce, grandparents have a bigger role in the lives of their grandchildren when their child retains custody as opposed to their child-in-law (Roberto and Stroes 1992; Henderson, Hayslip, Sanders & Louden 2009). Studies have shown that the majority of divorces end with the mother retaining custody of the children. As a result, it is most
often maternal grandparents who maintain the strongest relationship with grandchildren following divorce of the middle generation (Spitze and Ward 1998; Aldous 1995; Kemp 2007). Paternal grandparents’ contact with their grandchildren depends on the father’s post-divorce contact with his children, which is limited (Drew and Smith 1999; Kruk and Hall 1995). If the middle generation daughter remarries, the likelihood of contact with grandparents from the father’s side is diminished even further (Hogan et al. 1993; King 2003; Spitze and Ward 1998).

*Other Determinants of Grandparent-Grandchild Closeness*

The majority of research focuses on grandparent age, grandchild age, gender, matrilineal and paternal lines, and the interplay between generations as determinants of closeness for grandparents and grandchildren. Some studies have highlighted some other determinants of this closeness, including proximity, grandparental divorce, farm living, religion, and education.

Proximity is a strong predictor of involved grandparenting as it plays a crucial role in facilitating contact (Aldous 1995; Cherlin and Furstenburg 1986; King 2003). The data show a strong relationship between physical proximity and the frequency of contact: the closer the generations live to each other, the more frequently they interact. For grandchildren and grandparents whose bonds have grown tenuous over time, the overwhelming reason is an increase in physical distance (Hodgson 1992; Hilton & Macari 1997).
Divorce in the grandparent generation can hinder grandparent-grandchild ties. Ever-divorced grandparents live further away from children and grandchildren, and they report weaker bonds to the adult children than do never-divorced grandparents. This is most likely to occur for paternal grandfathers (King 2003). Divorced grandfathers have less contact with their grandchildren as compared with divorced grandmothers or married grandparents (Uhlenberg and Hammil 1998).

Grandfathers who are divorced from grandmothers are more likely to be isolated from their children in later life, and consequently, their grandchildren (Bulcroft and Bulcroft 1991; Cherlin and Furstenburg 1986; King 2003). Divorced grandparents, especially grandfathers, are more likely to be geographically isolated from their grandchildren, resulting in a weaker grandparent-grandchild tie (Lawton, Silverstein and Bengston 1994; White 1992). Ever-divorced grandparents exhibit significantly lower levels of contact, shared activities, and sharing skill experiences and report higher levels of conflict with their adolescent grandchildren compared with ever-divorced grandmothers and never-divorced grandparents (King 2003).

The separation that occurs because of the grandparent’s divorce becomes even greater if their child divorces. Children are more likely to divorce if their own parents are divorced (Amato 1996; King 2003; Sassler, Cunningham & Lichter 2009). The isolation that occurs between a father and his children upon divorce is coupled for paternal grandparents who have divorced. A grandfather, already alienated from his own son, may be isolated from his grandchildren even further if his son divorces. Multiple
generations of divorce and the communication dynamics which incur result in decreased intimacy between grandparents and grandchildren.

Ties between grandparent-grandchild dyads are especially close for farm families. For these families, relations between grandparents and their adult children and grandchildren are different from non-farm families. Contact with grandparents is not limited to occasional visits, vacations, or holidays. Grandparents are relatively accessible in the farm child’s everyday life. Additionally, because farming and land ownership is linked through paternal lines, paternal grandparents are most salient in the lives of farm children (King and Elder 1995).

Education differentiates the types of roles that grandparents play. Highly educated grandparents are more likely to give advice and to mentor grandchildren, whereas less educated grandparents have more contact and are more likely to play the role of a friend (King and Elder 1998).

**Grandparent Age**

Grandparenting involves the role relationship between two distinct generations within families, but does not necessarily revolve around old age. Today's grandparents may range from age 30 to age 110 (Pruchno 1995). Unlike role transitions in later life that are selected voluntarily, becoming a grandparent is beyond the control of the older generation (Sprey and Matthews 1982). The timing of grandparenthood in one’s life course is dependent on the middle generation.
There is a split today among children in this middle generation. Some couples are marrying and bearing children at older ages, and single, younger mothers are having children at younger ages. These marriage and fertility patterns lead to very different intergenerational dynamics, including different age groups of grandparents. The younger group of grandparents is often still actively working, and in "middle age" themselves. The second group, characterized by later childbearing, is older and at different life stages including possible retirement, and even failing health.

This heterogeneity produces differentials in the time spent as a grandparent, the number of resources given to adult children and grandchildren, as well as the type of relationship endured between grandparents and grandchildren. Research has shown that older grandmothers tend to have significantly less contact with their grandchildren than do younger grandmothers (Roberto and Stroes 1992). Grandparent-grandchild ties are generally stronger for younger grandparents (Aldous 1995). Grandparents tend to enjoy the grandparenting role more when they experience the transition into this role at the same time as their peers (Kaufman and Elder 2003). These studies of contact and closeness have to be viewed with caution. Younger grandparents may be having more contact and reporting stronger ties with their grandchildren because their younger adult children are unable to care for their children independently. There is a norm of non-assistance for adult intergenerational dyads, and stress may incur for those grandparents who are asked to provide assistance to their children and grandchildren. Younger grandparents fill this role more often than do older grandparents.
Grandchild Age

Just as all grandparents are not old, all grandchildren are not “children” (Pruchno and Johnson 1996; Mills, Wakeman and Fea 2001; Hodgson 1992). The relationship between grandparents and grandchildren changes over the course of the grandchild’s life. Grandparent-grandchild interaction styles change over the course of the relationship (Roberto and Stroes 1992). When grandchildren are young, this often provides grandparents the opportunity to spoil them, and to have a relationship with the middle generation that stresses downward assistance (Hogan et al. 1993). The grandparent role during early childhood is one of companionship to grandchildren. Most grandparents enjoy a friendly relationship with grandchildren, leaving discipline to the parents. The contemporary grandparent is adjacent to the nuclear family, especially when grandchildren are young (Cherlin and Furstenburg 1986).

Grandparent-grandchild interaction styles often change during the course of the relationship (Roberto and Stroes 1992). When children are young, the relationship between grandparents and grandchildren is mediated by that middle generation. The amount of interaction between grandparents and their grandchildren seems to lessen as grandchildren reach late adolescence. During this time, grandchildren tend to focus their energy on personal growth and relationships outside the family. Their relationship with grandparents takes on a less salient role in the lives of grandchildren at this stage, but adolescent and young adult children still report their relationship with their grandparents is of great importance (Roberto and Stroes 1992).
As the child gets older, relationships with grandparents become more independent of the middle generation. The nature of the relationship becomes more reciprocal (Cherlin and Furstenburg 1986). As a grandchild matures, they tend to form a more voluntary relationship with grandparents rather than one based solely on family obligation (Roberto and Stroes 1992).

Relationships between grandparents and grandchildren are likely to be renegotiated when grandchildren become independent (Silverstein and Long 1998; Hodgson 1992). The nature of the reciprocity in the adult grandchild-grandparent relationship is more independent of the parental generation. Older grandchildren indicate that they want to be active participants in their grandparents’ lives, and are willing to provide emotional support and concrete help (Ashton 1996; Langer 1990). The reliance on the middle generation to facilitate this exchange is decreased as a grandchild ages. Adult grandchildren’s strongest motivators for maintaining a relationship with grandparents seem to be enjoyment of the relationship, emotional ties with grandparents, and feelings of obligation (Roberto and Stroes 1992).

Grandparents are important sources of social support, caregiving and socialization for their grandchildren throughout childhood. As families age and roles change, grandchildren can provide substantial emotional and concrete help to their grandparents (Ashton 1996; Frahauf, Jarrot & Allen 2006; Fruhauf & Orel 2008). As grandchildren enter adulthood, the exchange pattern changes from one of downward assistance from the grandparent to the grandchild to a pattern of mutual exchange. Grandparents often
provide financial support and advice to grandchildren, while children often provide support through staying in contact and helping with chores and transportation (Cherlin and Furstenburg 1986). Adult grandchildren tend to give more support than they receive, and in general give more emotional support than concrete help (Langer 1990; Ashton 1996).

The relationship ties between grandparents and adult grandchildren are greatest for those dyads that participate in a symmetrical mode of exchange over a lifetime (Giarrusso, Feng, Silverstein, Conroy, Wang, Giarrusso and Bengston 2002; Hodgson 1992). This relationship may become more non-reciprocal as the grandparent ages. Grandparents and grandchildren report feeling comfortable with this change in relationship dynamics, because the contributions of grandparents at earlier times make up for the asymmetry (Ashton 1996).

Overall, grandparent-adult grandchild relations appear to be strong. Strong grandparent-grandchild relations in childhood tend to remain the strongest time. Whether the robustness of this relationship would continue after the grandparents become frail has not been investigated (Giarrusso, Feng, Silverstein and Bengston 2001).

**Adult Grandchildren and Frail Elderly Grandparents**

One factor that existing research examining the roles of grandparents has assumed is that the grandparent is predominately healthy and living independently in the community without need for assistance from informal or formal caregivers. There are few studies that examine the aspects of the grandchild/grandparent relationship if the
grandparent is either frail or institutionalized. Studies by Beach (1997) and Dellman-Jenkins et al (2000) are exceptions; however, these studies focused on the
grandchildren’s responses to caregiving, not the role of their relationship with their
grandparent. Other studies look at the role of grandchildren as part of the larger family
system (Levine, Hunt, Halper, Hart, Lautz, & Gould, 2005; Piercy & Chapman 2001;
Shaw, Patterson, Semple, Grant, Yu, Zhang, 1997). Some studies have started to examine
the role of the grandchild’s feelings and responses to caregiving, but these studies do not
rely on an adult grandchild population (Fruhauf, Jarrot & Allen 2006; Fruhauf & Orel
2008; Celdrán, Triadó, & Villar, 2009).

Much of the current and past research on the role of grandparenthood has focused
on a new, younger, actively healthy grandparent. Overall, the average age of grandparents
has decreased. One can expect to become a grandparent at a much younger age than in
the past, as well as encountering the grandparent role at an earlier stage in life than in the
past. The variety and length of various family roles, including grandchildhood and
grandparenthood, have increased (Roberto and Stroes 1992; Uhlenberg 2009).
Concurrently, the image of the "frail" elderly has arguably become outdated for the
majority of the grandparent population. While this research does not argue this reality,
sociologists also have the responsibility to research the relationship dynamics existing
between adult grandchildren and their frail elderly grandparents. Too often, it is assumed
that once a person falls ill, the possibility of maintaining relations with grandchildren is
nonexistent (e.g., Ashton 1996, Cherlin and Furstenberg 1986).
To simply dismiss these dyads as statistically insignificant or non-functioning is a great disservice to those individuals in an upward-caregiving role. It implies that neither the grandchild nor the grandparent experiences any opportunities, rewards, or even burdens as a result of this relationship. Ignoring this population will also prove to be a great disadvantage for the future, as the baby-boom generation peaks into old age. One-third of American grandparents will be baby-boomers by the year 2000 (Longino and Earle 1996). The likelihood of grandchildren having grandparents alive throughout childhood and even into adulthood will continue to rise. It is no longer uncommon for an individual to be a grandparent for four decades (Hagestad 1988). It is illogical to assume that every grandparent-grandchild dyad will enjoy a relationship absent of any chronic and enduring illnesses on the part of the grandparent.

The frail elderly are often overlooked in grandchild-grandparent research for many reasons. Most research on the grandchild-grandparent relationship has been from the perspective of grandparents. Frail grandparents are hard to study. First, their various illnesses makes this group harder to sample, and more difficult to interview. In addition, many of the frail elderly in our society have some form of cognitive impairment (High 1990), making them difficult to study. Often, frail elderly are homebound, making the possibility of participating in group interviews impossible. Second, many frail elderly are "frail" because of dementia and other mind-impairing illnesses. It is a fine ethical line in obtaining consent from these people, and even if consent is given, the nature of dementia often makes the responses of these individuals incoherent. However, researchers assume
that all frail elderly are incapable of maintaining independent relationships with grandchildren, because of their illness. Further, the perspective of adult grandchildren participating in this relationship has been virtually ignored. As a result, this has created a gap in our understanding of the role dynamics between grandparents and grandchildren.

The absence of this literature is a serious oversight, because the majority of the frail elderly are still living within the community, often with increased contact and reliance on both their children and their grandchildren. If we exclude them from the discourse of the role and meaning of grandparenthood, we are assuming that their relationship styles and reciprocation with grandchildren are identical to those of healthy grandparents, or to the other extreme, simply non-existent.

The existing literature on grandparent/grandchild relations provides support for the likelihood of adult grandchildren providing help to their frail grandparents. Changes in grandparent-grandchild relationships over time have implications for caregiving patterns of adult grandchildren. Based on the findings in grandparent-grandchild literature, we know that most grandparents do have a life-long relationship with at least one grandchild. This relationship is rated as important from both the grandparent’s and the grandchild’s perspective, implying that this dyad could work cohesively together in a caregiving context. Variations in grandparent-grandchild relationships do exist, which may affect the likelihood of which, and when, grandchildren help.

The parental generation is an important mediating link between grandparents and grandchildren. The quality of the relationship that the middle generation has with both
their own parents and their children is a determinant of how often grandparents see children throughout childhood, and how close the grandparents are to grandchildren. Research acknowledges that relationships between grandparents and grandchildren become less mediated by the parent generation as grandchildren move into adulthood. Parents become less important for interaction between adult grandchildren and their grandparents, but the closeness that exists between these two generations is also dependent on earlier relationship dynamics that adult children either facilitated or hindered. It is likely that the grandchildren who have had life-long relationships with their grandparents are more likely to help in times of need. The symmetrical exchange occurring between adult grandchildren and their grandparents is the continuation of life-long patterns of exchange. It is reasonable to assume that these exchanges may evolve into a caregiving role for grandchildren over time.

Gender plays a prominent role in the patterns of grandchild-grandparent involvement over the life course. Grandmothers live longer than grandfathers, increasing the likelihood that an adult grandchild would be caring for their grandmother. Research has shown that maternal grandmothers are often closest to their daughter’s children. It is likely that grandchildren are providing care for maternal grandparents. Based both on these relationship dynamics and on gender norms, it would be expected that more granddaughters, rather than grandsons, are providing care.

Other factors that may affect the likelihood of an adult grandchild providing help to a grandparent include parental and grandparental divorce, growing up in an
intergenerational household, and race. After parental divorce, grandchildren are more likely to stay in contact with maternal grandparents. This is especially true if the grandchildren are young at the time of the parental divorce. In these cases, we would expect these grandchildren to be more likely to help a maternal grandparent over time. If the divorce occurred in the grandparent generation, grandmothers are more likely to be the ones who stay in contact with grandchildren throughout their lives, and hence will be more likely to gain support from grandchildren in times of need. Grandchildren who grew up living with a grandparent have an especially close relationship with that grandparent. As adults, these grandchildren are more likely to feel indebted to their grandparents. They are also more likely to still be in close contact with their grandparents.

This research seeks to answer two questions about the relationship between grandparents and grandchildren: (1) how do the dynamics of the existing grandparent/grandchild relationship affect caregiving processes of grandchildren? and (2) how does caregiving for a grandparent changes the grandchild/grandparent relationship? Because this study incorporates qualitative research, I will be able to answer these questions for the grandchildren involved in my study. To accomplish this, several questions about variations in grandparent/grandchild relationships will be asked including what the gender of the grandparent is, what the ages of the grandparent and grandchild are, how their relationship has changed over time, and how various demographic factors have calculated into variations in their relationships. In addition, questions regarding the
relationship between the grandparent, parent and grandchild generation will be asked. These themes will be woven through the interview to provide an intersection through which to examine grandchildren providing care to a grandparent. The focus on variations in the grandparent-grandchild bond is essential to understanding what dyads are more likely to be in caregiving situations, and what factors contribute to a successful or unsuccessful caregiving experience.

The grandparent-grandchild literature has yet to address this subgroup of adult grandchildren and frail grandparents. This lack of previous research on adult grandchildren and frail elderly grandparents leaves several key theoretical and practical questions unanswered. The proposed research will serve to bridge this gap in our understanding. It is necessary to conduct qualitative research because of the breadth of questions still unanswered. Qualitative methods allow for rich data and explanation. Using the overall patterns in the grandparenting and caregiving literature, this study will examine how caregiving affects the grandparent-grandchild relationship, and how the history of the grandparent-grandchild relationship dictates caregiving patterns and norms between these dyads.
Chapter Two: An Overview of the Informal Caregiving Literature

This chapter will provide an overview of the general themes present in caregiving literature. First a history of how caregiving became a sociological concept will be discussed, followed by the reasons and circumstances through which people provide care. Reasons for providing care including reciprocity, locational proximity, and feelings of responsibility towards the care recipient have all been cited in the literature.

Next, the positive and negative aspects of providing care will be explored. Much attention has been given to the informal and formal supports of caregivers. This chapter will review the sources of social support for caregivers. In addition, the likelihood and frequency with which caregivers attain formal and community supports will be discussed.

Throughout this chapter, the general themes discussed will be linked to the concerns of adult grandchildren. Research directions for this project will be discussed throughout the chapter.

The caregiving literature, while well developed in vast areas of caregiver concern, minimizes an entire subgroup of caregivers: grandchildren. The circumstances through which grandchildren provide care, the positive and negative effects of providing this care, and the available supports that grandchildren utilize may differ drastically from their parents’ or grandparents’ generations. Ultimately, patterns found in spousal and child caregiver populations must be reexamined for adult grandchildren. The experience of becoming a caregiver and providing a substantial amount of care likely differs between grandchildren and other generations. Research aimed at this group will help to
determine how the caregiving experience is both similar and different from the experiences of adult children and spouses who provide care for the frail elderly.

Caregiving literature has all but ignored the increasing trend for adult grandchildren to take an active part in caregiving for their grandparents. Statistically, we have no data on how many grandchildren provide care; nationally representative data breaks caregivers into “spouse, son, daughter, or other relative” when discussing types of caregivers (see, for example, Spector, 2000; AARP and National Alliance for Caregiving 1997; Health and Human Services 1998; Family Caregiver Alliance 2003). Age of caregiver is often accounted for, but not in combination with the type of relationship to the care recipient: 22% of caregivers are under the age of 35 (Health and Human Services 1998), but the generational position of these younger caregivers has not been identified. Various studies and articles have acknowledged that grandparental caregiving may be occurring (Giarusso, Silverstein, and Bengston, 1996; Beal 2002; Dellman-Jenkins, Blankemeyer, and Pinkard 2000; Silverstein & Marenco 2001, Beal 2002), but this population has rarely been examined exclusively, and the few studies concentrate on small samples which do not require grandchildren to be over the age of 18 (Fruhauf, Jarrot & Allen 2006; Fruhauf & Orel 2008).

The History of Caregiving as a Sociological Concept

In order to understand why grandchildren providing care to a grandparent has not been researched, it is necessary to first give a brief overview of the history of how caregiving became a sociological concept. Caregiving did not come into popular
literature until the early 1980s. This was a historically unique period in United States history. The women’s movement combined with the economic realities of the 1980s forced the issue of carework out of the private, female sector and into mainstream policy (Harrington-Meyer 2000).

The Reagan administration made unprecedented cuts to the federal support of the elderly during this time. Concerns about the costs of health and welfare services for the elderly population, and the government’s desire to curtail these costs, increased reliance on care provided by family, neighbors, friends, and volunteers (Arber and Ginn 1990). Concurrently, women were entering the workforce in larger numbers than ever before. Divorce within the adult child generation was occurring at rapid rates, creating more single mothers and divorced families than ever before. As a result, the caregiving previously unspoken of, and performed by wives and daughters, was in crisis.

The highlighting of caregivers as a social group sharing a common problem and a common interest was born out of feminist writing on the domestic labor of women, the recognition that this care work entails emotional work as well as labor, and the understanding that the social value of this work was largely unrecognized (Cancian and Oliver 2000; Land 1978; Finch and Groves 1980, 1982, 1983; Finch 1989). During the 1970s and 1980s, caregiving was recognized as one facet of the gendered care that women provide, which is devalued by society. The Feminist movement combined with the oppression of the 1980s politics propelled caregiving into the mainstream consciousness. As a result, the needs of care recipients and the needs of caregivers,
namely wives and adult daughters, were propelled into the cause of the women’s movement. Caregiving was seen as a pressing social issue. As an illustration of this phenomenon, one only has to research the term “caregiving” in the decade of the 1970s versus the 1980s. The term appears only on four research articles in Sociological Abstracts from 1970 to 1980. This number increases to 1,059 from 1980 to 1990.

As a result of this surge in both popular and academic interest in caregiving, we have a broad knowledge of the caregiving concerns of both spousal caregivers and adult children caregivers. This literature has emerged into three general themes: (1) why/under what circumstances relatives provide care to the frail elderly; (2) the negative and positive effects of providing this care, and (3) the available supports and needs of these caregivers.

**Why/Under What Circumstances People Provide Care**

*Who Provides Care*

Of critical importance to caregiving is the description of who is likely to provide care to an elderly person residing in the community. It is a common myth in the United States that most frail elderly persons receive formal, or paid, care. In fact, the majority of care that older persons receive is from informal, or unpaid, caregivers (U.S. Administration on Aging 2009). The majority of older care recipients lives either independently or with family in the community, and relies on family members and friends to provide care.
Adult spouses and children provide the majority of care for the frail elderly. Various studies have given estimates on how many spouses, and how many children, provide this care. Because no data have been collected on the number of grandchildren providing care, we do not know how many grandchild caregivers there are. We have no estimates of the average length of the caregiving role for adult grandchildren. We do not have any data regarding the types of tasks that grandchildren take on as caregivers. Further, we know the reasons why spouses and adult children provide care to their spouses and parents, but we do not know what drives adult grandchildren to take on this role. As important, we do not know what factors preclude other family members from stepping in to provide care instead of grandchildren. This is important both at an individual family level and at a larger societal level. This research aims to bridge this gap in our knowledge.

Reciprocity

Different theoretical models have been used to explain the reasons people become caregivers. One such model is the Reciprocity Model: caregivers provide care to the care recipient because they are repaying that person for past care that was received by them (Bliezner and Hamon 1992, Lee 1992, Haraven 1994, Horowitz and Shindelman 1983, Arber and Ginn 1990, Wallsten 2000). This model is most often used to explain reasons for adult children feeling the need to care for their elderly parents.

Theoretical models used to explain reasons for becoming a caregiver have never been tested on grandchildren. For example, the Reciprocity Model states that a caregiver
provides care because they are repaying the care recipient for past care that was received by them. The intergenerational nature of the grandparent-grandchild relationship may or may not weaken this notion of reciprocity. For one, the grandchild has had a shorter lifetime of help from the grandparent, which may make their need to repay the grandparent weaker. Second, because most grandparents today have a companionate relationship with their grandchildren, they may not be actually assisting their grandchildren to any great degree. Third, the grandparent may not feel as compelled to expect help from a grandchild as much as they would from their own child, making the grandchild’s sense of reciprocity lessen. On the other hand, we know nothing about the norms of reciprocity for grandchildren either who grew up in intergenerational households, or who were solely raised by their grandparents. Additionally, grandchildren may be caring for their grandparents not because of a feeling of reciprocity to the grandparent, but rather, a norm of reciprocity between the grandchild and their own parent. We do not know if grandchildren providing care to grandparents do so to somehow repay their own parents. This merits further study.

*Locational Proximity*

The Locational Proximity Model (Horowitz 1985, Campbell, Martin-Matthews 2000) states that the most likely caregiver is the one that is closest to the elderly care recipient. This model is most relevant to families with more than one adult sibling; the sibling closest to the parent is most likely to provide care. However, this model did not incorporate gender into its structure. Researchers point out that it is most often wives and
adult daughters who provide the care. It has been found that sons are more likely to use geographical distance as an explanation for opting out of providing care, rather than as an explanation for why they provide care (Campbell and Martin-Matthews 2000). Daughters are also more likely to travel further distances than sons are to provide care, and are more likely to relocate in order to be closer to the parent needing assistance (Hallman and Joseph, 1999; Himes, Jordan and Farkas 1996).

The Locational Proximity model has not been tested with this third generation. We do not know if grandchildren who provide care do so because they live the closest to the grandparent. Alternatively, we do not know if the grandchildren who provide care do so because they are in a point of life which makes them more readily available to provide care, such as just out of college, or unemployed.

Feelings of Responsibility

Many caregivers who have provided care have noted a feeling of responsibility as their rationale for being a caregiver. For these individuals, they may have never received direct care from the care recipient, and may not be the closest in locational proximity to the care recipient, but may feel the need to care for them. Studies have concentrated on children and neighbors who provide care out of their feelings of responsibility. This normative response is present even in adult daughters whose fathers have been divorced from their mothers—these daughters feel responsible to give them care just because “he is my father.” There is a strong sense of cultural norms and/or emotional connections for children who caregiver out of responsibility. One last rationale for why people become
caregivers is due to the expectations and pressures from those around them. Many spouses and children are caregivers because it is expected of them. This also includes the gender role norms and expectations which dictate that daughters are more likely than sons to provide care (Coward and Dwyer 1990).

Norms of responsibility which drive many children to provide care, even if they have a strained relationship with their parent, may be less stringent within intergenerational relationships between grandchildren and their grandparents. We do not know if grandchildren providing care do so because of a feeling of responsibility to their grandparents. It is possible that these norms of responsibility differ for grandchildren who were raised by their grandparents. Further, we do not know if their care stems from feelings of responsibility to their parents, who are asking them to assist. Research needs to focus specifically on the filial obligations of adult grandchildren, the gender norms that dictate their sense of filial duty, and their position in the larger family network. A theme that this research will explore is the reasons why adult grandchildren provide help to their grandparents.

*Why People Provide Care: Gender*

Gender plays a significant role in the profile of caregivers today. More women provide care to the elderly than men do in every generation. Women, especially elderly wives and adult daughters, are most often informal caregivers (Finley 1989; Miller and Cafasso 1992; Ingersoll-Dayton, Starrels and Dowler 1996; Ron 2009). Wives are more likely to be caregivers for their husbands, and adult daughters are more likely than adult
sons are to provide caregiving. Spector et al (2000) found that adult daughters were the largest group of primary caregivers, comprising 26.6% of all caregivers. Comparatively, wives providing care to an elderly spouse made up 13.4% of caregivers. The expectation for women to provide care is a strong gender-linked socialization norm in society. The term “women in the middle” (Brody 1981) exemplifies the gendered norm and stereotype that women are caregivers. This term is used to describe the typical woman caregiver, usually between 30 and 40 or 50 and 60, who is caring for both her children under the age of 18, and her parents over 65. This terminology is important for two reasons. It acknowledges that most women are caring for more than one generation at a time. As important, it minimizes the recognition of men who provide care. This gendered language only recognizes women as caregivers. It implies that women feel a stronger obligation to provide care to family members, and men feel entitled to receive it (Coltrane and Galt 2000).

Approximately 75% of informal caregivers are women (Health and Human Services, 1998; AARP and National Alliance for Caregiving, 1997). This overrepresentation by female family members can be explained through both demographics and theory. Women live longer than men do, and also tend to marry men who are older than they are. “In 2000, persons reaching age 65 had an average life expectancy of an additional 17.9 years (19.2 years for women, 16.2 years for men) (Administration on Aging 2002).” It is more likely that an elderly wife is going to provide care to an elderly husband, because more women live longer. These
demographic trends must be viewed in combination with filial and gender expectations which explain what motivate people to provide informal caregiving in our society.

We expect that spouses will care for one another upon illness. Most often, it is the husband who needs assistance; therefore, elderly wives provide the majority of spousal caregiving in the U.S. However, there are also firm normative expectations of who will provide this care if a spouse is not available. The Hierarchical Availability Model (Shanas 1968; Cantor 1979) relies on this premise. This is the most popular “theoretical” model in aging to describe who is likely to provide care. Accordingly, this model relies on an availability assumption: the person closest to the care recipient in relationship will likely be the caregiver; if this person is unavailable for some reason, the person in the next concentric circle of closeness will fill the role. Therefore, a spouse would be the most likely to care for an elderly person. If the spouse is unavailable, an adult child is the next most likely to care for that person. Adult daughters most often fill this role, irrespective of whether they are geographically closest to their parents.

Caregiver gender affects not only who provides the most care, but also what types of care that person typically performs, and how comfortable they are in providing that care. The intimate nature of providing care -- personal care, household tasks, cooking, and shopping -- is gendered in our society as “female.” These gender norms pertain to work performed throughout a woman’s life, not only in reference to caring for an elderly relative. Women are more likely to be expected to perform the majority of child-rearing tasks, they are more likely to do the majority of chores and ‘housekeeping’ within her
household, and she is more likely to take time out of her career to perform these tasks (Coltrane 2000; Shelton 1992).

Caregiving for an elderly relative provides no exception to these gender norms. Women are more likely to be called upon to become a caregiver, even if both genders are available to take on caregiving responsibilities. When a man does provide the care, he is more likely to readily receive outside help to assist him in these tasks (Miller 1990; Ron 2009; Brown & Shu-li 2008). Caregiving tasks are traditionally gender-based. Women provide more intimate, hands-on care, such as bathing, feeding, cooking and cleaning, which takes more time and effort than the non-intimate tasks that men typically perform, such as yard work or driving (Horowitz 1985; Miller and Cafasso 1992; Kramer and Kipnis 1995, Dwyer and Coward 1991, Kaye and Applegate 1990, Dwyer and Seccombe 1991, Seccombe 1992).

The current cohort of older adults has endured a lifetime of a strict societal gender division of labor. As a result, the impact of caring for a spouse tends to be gender-specific (Stoller 1982). Wives caring for an ill husband are more likely to provide long-term care without any formal assistance (Miller 1990; Brown & Shu-li 2008). Male spousal caregivers are less likely to perform personal or household tasks (Miller and Kaufman 1996).

Caregiving among adult children follows similar gender patterns, with slightly less strict gender norms dictating what a woman is “supposed” to know how to do in comparison to a man. Even so, we have a much larger proportion of women than men
fulfilling the role of caregiver to her parents. The adult daughter is most often called upon to provide this care. This cannot be explained through availability or less role strain for daughters; women are more likely than men to have several sources of role strain (such as caring for their own children, working, responsibilities for housework, etc.) (Brody 1981; Kramer and Kipnis 1995; Wallace, Dillworth-Anderson & Goodwin 2003). Adult sons are more likely to be “excused” from providing care if they have family or work responsibilities, even if they live closer to the ill parent than siblings (Finch and Mason 1993, Campbell and Martin-Matthews 2000). These findings offer evidence that gender role expectations present the rationale for adult daughters to provide the majority of care to their parent.

Much of the gendered work in our society is learned through socialization. Today’s grandchildren differ from previous cohorts because they have been more likely to see their own mothers working outside of the home. These grandchildren were more likely to be born during, or shortly after, women’s liberation. They are more likely to have been raised in a single-mother household than previous cohorts. The combination of these events may influence their feelings towards a gender responsibility towards care. The gender norms that exist for their parents’ and grandparents’ generation may not be as stringent for this generation. The assumption that granddaughters will provide care to their grandparents simply because they are a granddaughter, rather than a grandson, may not hold merit. At the same time, grandsons may feel more equipped to provide care to a grandparent than previous generations because of these same changing norms. On the
other hand, the family’s expectations of these women, regardless of their own feelings toward gender equality, may exert pressure on them to become a caregiver. Grandsons may be overlooked as potential caregivers because of their gender. This research will determine what gender norm expectations have been placed upon the grandchildren in this study to provide care to a grandparent, who enforces these expectations, and whether this is an area of concern for these adult grandchildren.

The types of care that a grandchild provides may or may not follow the same gender patterns as previous generations. For example, it is possible that a granddaughter would provide more intimate, hands-on assistance to a grandparent because of gender norms. However, especially in the case of grandfathers and granddaughters, the intergenerational nature of their relationship may make this type of assistance too awkward to fulfill. Grandsons today may feel better equipped than their fathers’ generation to assist with intimate details of care for their grandparents. This is a generation who is more likely to be assisting with childcare duties, cooking and cleaning, and it is plausible that these experiences may extend to assisting grandparents as well.

Even with the subtle changes our society has seen with gender norms in the past few decades, it is impossible to say with any determination whether these norms have affected caregiving patterns among grandchildren. The interview guide will ask grandchildren what types of tasks they perform as part of their caregiving responsibilities. A comparison of the gender breakdown of caregiving responsibilities for grandchildren and the gender norms for other caregivers will be made.
The areas that the caregiver literature cites as reasons for caring include reciprocity, locational proximity, feelings of responsibility, and gender. Distinct patterns exist for adult children and spouses caring for an elderly relative. This research aims to address which of these factors (reciprocity, locational proximity, feelings of responsibility, and gender) drive the grandchildren in this study to care for a grandparent, and whether these patterns mimic or differ from reasons for caregiving in spousal and child populations.

**Negative and Positive Aspects of Caregiving for an Elderly Relative**

*The Impact of Caregiving: Secondary Role Strains*

The impact of providing informal care is illustrated through a number of role strains including the effects of caregiving on work, the effects of caregiving on family and social obligations, and the effects of caregiving on caregiver stress and mental well-being. The all-encompassing task of caregiving can often interweave with the other responsibilities one has. Caregivers cite work disruptions, family strain, and personal stress resulting from their caregiving responsibilities. The negative aspects of providing care have been highlighted more regularly in the literature than the positive aspects of caregiving.

*Caregiving and Work*

Providing informal care has a large impact on work careers. The career effects of caregiving for an elderly relative are staggering. Estimates reveal that a full 25% of the entire American workforce is an informal caregiver (Bond, Galinsky & Swanberg 2001).
Of these workers, women face the most deleterious effects of caregiving and work. Female caregivers are more likely to decrease their work hours to provide care. They are more likely to be passed up for a promotion, training or assignment. Further, caregivers are more likely than their non-caring counterparts to take a leave of absence from work, switch from full-time to part-time status, quit their jobs or retire early (Reid, Stajduhar, & Chappell 2010; Health and Human Services 1998).

A 1999 Metlife study reported that 58% of American women aged 16 and older were in the labor force in 1995, with an additional gain of 5% forecasted by the year 2005 (Metlife 1999). Work interference is a large concern for both caregivers and their employers. This work disruption is more pronounced for employees who are caring for severely disabled care recipients and for caregivers in poor health themselves (Scharlach, Sobel and Roberts 1991).

Many elderly spouses providing care have had to take an early retirement in order to provide care—while work responsibilities are less prominent at this stage of life, early retirement and forced part-time work remains a salient frustration in spouse caregivers. For caregivers who do take time off from work to provide care, those who return to work are more likely to earn lower wages, have a “benefits-poor” job, and reduced retirement benefits (Dettinger and Clarksburg 2002). This impact is seen more dramatically for women than for men. Females are more often the primary caregivers; this, coupled with more frequent work disruptions and less status on the job, produces an especially stressful conflict for these caregivers (Kramer and Kipnis 1995). Women are more likely to state
that their supervisors make it more difficult for them to manage their work and caregiving responsibilities (Scharlach and Fredriksen 1994), and therefore find caregiving to be more stressful, and are more likely to quit a job due to caregiving responsibilities.

Women are more likely than men to take time out of their career to provide care (Family Caregiver Alliance 2003; Masuy 2009). Female spousal caregivers are more than five times as likely to retire early as their non-caregiving counterparts (Dettinger and Clarksburg 2002). Women are also more likely to have conflict between work and caregiving (Anastas, Gibeau and Larson 1990).

The effects of caregiving are deleterious for businesses as well as for individual caregivers. Since the majority of caregivers are working either part-time or full-time, this issue is pertinent not only from the standpoint of those providing care, but also from the standpoint of employers. Absenteeism, decreased productivity, and caregiver-related work interruptions all affect the workplace. For example, the cost to replace caregivers who have quit their jobs has been estimated at 3.3 billion dollars annually; absenteeism among women caregivers due to caregiving responsibilities costs businesses almost $270 million annually; and caregiving-related work interruptions are estimated at 3.8 billion dollars annually (Family Caregiving Alliance 2003). We can expect these costs to rise in coming years, as the proportion of the elderly in our population increases exponentially with the aging of the baby-boom generation.

Few studies have been conducted on younger caregivers (those caregivers under the age of 35). This cohort is typically at the beginning stages of a career and the above-
mentioned work stressors are multiplied for these employees. Some caregiving/work stresses that this younger cohort expressed included excessive work-place absences, a feeling that their career could not afford many absences from work, a frustration that these caregivers could not relocate for their career, and limited career opportunities and development resulting from their caregiving responsibilities (Dellman-Jenkins, Blankemeyer, and Pinkard 2000).

We do not yet understand the work ramifications for adult grandchildren who provide care to frail elderly grandparents. The long-term ramifications of providing care to grandparents may be more deleterious to this generation than any other. Unlike their parents or grandparents, adult grandchildren are at an earlier stage in their career, with fewer benefits, less vacation time, and less prestige. They are more likely to be just entering the job market, with less tenure, less accrued sick or vacation leave, and less seniority at their company. This situation is exacerbated by the weak economy of the new Millennium. Women of this generation make up a higher proportion of the workforce than previous generations (Hareven 1994). In addition, adult grandchildren providing care to grandparents do not fall under the provisions of the Family Medical Leave Act. Therefore, grandchildren are less likely to be able to afford taking time out of work to care for a grandparent.

Since adult grandchildren are younger, they are more likely to be at an age of their own family formation while simultaneously caring for a grandparent. As such, the competing demands of taking off paid or unpaid time to care for a newborn child or an
ailing grandparent may be a dilemma that this generation is more likely to face. Taking time out of the workforce to provide care to a relative may have a cumulative effect on the disrupted retirement benefits that are lost from this time off, the lack of promotion earlier in one’s career, and the reduction in benefits that an adult grandchild may experience from having to leave the workforce. This research will consider how participating grandchildren’s careers have impacted their caregiving abilities, and how their caregiving responsibilities have affected their careers.

*Caregiving and Other Relationships*

Caregiving can become an all-encompassing role due to the emotionally charged and physical draining tasks associated with giving care to someone. Family members that invest a lot of time into caring for an elderly relative often find less time for other family members, their own hobbies and interests, and themselves as a result of being a caregiver.

Caring for a spouse is particularly stressful, because in most cases, spouses are co-residing independently in the community. For the well spouse, this means that they are caring for their spouse on a full-time basis, often with little or no assistance from others. The “role engulfment” that occurs with caregiving can be all-encompassing. In this situation, spousal caregivers are isolated from family, friends, and sometimes work. Spousal caregivers often feel that the extremity of their caregiving duties preclude them from participating in any other activities for themselves (Dautzenburg et al. 2000; Neal et al. 1997). These caregivers cite an inability to socialize with friends, and a lack of
time or ability to pursue their own leisurely interests. In addition, wives and husbands who provide care feel that they do not have the capacity to provide care to children or grandchildren (Campbell and Martin-Matthews 2000).

In contemporary society, overall a larger proportion of assistance is downward, with the elderly parent providing care to both their adult children and grandchildren. This is due to a changing economic structure of the United States, increased divorce in the middle generation, higher rates of single parenthood than ever before, and higher rates of teenage pregnancy. In addition, the middle generation is more likely today to suffer from emotional or substance abuse problems than ever before, and it is often the grandparental generation that steps in to provide assistance when needed. With more adult children needing financial assistance, emotional support and help raising their own children than ever before, the pull of having to care for a spouse in addition to these needs can be very stressful for elderly husbands or wives. These caregivers are faced with a dilemma of either trying to support too many family members at once, or having to turn away from providing support to additional family members other than their spouse.

Adult grandchildren are demographically at an age that encompasses several competing demands. These adult grandchildren are likely to be in the beginning stages of their own family formation, often with young children or new marriages. Alternatively, with the demographic shift of a delay of first marriage, it is possible that several adult grandchildren are either dating and forming relationships that could lead to marriage concurrently with caregiving, or have had to postpone dating in order to provide care.
While it is true that an adult child may be caring for more than one parent or in-law, this possibility is even more extreme for the next generation. If an adult grandchild is providing care to a grandparent, they may be providing care to a total of four grandparents, their own parents, and their in-laws. Theoretically this is possible, although this has never been examined. Thus far, we know nothing about the competing demands of caregiving for this generation, or whether these said demands are even stressful for grandchildren. This research will seek to determine what types/extent of secondary role strains compete with the caregiving responsibilities of grandchildren who are participating in this study.

Adult children are typically in a stage of life where they have several competing family roles to that of being a caregiver to a parent. This generation is embedded within the family as both the child generation and the parent generation, embodying the role of the “sandwiched generation.” The terms “women in the middle” (Brody 1981) and “sandwich generation” (Schwartz 1979) describe the paradox that adult daughters or sons experience as caregivers. These terms are used to describe the typical woman caregiver, usually between 30 and 40 or 50 and 60, who is caring for both her children under the age of 18, and her parents over 65. This terminology is important for two reasons. First, it recognizes that most caregivers are women -- we have no term “men in the middle.” Second, it minimizes the visibility of grandchildren in this role -- sandwiched between generations implies a three-generation dynamic, in which the middle generation is the adult child.
Taking care of one’s own children, working full-time and having more outside activities are all sources of conflict for these caregivers. The diverse ages of adult children caring for parents have been well documented (Spitze, Logan and Lee 1994; Spector et. al 2000, Haraven 1994). The needs of their own children inevitably become a competing demand for many adult child caregivers. Attendance at children’s extracurricular activities, school meetings, college and other important events may all be jeopardized because of the parent’s caregiving responsibilities. This conflict has become exacerbated in today’s society, with more single parents, divorced parents, and dual-career families.

The decrease in time for family responsibilities is very salient for most adult child caregivers. Several adult children who provide care for a parent may also be providing care for a parent in-law, especially for women children. These competing demands to caregiving provide a stressful and burdensome situation for adult children. The negative aspects of this conflict are exacerbated if the caregiver does not have a supportive immediate family who understands the time commitment involved with providing substantial care to a parent (Harper and Lund 1990).

Younger adult caregivers cite the conflicts that arise between making time for caregiving, work, and any personal life. This youngest cohort experiences many more life role entrances and exits than other cohorts: dating, marriage, births and adoptions, promotions, and social activities. Young adults have indicated struggles with their social activities and dating (Dellman-Jenkins, Blen kemeyer, and Pinkard 2000). For some
young adults, this results in a delay of other life experiences because of the caregiving situation— for example, passing up promotions, delaying relocation or even passing up dating or having children.

In today’s society, we need to modify the terms “women in the middle” and “sandwich generation,” as we have additional layers to contend with. Adult grandchildren providing care to a grandparent are also sandwiched between generations; it is feasible that a grandchild between the ages of 18 and 35 could be raising their own children while also dealing with the caregiving issues of both their grandparents and their parents. Carol Abaya, who hosts a website on the Sandwich Generation, had coined the term “club sandwich” to refer to those in their 30s and 40s with young children, aging parents and grandparents (Abaya 2003). This becomes even more salient with research disputing the prevalence of the “women in the middle” crisis. Researchers dispute the accuracy of this claim, noting that most women are past the point of caring for their own children when they begin caregiving for their elderly parents (Spitze and Logan 1990; Loomis and Booth 1995). With the advent of a longer lifespan, it is conceivable that this generation is caring for a parent at a later point in their lives. However, the “crisis” still very much exists for the grandchildren who provide care; this cohort is more likely than their parents’ generation to be in the starting phases of raising a family while also caring for a grandparent.

*Financial and Legal Issues*
Informal caregiving is a costly pursuit. In addition to the employment issues of the caregiver previously mentioned, there are several other costs of providing this care. Some examples of costs associated with informal caregiving include medical equipment in a household, medication costs, insurance costs, transportation costs, and property upkeep costs. In addition, costs include any formal assistance sought, including home health care, respite care for the caregiver, adult day care, or housekeeping services. Care recipients may have the resources to pay for this care, or these costs may be the financial responsibility of the caregiver. For example, if a care recipient owns a house, their illness may prevent them from maintaining the property. This responsibility falls to the caregiver. Tasks such as mowing a lawn, plowing a driveway, making a residence handicapped-accessible, fixing broken and outdated appliances and other housekeeping tasks are costly, and this financial burden may fall to the caregiver.

The legal issues of providing care are sources of great distress to many caregivers. Some legal issues include power of attorney, health proxies, and Medicaid and Medicare. The legal terms associated with elder care are often unfamiliar to caregivers. A Power of Attorney is a legal instrument that is used to delegate legal authority to another. The person who signs a Power of Attorney is called the Principal. The power of attorney gives legal responsibility to another person to make property, financial, and other legal decisions for the Principal. If a care recipient is incapacitated, they may have assigned the role of Power of Attorney to the caregiver, making them responsible for any legal and financial responsibilities on behalf of the caregiver.
In many cases, the care recipient also assigns a Health Proxy Agent, which is a person designated to make medical decisions for the care recipient if they are unable to give consent on their own. New York State law allows individuals to appoint someone they trust to make health care decisions for them if they lose the ability to make decisions for themselves. By being a Health Proxy Agent, caregivers are able to ascertain that health care providers follow the care recipient’s wishes. The care recipient may give instructions to a Health Proxy agent that they must follow. This is especially stressful for caregivers if the wishes of the care recipient differ from their own opinions. Health Proxy issues are also stressful for caregivers if the primary caregiver is not the person who is the legally appointed Health Proxy Agent.

The combined legal and financial issues of Medicaid and Medicare are complicated and often fall to the caregiver to understand. Medicaid refers to the federal and state insurance program designed to provide access to health services for persons below a certain income level. Medicare is a federal health insurance program designed to provide health care for the elderly and the disabled. People who qualify for Social Security benefits are automatically eligible for Medicare. The definitions and reimbursement claims associated with Medicaid and Medicare are often confusing for caregivers to understand. This task is even more daunting if the care recipient is incapacitated. The forms are cumbersome, and many caregivers find the paperwork overwhelming. While there is little research assessing the stress associated with the financial and legal aspects of caregiving for an elderly person, this is an area that warrants further investigation.
Grandchildren who provide care may be subjected to more or less stress than their parents or grandparents. As previously stated, we do not know if the majority of grandchildren who provide care to grandparents are gainfully employed. The financial ramifications of caregiving for those who are not employed include a delay in gainful employment, and therefore a long-term effect on retirement benefits, vacation accruals and promotions. For those who are employed, caregiving may cause more job resignations than in other cohorts because the Family Medical Leave Act provision does not extend to grandchildren providing care to a grandparent. For all grandchildren, the costs associated with caregiving such as upkeeping the residence of the care recipient, may or may not fall to them. This will vary according to what other supports the grandparent has. For example, while a grandchild may be the person providing the majority of care, it may be their parents who provide more financial assistance to the care recipient. This research aims to determine what financial responsibilities the grandchildren in this study have toward their grandparent’s care, and how the intergenerational links between grandchild, parent and grandparent affects these responsibilities.

There is not data available on how likely it is that adult grandchildren providing care to a grandparent have legal obligations. The roles of Power of Attorney and Health Care Proxy have not been examined at this generational level. In the cases of grandchildren who provide care but do not have these formal legal roles, their caregiving stress may be exacerbated by someone in the middle generation holding these
responsibilities. It is necessary to research the frequency with which grandchildren provide care without having legal responsibility for their grandparents, and the differences between those grandchildren who do have these responsibilities compared to those who do not. This research will ask: What are the legal stresses and obligations faced by the grandchildren in this sample who are acting as caregivers to their grandparents? How does the intergenerational link between grandchild, parent and grandparent affect these legal stresses and obligations?

*Stress and Burden Associated with Caregiving*

The mental, physical and emotional ramifications of providing care for someone have serious policy and sociological consequences. A wide breadth of research exists which focuses on the causes of stress and burden, the effects of this stress and burden, and mediating factors that alleviate these negative consequences of providing care to an elderly relative.

The stress that results from caregiving is detrimental to both caregivers and their care recipients. The stresses of caregiving have multiple layers. Four domains make up the stress process, each comprising multiple components. The domains are the background and context of stress, the stressors, the mediators of stress, and the outcomes or manifestations of stress (Pearlin et al. 1990).

The stresses, burdens, and role strains associated with caregiving differ for spouses and adult children providing care. In turn, these two groups are very different from adult grandchildren, both in their relationship to the care recipient, their position in
the wider family structure, and their position in their life course trajectories. We would be remiss to assume that these same stressors apply to adult grandchildren, or to assume that other, unique stressors, do not apply to this group.

Stress and Demographic Factors

The background and context of stress refer to the socioeconomic characteristics of the caregiver and care recipient, the caregiving history, the family and network composition, and the program availability. Caregivers and care recipients with fewer financial resources are often more stressed in the caregiving situation. The caregiving history refers to the relationship between the caregiver and care recipient throughout the context of the life course. The type of relationship (ex: spouse, child, grandchild) and the nature of this relationship (amicable, strained or turbulent) can have an impact on the quality of the caregiving relationship, and the stress associated with this pairing (Cicerelli 2000; Bainbridge, Krueger, Lohfeld, & Brazil, 2009). Other aspects of the caregiving history include the length of the time that the care recipient has required care, and the extent of care that the care recipient previously has provided the caregiver with. Both spouses and children, for example, have expressed extreme discomfort over having to take over the personal, intimate care of the care recipient (ex: bathing and dressing). Often, this stress comes from a structural change in a relationship that has been forged over decades. These various background and contextual characteristics have a direct impact on the extent to which primary and secondary stressors become problematic for the caregiver.
The caregiving history, which includes the relationship of the caregiver to the patient, and the length of time that the care recipient has required care, has different implications for grandchildren than for other generations. Because of the younger age of adult grandchildren, their overall time in a relationship with the grandparent is shorter than their parents. Therefore, the adult grandchild may struggle with the changing nature of their relationship with the grandparent, especially if the grandparent was healthy for the majority of the grandchild’s life. The relationship history for spousal caregivers and adult children and their parents has a direct impact on the quality of the current caregiving situation, and whether there is a strong feeling of obligation to provide that care. Those spouses and children who have had a lifetime of interactions and exchange with the care recipient are more likely to provide care if the relationship is an amicable one.

For adult grandchildren, the dynamics of a life-long relationship with a grandparent is very much dependent on the middle generation. This additional layer of the relationship can either mediate or prohibit a lasting bond between the grandparent and grandchild. This rationale is based on family systems theory (Cox & Paley, 1997), which holds that any relationship cannot be divorced from the larger family system and past findings that the gatekeeper role of the middle generation links young and old and affects relationship quality (King & Elder, 1998; Rossi, 1993). We need to address this contextual family history when assessing stress of grandchildren providing care. They may experience more or less stress based on their relationship with their parents as well
as their grandparents. This research will ask the grandchild how their background history with both their parents and their grandparents has affected their ability and desire to provide care to their grandparent.

*Primary Stressors*

In order to appreciate the full extent of caregiver stress, one must examine primary stressors. The Stress Process Model (Pearlin et al. 1990) accomplishes this. Primary stressors for caregivers are those stressors embedded within providing care, and the impaired condition of the care recipient. They develop directly from the frustrations and obstacles that stream directly from the needs of the care recipient, and the care necessitated by these needs. In essence, the stressors are primary because they are integral components of the underlying illness that has created the demand for caregivers. Primary stressors include the objective conditions of caregiving: cognitive impairment, problematic behavior, activities of daily living dependencies, and patient resistance, and the subjective reactions to caregiving: role overload, role captivity, and the loss of intimate exchange.

Past research has shown a direct link to increasing levels of stress associated with more difficult objective conditions of caregiving. Family members providing care to dementia patients experience higher levels of stress than their non-dementia counterparts (Shifren 2001; Sheehan and Nutall 1988; Haug et al. 1999; Chappell and Reid 2002; Miller and Cafasso 1992; Ory, Hoffman, Yee, Tennstedt, Schulz 1999; Schulz et al. 1995; Raccichini et al. 2009). Providing care for a person who is having memory
problems often results in higher levels of custodial care and induces more stress than non-dementia care. Problematic behaviors of the care recipient have been shown to increase caregiver stress (Sheehan and Nutall 1988; Chappell and Reid 2002). These behavioral problems, such as crying, hitting, yelling, or exhibiting socially inappropriate behaviors can result in increased embarrassment, frustration, and depression for caregivers, all caused by increased stress. All-encompassing care situations where care recipients are fully dependent on their caregivers can cause increased stress for caregivers (Chappell and Reid 2002; Miller and Cafasso 1992). The more time spent in the caregiving situation, both on a day-to-day basis and in terms of the longevity of the caregiving situation, creates stress for caregivers.

Primary stressors include those stressors embedded with providing care, and the impaired condition of the care recipient. For spouses and adult children, difficult behaviors and the declining health of the care recipient are especially stressful. The stress associated with dealing with this can be attributed to difficulties of seeing a loved one change so completely, and the lack of resources a caregiver has to deal with these changes. Adult grandchildren may suffer more or less from these changes in the care recipient. These caregivers are less likely to have previous experience caring for someone in their life, and hence, may not be socialized into accepting these changes. On the other hand, a shorter duration of a relationship with the care recipient may buffer some of the devastating effects of watching a grandparent suffer.

*Subjective Reactions to Caregiving*
The subjective reactions to caregiving, which are indicative of caregiver stress, include role captivity, role overload, and the loss of intimate exchange (Pearlin et al. 1990). Role captivity refers to the internal experience of being overwhelmed by the care-related tasks and responsibilities. This includes a sense of being an involuntary incumbent of the caregiver role. Role overload points to the tension between what one must do and what one wants to be and do, especially in reference to the competing roles in ones life. The loss of intimate exchange refers to the lack of interaction both with the care recipient, and with other individuals, on a personal level. Often, providing large levels of care to an elderly patient result in decreased social interaction between the care recipient and the caregiver because of an inability to communicate or express oneself due to the illness. The caregiver in this situation can feel isolated, alienated and caught in an unending cycle of care.

The objective conditions of caregiving, combined with the subjective reactions to caregiving, constitute the primary stressors involved in a caregiving situation. The severity of the background and context of the caregiving situation, compounded by the severity of primary stressors, in turn create secondary role strains and intrapsychic strains. These strains are also referred to as secondary stressors.

*Secondary Role Strains*

Secondary role strains are stresses in relationships and roles that the caregiver encompasses outside of their realm as a caregiver. Role strains include family conflict as a result of caregiver responsibilities, job-caregiving conflict, economic problems, and the
constriction of social life due to caregiving. These various strains have been discussed at length in this paper.

The secondary role strains that a grandchild suffers differ from other cohorts because of their position in the life course. The timing of life transitions involves the balancing of an individual’s entry into and exit from different roles- education, work, family and community- over their life course (Haraven 1994). Adult grandchildren are often at the beginning stages of all of these roles, and as such, may experience a great deal of role strain. Alternatively, adult grandchildren may postpone these other life course entries and exits in lieu of caregiving, and therefore are not experiencing the same life course transition as their peers. While this would result in less role strain, it would result in apprehension from having “off-time” events in comparison to peers. Over the twentieth century, transitions to adulthood have become more uniform, more orderly in sequence, and more rapidly timed. Overall, this timing has become more regulated according to specific age norms, rather than in relation to the needs of the family (Hareven 1994). Adult grandchildren opting to schedule their life events according to the needs of their extended family will experience non-normative life pattern changes as a result.

Intrapsychic Strains

The last component of the stress process is intrapsychic strain. This refers to the dimensions of self-concept and overall well-being that are diminished as a result of caregiving. Caregivers often have lower levels of self-esteem and mastery (Marks,
Lambert and Choi, 2002; Maria-Victoria, LlácerCentro, & Béland 2002). The negative aspects of caregiving, and the depression that ensues in several caregivers, can result in a feeling of overall helplessness and vulnerability to negative self-thought. Caregivers often report that they cannot do enough to help their care recipient, and they feel great feelings of guilt that may result in a change in their self-concept. Caregivers also exhibit higher levels of role captivity and loss of self, and by the end of their caregiving career, may exhibit lowered levels of competence and gain. Loss of self happens when a caregiver becomes so consumed with the caregiving role that they do not have time for anything else other than caregiving—hence, their “loss of self.” The identity and life of the caregiver has become so bound to that of the care recipient that the caregiver’s own identity becomes blurred.

Manifestation of Stress

The stress of caregiving manifests itself in a variety of outcomes, including depression, anxiety, cognitive disturbances, and declining physical health of the caregiver. Spousal and adult child caregivers are more likely than the general population to suffer from depressive and anxious symptoms (Wallsten 2000, Haug et al. 1999). The risk of depression increases with the number of hours a person provides care (Sheehan and Nutall 1988; Call, Finch, Huck, & Kane 1999). Caregivers providing substantial care to the care recipient are at risk of causing their own health to deteriorate (Sheehan and Nutall 1988; Wallsten 2000; Haug et al. 1999). Negative physical effects of caregiving include symptom distress and fatigue (Haug et al. 1999), caregiver exhaustion (Gold et al. 65
1995) and exacerbated medical conditions and increases in the use of prescription medication (Cefalu, Ettinger, & Espeland, 1996; Haug et al. 1999). This is especially problematic in today’s privatized society because we rely on informal caregivers to provide the majority of care. If caregivers are unable to care for the elderly population because of their own ailments, the need for formal services will increase, straining an already fragile economy.

The outcomes of stress are measured through depression, anxiety, physical health declines, and yielding the role of caregiver. To date, we have no research on how depressed adult grandchildren providing care are. We also have no data relating the anxiety of these caregivers, or declines in physical health. There is no observational data which yields the average length of caregiving among adult grandchildren, and whether this time is shorter or longer in duration than for other generations providing care. This research aims to determine how stress manifests itself for the grandchildren in this study. They will be asked questions on the types of emotions they feel because of their caregiving situation, including depressive and anxious symptoms.

**Mediators of Stress**

The deleterious effects of the stress associated with the caregiving process may be mediated by coping mechanisms, roles outside of being a caregiver, positive affect, and social support. Not all caregivers in similar situations react to the stress of caregiving in the same way. It has been shown that caregivers who have better coping mechanisms (e.g. management of the situation giving rise to stress, management of the meaning of the
situation such that its threat is reduced, and management of the stress symptoms that result from the situation) exhibit less of the manifestations of stress detailed above.

Studies conflict in accounts of whether women or men as caregivers have better coping skills. Some studies, for example, claim that women are more vulnerable to the effects of caregiver stress than men (Chappell and Reid 2002; Spaid and Barusch 1991; Miller and Cafasso 1992). One view is that this differential is due to earlier socialization factors such as sensitivity to relationships, nurturing versus instrumental behaviors, and coping styles (Barusch and Spaid 1989). This gender role socialization hypothesis is debated; other researchers claim that earlier socialization experiences on the part of individual caregivers are not responsible for differences in coping strategies of men and women; rather, female caregivers experience more distress because they have more stressful experience, less support, and greater role strain than men who provide care (Miller and Cafasso 1992). Other studies claim that there is little difference in the amount of stress for men versus women in caregiving, and that other factors such as age, caregiver illness, and behavioral problems of the care recipient were more indicative of predicting stress (Pinquart & Sörensen, 2006).

Age also contributes to the amount of coping skills a caregiver possesses. For example, children providing care to an ailing parent may have less experience providing care in their lifetime. They may be inexperienced at caregiving because of their age. Caregiver age also contributes to coping skills because older persons may expect to be caregivers. As a person ages, caring for an ill spouse or parent becomes more normative,
and an “on-time” event. The person may have better coping skills because others like them are experiencing a similar situation. Younger caregivers are less likely to have this commonality to draw on as a coping mechanism (Bainbridge, Krueger, Lohfeld, & Brazil, 2009).

Research on the effects of other roles in addition to caregiving has been mixed. A multitude of studies focus on the deleterious effects of having too many conflicting social roles, and the contribution this has to stress for caregivers. Other studies have shown that roles other than that of being a caregiver can actually decrease burden, mediating the caregiver role for these caregivers. For example, going to a job can have a buffering effect on the isolation and depression of being a full-time caregiver (Scharlach and Fredriksen 1994). Several researchers have found that for caregivers who do have paid employment, job classification, hours worked, work demand, workplace support and job flexibility all were factors for role strain differentiation. Women are more likely to experience role strain from their jobs, and workers with less prestige and more conflict on the job were more likely to consider their job a source of role strain (Edwards, Zarit, Stephens, and Townsend 2002; Dautzenberg, Deidricks, Philipsen, Stevens, Tans and Vernooij 2000; Fredriksen and Scharlach 1997; Fredriksen 1996; Reid, Stajduhar, & Chappell 2010).

The mediators of stress that other cohorts rely upon are coping mechanisms and social support. Adult grandchildren enter the caregiving role earlier in their life course, and may not have developed strong coping mechanisms to help buffer the negative
consequences of caregiving. Social support networks for adult grandchildren differ from those of spouses and adult children providing care because of the previously discussed life course position and family networks of adult grandchildren in this position. We do not know who adult grandchildren rely upon, or to what extent they can count on this support. Research has yet to address the effect of the stress process on adult grandchildren. The interview will ask grandchildren what factors help to mediate their stress level, and what factors they feel escalates their stress level.

The caregiving literature has a breadth of research on the deleterious effects of providing care to an elderly person. The most common themes in this literature include the effects of caregiving on employment, the role strains involved when someone provides care, the financial/legal aspects of providing care to an elderly relative, and the stress and burden associated with this care. Thus far, research has focused on adult spouses and children as units of analysis for these issues. This research will address these concerns from the perspective of adult grandchildren providing this care. Questions asked of grandchildren will address their concerns with these four areas of negative effects of providing care to a relative: work, role strains, financial/legal aspects of caregiving, and stress and burden.

**Positive Aspects of Providing Care for an Elderly Relative**

Caring for an elderly relative is a stressful task for most family caregivers. It involves a lot of time, resources, and patience. The majority of literature focuses on the negative aspects of caregiving because the majority of articles on the subject have been
written by service providers and social scientists that have focused on the needs of this population. While most caregivers acknowledge several stressors associated with caregiving, they also cite that there are several positive rewards that have resulted from their caregiving experiences. It is important to acknowledge the presence and influence of positive aspects of caring for a relative. Often, the positive aspects of caring help to alleviate the stress and burden associated with caregiving.

Positive aspects of caregiving have been referred to as “caregiver esteem”, “uplifts of caregiving”, “caregiver satisfaction”, “caregiver gain”, and “meaning in caregiving” (Hunt 2003). These various terms conceptualize the positive effects of caregiving differently. Most studies that have examined these positive effects have been qualitative, suggesting that the positive aspects of caregiving are more difficult to measure than are negative aspects of caregiving.

Caregiver esteem refers to the extent that providing care to someone helps raise the caregiver’s self-esteem (Hunt 2003, Given et al. 1992). It is the confidence or increased self-efficiency that a caregiver attributes to their caregiving experience. Self-esteem is an important positive variable to consider. A gain of self-esteem from caregiving has been shown to minimize the amount of depression for caregivers.

Uplifts of caregiving include events from which one derives joy, gladness, or satisfaction. Uplifts buffer the effects of the hassles associated with caregiving. In an examination of the uplifts and hassles of caregiving, caregivers reported less distress when uplifts outweighed hassles (Kinney et al 1995).
Caregiver satisfaction is the accumulation of positive caregiving experiences from which a person derives self-worth or pleasure. A person can derive satisfaction from a caregiving situation even in the face of difficult and burdensome tasks. The amount of satisfaction that a caregiver feels often alleviates the negative effects of caregiving. Research has shown that the amount of satisfaction one derives from their role as a caregiver determines the overall positive or negative affect they ascribe to their caregiving role (Lawton et al. 1989; Lawton et al 1991).

Deriving meaning from caregiving refers to the processes used by caregivers to make sense of their role as a caregiver. The process includes setting expectations for the caregiving career, deriving explanations to account for discrepancies among expectations and actual events, and strategies taken to actualize expectation (Ayers 2000). Finding meaning is an important positive psychological resource for caregivers. Research has shown that caregivers who are able to find higher levels of meaning had lower depression scores (Farran et al, 1997).

Caregiver gain is the positive return to a caregiver as a result of the caregiving experience. In a 1997 review, Kramer found that caregiver gain was often overlooked in caregiving research. An examination of caregiver gain have shown that caregiver resources such as social support and coping skills is positively associated with caregiver gain. Further, gain moderates the relationship between stress and negative affect, and the effects of gain are independent of negative appraisals of strain (Rapp and Chao 2000; Koerner, Kenyon, & Shirai 2009).
Studies which have focused on these positive experiences are limited, and findings indicate different positive rewards for spousal caregivers, adult child caregivers, and grandchildren who are children living in an intergenerational household providing care for a relative. The conclusions reached in various studies of the positive aspects of caregiving cite a correlation between identifying and feeling positive effects of giving care, and a decrease in the amount of stress, burden and depression associated with providing care. The lack of attention given to the positive dimensions of caregiving seriously skews perceptions of the caregiving experience, and limits our abilities to enhance theories of caregiver adaptation. Further, research on caregiver gain may provide clues as to how to enhance or increase positive aspects of care provision (Kramer 1997). Research has yet to isolate the positive gains of caregiving from an adult grandchild’s perspective.

*Positive Aspects of Caregiving for Spouses*

To understand the positive experiences that grandchildren would derive from caregiving, it is useful to review the findings on positive aspects of caring for spouses and adult children. For spousal caregivers, some reported benefits of caregiving are derived from the ability to help a spouse in times of sickness. Spouses often cite that they feel fortunate to be able to be helping their husband or wife by caring for them. Husbands and wives derive high levels of satisfaction from the caregiving role. They also indicate that they feel they can provide a better quality of care than anyone else, and are thankful for the opportunity to provide that care. Spouse caregivers feel that their relationship
with the care recipient has been enhanced because of their ability to provide care. These caregivers feel that their relationship is a partnership with the care recipient, and the care recipient would do the same thing for them if they were sick (Toseland, Smith and McCallion, 1995). Love is a construct and emotion that allows spouses to find meaning in providing care, and a reason for feeling positive about giving that care to their partner. Elderly spouses have cited that they feel an increased of self-esteem, self-efficacy, and an enhanced sense of purpose and meaningfulness in their life as a result of caring for their husband or wife. Finally, spouses report a sense of accomplishment for coping successfully with a potentially difficult and challenging life situation (Schalach, 1994).

**Positive Aspects of Caregiving that Younger Caregivers Experience**

The positive benefits of caregiving that are frequently listed by adult children differ from the reasons most commonly given by spouses. For children, the sense of reciprocity that they feel in being able to provide for a parent is tremendous. This feeling of contributing to the family cycle of reciprocity is an uplift of caregiving for children. It is a concept that allows children to feel a sense of meaning in their caregiving experience as well. Most children, who feel that their parent spent a significant amount of time taking care of them throughout childhood and young adulthood, experience this positive effect of caregiving. Adult children also claim that their relationship with their parent becomes closer as they provide care to that parent (Gerstel and Gallager, 1993). Children caring for a parent feel relief that their efforts have resulted in avoiding nursing home placement for their parent, which enhances positive meaning for their caregiving
experience (Dellman and Brittain, 2003). Last, some adult children who provide care to a parent feel a sense of relief that because of their care, someone will in turn take care of them when they are older (Simon 1988). The motivations and impact of caregiving for adult children are particularly strong because of their life-long relationship with their parent.

The most frequently cited benefits for young adult caregivers (without regard to their relationship with the care recipient) involved generational reciprocity, financial assistance from the older generation in exchange for caregiving, and the ability to maintain a close relationship with their parent or grandparent (Dellman-Jenkins, Blankemeyer, and Pinkard, 2000). Adolescent relatives of caregivers co-residing with the care recipient have reported that the caregiving situation had a positive impact on their family relationships, that they felt more understanding of older adults as a result of caregiving, and that the caregiving situation resulted in a significant impact on the pattern of the adolescent’s selection of peers (Beach 1997).

The positive aspects of caregiving have been an integral part of painting the full caregiver picture for spouses and adult children. To date, we have no accounting for what gain adult grandchildren may receive from the caregiving situation. The positive effects that may be gained from providing care for a grandparent warrant consideration. Adult grandchildren are one-generation removed from their grandparents, and the notion that they would feel an overriding sense of obligation or reciprocity at all, is unknown. There is no evidence to claim that by fulfilling caregiver responsibilities, adult
grandchildren would feel good about reciprocating care given to them. Adult grandchildren who provide assistance to a grandparent may have been raised by them, but no research indicates whether this pattern is salient. It is possible, but unknown, that adult grandchildren who are providing care may be benefiting financially either through being paid by the grandparent, or by co-residing with the grandparent in exchange for providing care. Because we do not know what propels an adult grandchild to provide care, we cannot determine the positive aspects of that caregiving experience. This research will ask grandchildren what good things have come from their caregiving, and what the benefits of caregiving are for them.

Available Supports for Caregivers

Social Networks and Social Support

In addition to coping style, social networks and social support has a direct buffering effect of the extent of stress that a caregiver feels. Social support may directly prevent or inhibit the development of secondary stressors (Pearlin et al. 1990). Research has shown that social support greatly affects the quality of care that a caregiver can deliver, as well as the stress that the caregiver goes through. Other researchers note that it is not the amount of support received, but rather the perception of support available that mediates the stress process for caregivers (Chappell and Reid 2002; Gold, Cohen, Shulman, Zucchero, Andres, & Etezadi 1995). For example, although spouses have smaller support networks than do other caregivers, they often feel that their children would help out if necessary (Miller and McFall 1991). Caregivers who report breaks in
their caregiving have higher self-esteem, and a lower probability of high levels of burden (Chappell and Reid 2002; Harper and Lund 1990). Overall, caregivers with higher amounts of support fare better than their isolated counterparts. Social support serves to mediate the negative effects of the caregiving experience. The networks to which caregivers have attachments usually include other siblings, neighbors, friends, and children.

Adult grandchildren may or may not have social networks available to them; these caregivers may be providing care because there is a lack of other support available. They may not be able to depend on their parents to help provide care to their grandparents. Also, grandchildren providing care are doing so at a time when it is not a normative life course event to do so. Spouses and adult children normally have larger networks of support because they have other people at similar stages of life embarking on the same type of caregiving. Adult grandchildren are less likely to be able to rely on peer groups or friends, and they are less likely to have forged lasting relationships with neighbors as adults. This research will explore the social supports of the adult grandchildren studied, and how these supports have changed throughout their careers as caregivers.

The Use of Formal Support

There are some elderly persons who receive very little informal support in the course of their illness, and rely exclusively on formal supports. However, this group is very small- the majority of older persons needing assistance rely on informal supports. This unpaid assistance from family members or friends is usually supplemented at some
point with formal care. There are two competing models to describe the interplay between these two systems: the Substitution Model and the Complementary Model (also referred to as the Task-Specific Model).

The Substitution Model assumes that informal caregivers only rely upon the formal support system as a substitution for informal care services. As such, informal and formal services are seen as dichotomous. Family caregivers are likely to provide as much care as possible, substituting with formal care only when the need arises (Cantor 1991). The Complementary Model asserts that the formal support system is used in conjunction with informal support systems, and these two modes of support are most effective when used in conjunction (Litwack 1985; Chapell, 1987, Logan and Spitze 1994).

There are strict generational differences in these two models: spousal caregivers are more likely to ascribe to a substitution model of care, only asking for help from formal supports if they can no longer do everything themselves. From this perspective, formal support is seen as a failure of the private individual to provide all of the care. Spousal caregivers often care for each other to the exclusion of finding additional help (Chatters, Taylor, and Jackson 1986; Fei, Roff, Klemmack,& Burgio 2008). Although spouses are older than other caregivers, and are in poorer health, they are usually the last group to give up their roles as caregivers (Wallsten 2000). Some spouse caregivers are reluctant to seek any formal support because they are fearful that seeking help may stimulate their families and friends to encourage them to think about nursing home placement for their spouses (Wallsten 2000). The independence and isolation of
caregiving are much starker for this group than their younger counterparts, and the Substitution Model defines the attitudes that this generation has towards receiving help.

The Complementary Model, most often reflected in adult child caregiving patterns, emphasizes that informal care and formal care work well together. Caregivers who have respite and daycare available to them have a reduction in burden (Mittleman et al. 1993; Wimo, Matteson, Alldofsson, Eriksson and Nelvig 1994; Deimling 1991). The stigma associated with leaning on formal care for those who ascribe to this model is much less prominent than the Substitution Model. These models have only been tested on adult children and spouses as units of analysis.

The motivations of refraining from, or receiving, formal supports have been clearly laid out for spousal and adult child caregivers. We have no notion of what formal supports adult grandchildren utilize, nor do we understand why these supports are called upon. We do not know if grandchildren would be more likely to use formal services as a substitution for, or in conjunction with, their caregiving. This research will determine the formal support reliance for grandchildren participating in this study, and whether their use follows a Complementary or Substitution model of support.

Support Groups

An additional source of support for caregivers can be found through support groups. These groups are usually in-person groups, but can also be conducted over the telephone or through internet bulletin boards and chat rooms. Caregivers are able to share their experiences and frustrations with other caregivers, provide support to others in
a similar situation, and seek solutions to pressing problems that they have as caregivers. Support groups can be run by volunteers, or they can be headed by a professional in the field, who acts as a group facilitator.

Outcome measures have reflected the effectiveness of these caregiver supports. Psychosocial and educational programs and support groups for caregivers have maintained and improved caregivers’ emotional well-being, lowered depressive symptoms, enhanced mental health, and lessened the extent of pressing problems (see, for example, Yang et al 2003; Toseland et al 2001; Mittleman et al 1993). To date, support groups have been aimed at spouses and adult children. Factors that inhibit participation for these groups include accessibility, personal factors, concerns for confidentiality, and not knowing anyone who was a group member (Biegel and Song 1995; Smith, Toseland, Rizzo and Zinoman 2004). Support groups work as a bridge between the informal supports that family and friends provide, and the formal supports available in the paid sector.

Adult grandchildren have not been studied as subjects of support groups. As a result, we cannot determine whether these groups are helpful for them. Previous research shows that the target population of a support group dictates how helpful the group is for individual members (Monohan 1994). No research has been aimed at how many adult grandchildren attend support groups. Based on Monohan’s analysis, we can assume that adult grandchildren are not as numerous as adult children or spouses in support groups because they lack the element of cohesion to other members because of their age and
generational disparities. However, personal factors such as lack of time, lack of need, or social discomfort may also prohibit adult grandchildren from attending support groups. Grandchildren may not understand what support groups provide. This research will aim to determine whether the adult grandchildren in this sample are attending support groups. In addition, for those attending, the positive/negative aspects of the group will be discussed. For grandchildren not attending support groups, the reasons why they do not attend will be probed.

Supports for caregivers are varied. Social support focuses on family and friends who are available for caregivers to help them or even to emotionally support them. Formal support refers to paid support given by different agencies. Finally, support groups are community supports. Spouses and adult children providing care to an elderly relative have differing levels of social support, formal support and support from support groups. This study will determine the extent to which the grandchildren studied can rely on similar sources of support. Attention will be given to the role of informal supports, formal support, and support groups.

Discussion

The caregiving literature to date has encompassed a wide variety of topics. The general themes that have emerged from this literature provide a starting point from which to examine a third group of caregivers, adult grandchildren. Overall, the lack of previous research on adult grandchildren leaves several key theoretical and practical questions unanswered. We do not know why/under what circumstances adult grandchildren
provide care to the frail elderly; (2) the positive and negative effects of providing this care, and (3) the available supports and needs of these caregivers. This research aims to bridge this gap between previous research and the realities of caring for an elderly grandparent. The interviews should provide insight into the themes reflected in the grandparent/grandchild literature, and the themes presented in the caregiving literature.

Specifically, this research aims to answer several questions both about the grandchild/grandparent relationship dynamics and the caregiving process for adult grandchildren. These different themes have been organized into the six themes that have run through this text:

(1) Why/under what circumstances do adult grandchildren provide care for their grandparents?

1. What factors push and pull grandchildren to care for a grandparent? Do these mimic or differ from reasons for caregiving in spousal and child populations?

2. What gender norm expectations have been placed upon grandchildren to provide care to a grandparent, who enforces these expectations, and is this an area of concern for adult grandchildren?

(2) How do the dynamics of the existing grandparent/grandchild relationship affect caregiving processes of grandchildren?

3. How does an adult grandchildren’s background history with both their parents and their grandparents affect their ability and desire to provide care to their grandparent?
(3) How does caregiving for a grandparent change the grandchild/grandparent relationship?

(4) What are the negative effects of providing this care?

4. What types/extent of secondary role strains compete with grandchildren’s’ caregiving responsibilities?

5. What financial/legal responsibilities do grandchildren have toward their grandparent’s care and how does the intergenerational link between grandchild, parent and grandparent affects these responsibilities?

6. How does stress manifest itself for grandchildren? What are the types of emotions grandchildren feel because of their caregiving situation?

(5) What are the positive effects of providing this care?

7. What factors help to mediate adult grandchildren’s stress level?

8. What good things have come from their caregiving, and what are the benefits of caregiving for grandchildren?

(6) What are the available supports and needs of adult grandchildren?

9. What are the social supports of adult grandchildren and how have these supports changed throughout their career as caregivers?

10. What formal supports do grandchildren rely on in providing care to a grandparent and does their use follow a Complementary or Substitution model of support?
11. Do adult grandchildren attend support groups? For those attending, what are the positive/negative aspects of the group? For grandchildren not attending support groups, what are the reasons why they do not attend?
Chapter Three: Research Methodology

The central question that guided this project was: What is the caregiving experience like for adult grandchildren providing care to a grandparent? Specifically, this study sought to determine (1) why/under what circumstances adult grandchildren provide care for their grandparents; (2) how the dynamics of the existing grandparent/grandchild relationship affect caregiving processes of grandchildren; (3) how caregiving for a grandparent changes the grandchild/grandparent relationship; (4) the negative effects of providing this care, (5) the positive effects of providing this care, and (6) the available supports and needs of these adult grandchild caregivers. The very nature of these questions necessitated a qualitative approach, specifically in-depth interviewing. To adequately explore these issues, it was essential to talk directly to grandchildren who had this experience. This section will discuss the following issues: recruitment strategies; protecting confidentiality and human subjects; compensation; the interview guide; timing of interviews; procedures for data management and analysis, and sample description.

The unit of analysis in this study was the grandchild who was providing care to a frail elderly grandparent. The roles of other social actors were important pieces to this research, but the views held by grandparents, parents, other family members, friends, and formal supports were not be directly investigated. Although these individuals could certainly provide interesting perspectives on the caregiving process, the experiences and perception of the adult grandchildren who were providing this care were the focus of this research.
Recruitment Strategies

Adult grandchildren providing significant amounts of care were difficult to identify. They use fewer formal services for themselves, and because they are third-generation carers, grandchildren were sometimes less likely to even be called a “caregiver” by themselves, their parents or their grandparents. This cohort attended church or community centers less often than preceding cohorts, traditional places through which to obtain a sample. Support groups for caregiving typically attract adult children and spouses of the frail elderly, not grandchildren. Caregiving as a young adult is considered an “off-time” event, and few grandchildren were in a similar caregiving situation to peers. These are all traditional modes of collecting snowball samples with other caregiving populations. In order to recruit a minimum of 35 research subjects, a variety of recruitment tactics were employed.

I recruited my sample from New York State. In order to do this, regional “gatekeepers” were necessary to help me navigate through the territory of geriatric care and support available to caregivers, including grandchildren. My four years as a Research Associate recruiting such groups was a key contributor for my entry into several agencies. The Institute of Gerontology, where I was previously employed, is housed within the School of Social Welfare at the University at Albany. Both the Institute of Gerontology and the School of Social Welfare have served as liaisons between community activism and social research. As such, I utilized the contacts both at
the University level and the community level that I have worked with on previous research projects. First, Dr. Philip McCallion, Director of the University at Albany’s Excellence in Aging Services Center, allowed me to use the Center’s mailing list of 700 geriatric professionals for recruitment (see Appendix C for the recruitment letter). The Center for Excellence in Aging Services was established in 1999 through a series of grants from the John A. Hartford Foundation designed to promote greater preparedness for a more aging society. Other sources of funding include The Hearst Foundation, National Service Corporation, Administration on Aging and New York State's Developmental Disabilities Planning Council, Department of Health and Office for the Aging.

The Center for Excellence develops and implements innovative practices and policies that address the needs of aging persons, their families, and professional caregivers. The Center is committed to excellence in teaching, scholarship and public service and to addressing the needs of vulnerable and oppressed populations. In pursuit of this mission the Center works with communities, state and local agencies and the Legislature to 1) improve outcomes for the most vulnerable older persons in society; 2) stimulate interest at local, state and national levels in the capacity, potential, and needs of older persons; and 3) raise community awareness of the needs and strengths of older persons from diverse cultures. These health care professionals, community service agencies, and mental health professionals working in conjunction with the Center for Excellence in Aging were asked to refer my name and contact information to any
individual adult grandchildren receiving formal services for their caregiving needs (for example, respite care or adult day care). In addition, these 700 professionals were mailed a flyer (see Appendix D for a copy of the recruitment flyer) to be displayed at their agency. This method of recruitment only yielded four participants for the study.

Second, Linda Mertz and Ricki Fortune, Ph.D., allowed me access to the Hartford Internships in Aging listserv. The Hartford Internships in Aging Project, funded by the John A. Hartford Foundation, provides education for geriatric social workers and stimulates development of new social and health care services to older persons in the Capital District. It is a collaboration among the School of Social Welfare and eight agencies that provide services to older adults in the Capital Region and rural northeastern region of NYS. They include: The Alzheimer's Association (AANENY), Northeastern NY Chapter, Capital District Physicians' Health Plan, Inc. (CDPHP), Centro Civico, Jewish Family Services of Northeastern NY (JFS), Northeast Health (NEH), St. Peter's Health Care Services, Stratton Veterans Administration Medical Center, Department of Veterans' Affairs, and Whitney M. Young, Jr., Health Center (WYHC). Each of the professionals at the agencies listed above are active members of a listserv created by the Hartford Internships in Aging Project, and community announcements, program listings, and calls for information are frequently posted here. I posted a message to the listserv (see attached: Appendix E). This yielded an additional five participants.
I also partnered with Marcus Harizan, the Assistant Director of the Local Office Divisions for the State Office for Aging. We have a long history of recruiting human subjects for various projects at the Institute of Gerontology. He works with the state’s 59 county and local Area Agencies on Aging, and contacted each of them on my behalf to solicit volunteers. Each of the Area Agencies on Aging has a responsibility to provide caregiver support. In addition, Marcus Harizan contacted New York State’s 17 Caregiver Resource Centers, inquiring about any possible leads through these offices. These centers are located in Broome County, Cattaraugus County, Clinton County, Cortland County, Fulton County, Genesee County, Madison County, Monroe County, Nassau County, Onondaga County, Orange County, Putnam County, Steuben County, Sullivan County, Tompkins County, and Westchester County. Outreach efforts to these various outlets included person-to-person contact via the State Office for Aging, flyers to distribute in their offices, and a request to refer future caregivers for the participation in the project. An additional two participants were yielded from this strategy.

The Institute of Gerontology has conducted a Telephone Support Group Caregivers program. The Senior Services Center of Albany has partnered with the Institute, and serves as the contact and screening for eligibility for the study. The Eldersource Line is a toll-free hotline that caregivers call the Senior Services through. This information source provides caregivers access to a professional with experience in a broad range of eldercare issues. The Eldersource line receives phone calls from caregivers who need assistance, as well as potential participants in the Telephone Support
Group Caregivers program. The Senior Services of Albany agreed to refer any adult
grandchild caregivers to me by asking them if they would like me to contact them, or
alternatively giving these caregivers my contact information. Unfortunately, this yielded
no additional participants.

In past studies, relying on professionals working in the field for recruitment has
sometimes been slow, yielding a small sample. Therefore, it was imperative to include
this recruitment method as one among several which were utilized. Some additional
methods sought to directly recruit caregivers, rather than relying on professional liaisons.
The additional methods included tabling, public service announcements to radio stations,
posting flyers, listing the research on Caregiving.com, listing on the Time Warner
Channel 18 Bulletin Board, and placing advertisements in newspapers throughout New
York State. These strategies resulted in only two additional recruits.

The New York State Capitol provides a ready environment in which to table
effectively. The New York State Plaza and State Concourse house contain over 5000
state employees. Tabling in these places was a highly visible method of recruiting from a
sizeable population. It was my hope that it would provide an effective recruitment
strategy for adult grandchildren who may be both working and caregiving. Recruiting at
their workplace had the potential to allow me to reach an otherwise-unreachable
population. Unfortunately, this did not yield any further participants.

Another recruitment technique was to post flyers in non-service related public
spaces, including flyers to 100 places of worship in the Capital District, 130 pharmacies
in New York State (NYS), 160 grocery stores in NYS, and 100 child daycare centers in the Capital District. Flyers can be an effective way to reach a population. I targeted places that a caregiver may have to spend time while waiting for their grandparent—namely, pharmacies, grocery stores, and places of worship. In addition, I targeted child daycare centers. Grandchildren with children of their own may identify themselves as caregivers more readily while performing competing caregiving tasks, such as arranging childcare. Last, advertisements were placed in area newspapers across the state (see Appendix F for a copy of the newspaper advertisement). Newspaper ads are effective tools for recruiting caregivers who are homebound, without formal service, or in non-traditional caregiving working environments. Specifically, an ad was placed in the Leader Herald (serving Fulton and Montgomery Counties), the Record, Independent, Saratogian, and Community News (serving the North Country), the Times Union (serving the Capital District), and the Post Standard (serving the Syracuse region). Unfortunately, this method of recruitment did not yield any participants. I have received funding from the Benevolent Research Fund, the Graduate Student Organization, and the Initiatives for Women to cover the expenses of postage, copying, tabling, and advertisement space.

An unexpected and advantageous method through which the majority of the sample was found was through posting ads on the internet, namely on YoungCaregiver.com and Craigslist. The caregivers in the study most often found me through these channels, perhaps because they were often navigating these same online
spaces. YoungCaregiver.com yielded an additional nine interviewees, and Craigslist.com yielded an additional 17 participants, 13 of which were interviewed.

Confidentiality and Protection of Human Subjects

The various recruitment strategies that I am employed all assured that the research subjects were recruited in a non-obtrusive manner. The various agencies who received a letter from me explaining the research were asked to have the adult grandchildren contact me directly, as opposed to providing me with the names to call the grandchildren with. Only in cases where the grandchild granted permission to the agency liaison was I able to make a direct contact. The number that I provided potential participants with was my work telephone number, which went directly into a confidential voicemail system if I did not answer. My name, academic affiliation, and title were all clearly stated on the message. I also provided my email address as a way to contact me. My email was a school email address that clearly identified my academic affiliation.

No research was conducted on subjects until a consent form was signed (see Appendix G). At the beginning of the interview process, the participants were reminded that their participation was voluntary, and that they could stop the interview at any time. In addition, the participants were told that they did not have to answer any questions that they did not want to. In the event that any question upset a participant, the interview would be halted, and the participant would be asked if they wanted to continue with the interview. This only happened in one instance when a granddaughter began crying. When asked if she wanted to continue, she replied that she did. As a safeguard, all human
subjects were given a list of referrals, which included social workers to provide counseling if the questions were upsetting, and a list of community agencies and supports that other caregivers have found helpful (see Appendix J).

Compensation

Caregivers often do not participate in research because they cannot afford the time away from the care recipient. In this population, the incentive of being paid for time is advantageous because it may provide the caregiver the opportunity to afford brief respite care while they participate in the interview. Adult grandchildren participating in this research were paid $10 for their time. This money was awarded through an ‘Initiatives for Women’ grant at the University at Albany. In addition to monetary compensation, I offered the research subjects in this study the opportunity to view the end product of this dissertation, or any portion of their interview. The vast majority of participants declined to be paid.

Audio taping

With participants’ permission, the semi-structured qualitative interview was audio-recorded. There was a separate space on the consent form either granting or denying permission of taping (see Appendix G). Audio taping the interviews allowed for a richer text, with more detail than possible from memory alone. Taping the interviews allowed for a full transcription of the interview for analysis. Pseudonyms were used in any written transcriptions, and any identifying information will be removed, as per the requirements of the University Institutional Review Board.
This research was approved by the University at Albany’s Institutional Review Board (IRB), and satisfied the conditions of human subjects protections as set forth by the University.

The Qualitative Interview Guide and Demographic Questionnaire

The combination of a qualitative semi-structured intensive interview and a questionnaire was used to study adult grandchildren providing care to their grandparents. Many qualitative researchers prefer to use intensive interviews because of the detail and richness of the data (Marshall and Rossman 1999, Lofland and Lofland 1995). This method of interviewing provides a more complete picture of a person’s interior experiences (Weiss 1994).

Qualitative research methods are of particular use for researching groups that we know little about. This methodology has three important distinctions. First, qualitative interviewing provides insight to social situations that we previously had no knowledge about (Glasser and Strauss 1967; Strauss and Corbin 1990; Weiss 1994). Second, qualitative research is useful for understanding interactions, complex meanings and investigating process (Marshal and Rossman 1999; Maxwell 1996; Taylor and Bogdan 1998). Third, qualitative research allows a wider breadth of understanding and detail than is available through quantitative research methods (Strauss and Corbin 1990). Since little previous research has examined the role of adult grandchildren providing care to a grandparent, intensive interviewing served to describe the experiences of these grandchildren, which we currently have limited data on.
The key themes in the intensive interviews resulted from an extensive literature review of the caregiving and grandchildren literature. These key themes in the literature were identified prior to collecting data. Different theoretical models have explained the general reasons that caregivers provide assistance, the negative and positive effects of providing this care, and the supports available to them. However, this previous research has not focused on grandchildren. While the existing caregiver and grandchild literature guided questioning, I did not have preconceived notions of why grandchildren provide care, what they considered to be negative and positive aspects of providing this care and what types of support adult grandchildren drew upon.

Grounded theory posits that researchers should ideally begin without preconceived notions, in the hopes that theory will emerge in themes evident in the data (Glaser and Strauss 1967). However, conducting qualitative research does not require the researcher to have no direction (Dey 1993). Approaches to interviewing vary along a degree-of-structure continuum. This research utilized a semi-structured interview format. This is the mode of choice when the interviewer knows what he or she does not know and can therefore frame appropriate questions to find it out (Lincoln and Guba 1985). This qualitative method is preferable to a fixed-order, standardized set of questions to get at the whole story (Weiss 1994:2). The interview questions that I developed created consistency for my sample, but allowed for flexibility in the answers. Probes allowed me to ask further detail to answers. In addition, the interview guide was flexible enough to continue down alternative paths of query as determined by the answers caregivers stated.
My experience as a gerontological researcher, combined with the breadth of available literature on caregiving, allowed me to have a semi-structured set of research questions with which to guide the interviews. By examining this literature prior to developing my interview guide, I was able to construct a conceptual framework to guide my research.

Section I and II of the interview guide (see appendix A) asked questions about the duration of care, time spent providing care, the level of care received, and the grandchild’s relationship to the grandparent. These were introductory questions appropriate to begin an interview regarding caregiving. Section III of the interview guide pertained to the reasons that the grandchild became a caregiver. These questions were aimed to uncover whether grandchildren provided care because of feelings of reciprocity, geographical distance, or because of expectations from others.

Section IV of the interview guide focused on the negative and positive aspects of caregiving. These questions focused on a variety of topics that have been researched on other caregiver groups. The first subsection, “Other Responsibilities”, focused on whether grandchildren who provide care to a grandparent were also providing care to other family members, and how their caregiving responsibilities affected their family life. Questions in the “Caregiving and Work” subsection provided a background of whether the grandchild worked, and if so, the type of job that they had, and the ways in which caregiving had affected their work performance. The next subsection, “Caregiving and Other Relationships” focused on how caregiving affected grandchildren’s family life,
social life, and other leisure activities they participated in. “Financial and Legal Issues”
detailed a number of issues relevant to caregiving including power of attorney, health
care proxies, and work benefits. These issues have never been examined from the
perspective of adult grandchildren who are providing care to a grandparent. “Stress and
Burden Associated with Caregiving” questions determined how stressful the role of
caregiving was for adult grandchildren. Issues such as whether the grandchild had any
previous experience with caregiving, whether their relationship with their grandparent
had changed because of caregiving, and whether their relationship with their own parents
had changed as a result of their situation were addressed. A final theme in this section
focused on the positive aspects of caregiving.

The next section of the interview guide was “Sources of Support”. These
questions focused on three types of support: informal supports (family and friends),
sources of formal supports, and support groups. The questions were aimed to determine
whether grandchildren sought formal supports in conjunction with, or as a substitution to,
informal supports. In addition, questions about the support group attendance of
grandchildren determined whether these grandchildren had lower rates of attendance
because of a lack of knowledge of the groups, a sense of discomfort while attending the
groups, or an alternative support group via the internet.

The interview guide ended with some general questions about family structure,
and the relationship quality between the grandchild and their parents and grandparents.
These questions were intentionally added to the end of the questionnaire because they
were 1) not as exciting to ask, and therefore not a good way to start the interview, and because 2) some of the questions were sensitive, and therefore more appropriate to ask at the end of the interview.

The flow of the interview guide mimicked the organization of the literature review section. Many of the issues raised in chapter 3 regarding the experiences of adult grandchildren who provide care to a grandparent were best examined through qualitative methods. The themes and theory found in the literature review served as a guide for determining the appropriate questions for the guide.

I constructed my interview guide with sociological theoretical perspectives on caregiving that shaped the presentation of my findings. With this in mind, the reasoning and elasticity of qualitative work and grounded theory remain central to the flexibility of this guide. As Strauss and Corbin (1990) explain, “new categories will emerge that neither we, not anyone else, had thought about previously” (p. 50). The 3 analytic categories that I planned to begin the study with were confirmed by analysis of the interview transcripts (Dey 1993). In other words, the theoretical concepts I utilized were grounded in the data. In addition, the development of new subcategories and the exploration of relationships led to the enhancement of the theoretical concepts. For example, as more grandchildren with deceased parents volunteered that they were angry at their parent for dying and leaving them in the position of being a caregiver, I chose to modify the interview guide to include this question to all participants with deceased
parents. In short, this qualitative methodology used a combination of deductive and inductive reasoning.

The wording and structure of the interview questions were guided by the insight of numerous consultants, and were tested with pilot interviewees, individuals who were previously caregivers to their grandparents but whose grandparents were deceased. Bowser and Seiber (1993) assert that if the research instrument is not “sensitive to the communication style and language of prospective respondents…respondents may not only misunderstand the questions, they may be offended by them and not give valid responses.” Based on this, four adult grandchildren who had provided care to grandparents in the past (and therefore were ineligible to participate in this study) served as pilot interviewees, which helped me to both 1) practice the interview, and 2) make any amendments to the interview that they felt were unclear. It is essential to conduct this practice interview with subjects with familiarity with the experiences and life situations of those who one is researching. Interviewing past caregivers provided me with insights I otherwise would have missed, such as having to be more descriptive in my expectations of what ‘caregiver emotion’ meant.

Adult grandchild caregivers were asked to fill out a short demographic form (see Appendix B) at the conclusion on the interview to provide any relevant demographic information that was not covered through the course of the interview. Demographic data provided a profile of the adult grandchild caregivers I studied. Items included in the demographic data regarding the caregiver included the respondent’s age, gender, their
housing arrangements, marital status, race/ethnicity, employment status, type of occupation, highest level of education completed, spouse’s primary occupation, average monthly household income, length of time spent in the caregiving role, hours per day spent on caregiving activities, whether other family members or friends helped provide care for the grandparent, and whether the respondent received any home care or respite care for their caregiving responsibilities. I ended up asking several of these questions throughout the interview itself; this form served as a safety net for any additional information that I may have needed for my description of the sample.

Data Analysis

Qualitative Data Analysis

The qualitative interviews were transcribed, usually within 24 hours of the interview. Transcribing the interview is the first step for data analysis of qualitative research. The transcribed pages resulted in anywhere from a 25 to 60-page document which then were coded and analyzed for prevalent themes. Three general categories identified prior to the interviews were examined: (1) why/under what circumstances adult grandchildren provide care for their grandparents; (2) the positive and negative effects of providing this care, and (3) the available supports and needs of these adult grandchild caregivers. In addition, themes within the data that were already been identified were examined.

To code the vast amount of data, ATLAS software was used. Several qualitative researchers had advised me that this computer-assisted analysis was preferable to the
traditional cut-and-paste method. For example, ATLAS allows the researcher to assign multiple codes to a unit of text, to perform instantaneous searches of all documents, to detect when codes have become saturated, to collapse categories in which the data appear thin, to attach memos to document emergent insights, and most important, to continually redesign the framework.

The codes and themes that presented themselves in the text of the interviews allowed me to form theory based on these groupings. This induction is a key element of grounded theory. Grounded theory analysis “amounts to systematically grouping and summarizing the descriptions, and providing a coherent organizing framework that encapsulates and explains aspects of the social world that respondents portray” (Holstein and Gubrium 1995 (p. 79)). This combination of grounding my theory in the data, as well as comparing the data themes to theories attributed to other caregiver groups allowed me to ascertain the uniqueness of the caregiving experiences of adult grandchildren who provide care to grandparents.

Empirical saturation was considered throughout the study. The decision to stop recruitment after thirty five interviews came from the determination that interview responses were starting to overlap, quotations gained from interviewees were similar, and no new themes were emerging from additional interviews. The one area that was not saturated was an examination of gender differentials between adult granddaughters and adult grandsons. This will be discussed at length through the summaries of the research results as well as within the implications for research, in the concluding chapter.
Advantages and Limitations of Study

This research was necessarily qualitative because of the limited information that we have on adult grandchildren providing care to grandparents. There were many advantages to an intensive interview design. First, this type of interview allowed for a preplanned outline of topics. The goal of intensive interviewing is to collect as much knowledge as possible about the interviewee’s background, attitudes, experiences, and actions. This method allowed me to probe for information about the grandchild’s situation. Qualitative analysis provides rich explanations. It is advantageous when a seldom-studied or small group is being researched. Finally, the interview design of this study allowed me to have close interaction with the subjects. As such, I was able to ask any additional questions as they arose. The intimate nature of interviewing provides a stronger camaraderie between the interviewer and the subject, which allowed me to address more sensitive issues than would have been possible through quantitative methods.

The research conducted here was a qualitative study. Results were based on a nonrandom sample of caregivers. The grandchildren in this study may be distinctive because they were motivated to participate in the research. Recruitment efforts took place in many service venues; therefore, the sample may have been more aware of issues surrounding caregiving, and may have more adapted to being a caregiver than the general adult grandchild caregiving population. As such, the conclusions drawn will not be broadly generalizable but still useful.
Another limitation of this study is that the shifting relationship dynamics between adult grandchildren and their grandparents were only examined from the viewpoint of adult grandchildren. The scope of this dissertation did not provide enough resources or time to also interview the grandparents being cared for by a grandchild, or any additional family members or friends. Including additional perspectives would enhance our understanding of these family changes.

Implications of Study Design

Despite these limitations, this research offers insight into the issues of family, life course, gender and intergenerational relationships. The significance of the present study rests on the intersection of the grandparent/grandchild relationship and the caregiving experience -- a territory that has been minimally explored empirically. Thus, it addresses two bodies of literature. This research illuminates how caregiving affects the grandparent/grandchild relationship, and how caregiving is similar and different for adult grandchildren providing this care. To achieve this goal, I have developed an integrated and manageable study design based on in-depth interviewing and qualitative analysis. The study contributes to the literature of both grandparenting and caregiving by focusing on a seldom-recognized group of caregivers. Aims of this research is to bring recognition to the needs of grandchildren providing this care, and attention to the family structure, relationship dynamics, and role changes and consistencies that occur for grandchildren caring for a grandparent. A qualitative, exploratory study was the appropriate venue
through which to examine these needs, family structures, relationship dynamics and role changes.

Sample

Sample Size

Non-probability sampling is necessary when researching groups that are difficult to locate and geographically dispersed. Adult grandchildren providing substantial assistance to grandparents are a hard-to-identify group, and several different tactics were used to recruit this sample. The number of interviews conducted depended on when new interviews were no longer providing new information (Lincoln and Guba 1985). Quality of interviews, rather than quantity of interviews, is focused on in qualitative techniques (Lofland and Lofland 1995).

This research recruited 39 subjects, and interviews were conducted with 35 participants. The four recruitments who did not participate were all men who were too stressed with their caregiving tasks to participate. The grandchildren recruited for this study were all over the age of 18. In New York State, a child becomes a legal adult at this age. This research focused on adults. In addition, Institutional Review Board limitations exclude those under 18 from these analyses. The participants must have been providing at least four hours of care to their grandparent each week. Definitions of caregiving vary according to different sources; however, most rely on at least a minimum of weekly contact for an individual to be considered a caregiver. No limitations were made on whether the grandchildren used formal services or whether the grandchild was
significantly burdened. The grandparent must have had at least one ADL (Activities of Daily Living) impairment in order to be classified as sufficiently ill for the grandchild to be considered for the study. The potential size of the subject pool would have been diminished too greatly if more limitations were imposed.

As Table 1 indicates, all except one of the study participants were female. There were two possibilities for this pattern. First, several men who were screened and deemed eligible for the study decided that they were too overwhelmed with caregiving to participate. Second, it may just be more likely that women are the ones providing the majority of care. In either case, it was much more difficult to recruit men than women for the research. The majority of the grandparents who were being cared for were also female.

Overall, the sample was comprised of a largely, white, well-educated group of grandchildren. It was rare for a grandchild to not at least have a college education, and several grandchildren were teachers, attorneys, and other professional positions. The majority of the grandchildren were employed, and in fact worked full-time. For those grandchildren who were not working, the usual reason for staying home consisted either of caring for their grandparent or concurrently caring for their own children as a stay-at-home parent.

Some (13 of 35) grandparents moved in with their grandchild in order to be provided care by that grandchild. Other grandparents lived alone within the community. Rarely, a grandchild would move in with the grandparent in order to provide them care.
Finally, a proportion of the sample of grandparents resided in assisted living communities.

Table 2 illustrates the relatively young age of the grandchildren in the study, and the relatively old age of the grandparents in the study. The age of grandchildren spanned from 19 to 48. Grandparents tended to all be older, sometimes exceedingly so. The youngest grandparent in the study was 81 years old, and several grandparents were 97 years old. This is indicative of a much older grandparent than we typically see, and it follows that their health was failing and they needed additional support and assistance from family members.

Grandchildren did not take this role on for short durations. The average number of years that grandchildren were already in the caregiving role was for 6.33 years. The least amount of time that a grandchild was in this role was for a span of three years. On the other extreme, some grandchildren had already been providing care for their grandparent for ten years at the time of being interviewed. The caregiving tasks took significant amounts of time for grandchildren to perform. In fact, the hours involved in providing care may be more than what is listed, because the maximum number of hours that was calculated for any one grandchild was forty. Usually grandchildren who were living with their grandparent felt that they were providing care 24 hours per day, seven days per week, but rounded that figure to forty for simplicity’s sake. The least amount of time that a grandchild spent caregiving was ten hours, which was still a two-hour per weekday time commitment on the grandchild’s part.
Sample Demographics

Table 1: Caregiver Demographic Statistics
Univariate Statistics
Demographic Variables

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<tr>
<th>Variable</th>
<th>N (Total Sample= 35)</th>
<th>Percentage</th>
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<tr>
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<tr>
<td>Female</td>
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<td>97.15</td>
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<tr>
<td><strong>Grandparent’s Gender</strong></td>
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<td></td>
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<tr>
<td>Female</td>
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<td>8.58</td>
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<tr>
<td>Latina/o</td>
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<td><strong>Education Completed</strong></td>
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<tr>
<td>Some College</td>
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<tr>
<td>Undergraduate Degree</td>
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<td>Graduate Degree</td>
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<td><strong>Grandchild’s Employment</strong></td>
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<tr>
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<td>14.29</td>
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<tr>
<td>Student</td>
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<tr>
<td><strong>Grandparent’s Living Arrangements</strong></td>
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<tr>
<td>Lived Alone</td>
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<tr>
<td>Lived in Grandchild’s Home</td>
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<td>37.14</td>
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<tr>
<td>Grandchild Lived with Them</td>
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<td>Assisted Living Facility</td>
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Table 2: Caregiver Demographic Statistics
Univariate Statistics
Demographic Variables

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<tr>
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<tbody>
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<td>7.17</td>
</tr>
<tr>
<td>Grandparent’s Age</td>
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<td>5.25</td>
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<tr>
<td>Number of Years Spent Caregiving</td>
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<td>Hours/Week Spent Caregiving</td>
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</table>
Chapter 4: Why Grandchildren Provide Care

There are many circumstances through which grandchildren provide care to their grandparents. Some of these reasons mimic the push and pull factors that adult children and spouses list as their reasons for providing care. Other reasons stated are unique to grandchildren. This section will first discuss grandchildren’s feelings of reciprocity, locational proximity, and feelings of responsibility as reasons to care. Next, gender norms among grandchildren will be discussed, including how this affects which grandchildren care, and the type of care they provide. Finally, how the adult grandchildren’s background history with both their parents and their grandparents affects their ability and desire to provide care to their grandparent will be examined.

Push and Pull Factors for Providing Care

Feelings of Reciprocity

Grandchildren who were interviewed almost always remembered a very nostalgic childhood relationship with their grandparents. The grandchildren who claimed their childhoods were enhanced by their grandparents’ presence readily acknowledged that this was a motivating factor for them to provide care to their grandparent.

“My grandmother was like my mom. I used to spend one out of every two to three weekends there at their house. My parents would drop me off on a Friday night, and I would eat dinner with my grandparents and go to school, go to synagogue, and on Saturday, we would hang out in the house. On Sunday, we would either do something, or she worked every other Sunday, but she worked in a tiny little store that she owned, so my grandfather would spend the day with me, and then we would go over to meet her. She got off of work at 4, cook us dinner—we could cook, do all kinds of stuff. And, it was normal, you know? They used to be like my second set of parents. I used to stay with them for like weeks at a time when my parents would go away. Yeah, that is something that makes it easier. I
try to remind myself, you would do this for your mother, and you don’t like your mother nearly as much as you like your grandmother (Rachel, 27-year-old caregiver).”

Few grandchildren mentioned feelings of reciprocity toward their own parents as their motivating factor to help care for their grandparents. For a grandchild to feel that he/she wanted to care out of reciprocity, that emotional exchange was always between themselves and the grandparent, with little regard to how their helping may be currently helping their parent. This often came as an afterthought.

“And, then there is also that my mom deals with her all the time, and I don’t do anything except go to school part-time, and I really should help my mom (Rachel, 27-year-old caregiver).”

The above two quotations are from the same grandchild, and the length through which she spoke of her affection for her grandmother versus her feelings of loyalty towards her mom reflect the intergenerational ordering of reciprocity. Grandchildren who grew up emotionally close to their grandparents often stepped up to caregiving without being prompted or asked by others, and took joy in being able to help their grandparents.

Norms of reciprocity are strong for grandchildren who had a history of spending large amounts of time with their grandparents during childhood, even with the presence of their own parents. Adult grandchildren cite many of the same notions of reciprocity as do older generations (Bliezner and Hamon 1992, Lee 1992, Haraven 1994, Horowitz and Shindelman 1983, Arber and Ginn 1990, Wallsten 2000). It is important to note that this notion of reciprocity was aimed at the grandparents and not the parents. Grandchildren
do not provide care to grandparents as a way to illustrate reciprocity to the middle generation.

*Locational Proximity*

Some grandchildren did take on the care of their grandparents because they were the closest geographically to their grandparents. This often was a grandchild who was residing with their own parents, and grew up in close proximity to the grandparents.

“She (my grandmother) lives in an apartment about a mile away from here. It’s about five minutes away. We were living with her for about six months, but we moved back to our house. She lives quote, unquote, alone. Her son, my uncle, has a full-time job, he has a wife, he has a ten-year-old, he has an eight-month-old. He lives 45 minutes away. Of course, he should not be her main caretaker (Georgia, 28-year-old caregiver).”

Providing care due to locational proximity versus relationship proximity had vastly different implications for the grandchildren, largely because being the closest locationally usually meant that there was a team of family caregivers available, and the grandchildren were supported by many others.

Several grandchildren took care of their grandparents because they were the closest in relationship proximity to their grandparents, rather than closest via locational proximity. This scenario was most common when the middle generation was deceased or critically ill, and the grandchild was the ‘next in line’. For these grandchildren who cared because they were the only ones available- regardless of distance- isolation, being overwhelmed, and indecision were very characteristic.

“Well, it’s basically because of there is nobody else around. There is no one else available to do it. It’s basically for health reasons, and there is nobody else except
me. My sisters are younger than me. They are much younger, and not in a position to do it. So, it’s just me or no one else to do it, and no one else is not a viable option (Amy, 34-year-old caregiver).”

The grandchild in the above quotation actually moved her grandfather into her home in New York State from another state 500 miles away. Caring for him certainly wasn’t easy in terms of locational proximity, but her relationship proximity (her mother was deceased) made caregiving for her grandfather a necessity. Several grandchildren drove or flew across the country to retrieve their grandparents if their health was failing, and there was nobody else to assume the role of primary caregiver. What makes this pattern unique is that the grandchild usually found out that their grandparents needed immediate care, and the grandchildren had little time to prepare for their role as caregivers.

“When they had her (my grandmother) in the emergency room, she was going up and down. She was really, completely out of it. And, uh, she had a systemic E. coli infection -- it got in her blood. And her doctor was helping and he said, I'm not going to release her to go home alone. You know, if you cannot make the arrangements when I’m ready to release her from the hospital, I'm going to send her to a rehab facility until you can arrange either for someone to be with her in her home 24/7 or make arrangements for her to come up and live with you. Well, I guess I had about a week to plan for her to live with me. I had about a week. It was Thursday or Friday that she went in the hospital, and it was like, I had that following week to try to get services in place for her. And then they arrived that Saturday at the house. Not a lot of time. I mean, I was just like really pushing things into high gear (Cecilia, 42-year-old caregiver).”

Housing, job accommodations, and intensive caregiving were all in flux upon their return with their ill grandparent. The instantaneous changes this brought to grandchildren’s lives were overwhelming. Caregiver models of locational proximity and gender that dictate that the closest daughters are most likely to provide care for parents
are repeated for the grandchild generation. Grandsons (siblings of the granddaughters providing care) are more likely to cite distance, family responsibilities and jobs as a reason to opt out of care, similar to adult sons (Campbell and Martin-Matthews 2000). Granddaughters were more likely to relocate themselves to their grandparent’s homes, or move the grandparent in with them in order to be able to provide more care. This mimics patterns seen among adult daughters who provide care (Hallman and Joseph, 1999; Himes, Jordan and Farkas 1996).

Feelings of Responsibility

Regardless of the grandchildren’s personal relationship history with their grandparents, the sense of responsibility to keep their grandparent out of a nursing home was a very strong theme for grandchildren. This theme was strong even for grandchildren who provided care to grandparents that they did not necessarily get along with throughout their childhood. The following quotation emphasizes this family decision to keep elders out of nursing homes:

“I don't think it was a really discussion. It was just that she was not able to be on her own. I don't know, we just don't do the nursing home thing in my family. Because before that, we had had my mom's other grandmother with us -- my mom's mother, actually, my other grandmother (Lynn, 44-year-old caregiver).”

The above quotation was taken from an interview with a granddaughter who had both her parents and her grandmother move in with her. Her father was critically ill, and her mother was working to pay for the medical needs of her father. The grandmother also became sick, and although the granddaughter was already caring for her father, and she did not really like her grandmother, she did not hesitate to also have her grandmother
move in. Similar sentiments were repeated by other grandchildren. This next quotation exemplifies the notion that grandparents should be cared for within private homes.

“Because it's also a tradition in our family to take care of your seniors. I knew my great-grandmother, my grandma's mom, and she lived her own home until the day she died at age 97. She was cared for by her older daughter. So there is sort of a tradition. And that's sort of, you know, what Grandma's desire would be (Debbie, 38-year-old caregiver).”

One thing that is striking is that when grandchildren mentioned the tradition of keeping grandparents out of nursing homes, the historical and family dynamics that made it possible to keep previous generations out of nursing homes did not factor into the grandchild’s understanding of what made it possible to keep relatives home in the past. Nursing homes were not as readily available, and women were more likely to be out of the formal workforce and available to care. These historically situated realities were not factored in when making the decision to carry on the ‘family tradition’ of not putting a relative in a nursing home. As a result, grandchildren placed a lot of pressure and guilt on themselves to continue this nursing home-free legacy.

Adult grandchildren had a lot to say about the personality traits of their grandparents. Being close to a grandparent did not necessarily mean that the grandparent was well-liked, or even kind. In these scenarios, the grandchildren do admit that they have more of a tolerance for their grandparents than other people do, because they grew up with that temperament, and were not scared by it.

“I mean, my family knows, um, you know, they know she's incapable and they can hear her getting snippy and cranky with me, and they're always like, I don't know how you do it. Of course, they've always been like that, you know what I mean? My family has always been like, they don't see how I do it because they
never have. My grandmother is infamous for being impossible to get along with. She can't -- I'm the only person who's ever actually gotten along with my grandmother in the whole family, you know? I get along well with my grandparents. Always have. But, um, you know, my dad is just like, I don't see how you do it. And I told him, I said, you know what, if grandma ever stopped yelling at me, I'd probably be afraid she doesn't love me anymore. I just -- the rest of my family has always railed against her nature, and against her. That's who she is and how she is and how she's always been. And isn't going to do anything to help that view. It's not going to change her any (Lorie, 44-year-old caregiver).”

Some grandchildren were caring for the grandparents simply because they were the only ones available to do it. As much as some grandchildren remarked on reciprocity being the reason for providing care, these grandchildren were struck by what a lack of reciprocity there was, and how they felt that they were having to take on more care than was feasibly fair as a result. They felt it was their responsibility, even when the reciprocity was not present.

“I don't remember a close relationship at all. Like I said, my first grandfather passed away before I was born, so I never knew him. And I was 9, I figured out the other day how old I was when they got married. And I don't remember her ever baby-sitting us. Which, I find kind of -- if you want to talk about being resentful, I guess I could be resentful because I'm like, here she never baby-sat us, and I feel like sometimes I'm baby-sitting her (Colleen, 29-year-old caregiver)”

This following quotation indicates the seriousness with which the grandchildren took their promises to grandparents. The granddaughter speaking actually made a promise to her grandmother when she was only five years old. While the grandmother repeated her wishes to stay out of a nursing home to all of her relatives, it is interesting that the granddaughter took responsibility for making sure that her grandmother’s wishes would be followed.

“She's always -- really, I cannot emphasize enough, she always lived in fear of
being put in a nursing home. I mean, this was an expressed, verbalized fear. This wasn't a one-time thing. This was, she expressed her fear to all of her siblings, she expressed her fear to her only child, she expressed her fear to all of her grandchildren and all her great-grandchildren. You know, this is a very deep-rooted fear. So, um, over the years, I have repeatedly reassured her that I would never let anyone put her in a nursing home (Sue, 34-year-old caregiver)."

The grandchildren who felt the greatest norms of responsibility to provide care were the granddaughters who had estranged, sick, or deceased parents. Those grandchildren who didn’t particularly get along with grandparents also cited a greater feeling of responsibility as their reason to care. As is the pattern with adult children, this feeling of responsibility is coupled with gender role norms and expectations that would dictate that granddaughters rather than grandsons would have a greater likelihood of a feeling of responsibility to provide care (Coward and Dwyer 1990).

*Gender norms among grandchildren*

Gender dynamics among grandchildren providing care to grandparents are similar to gender dynamics among their parents’ and grandparents’ generation. Out of five interviews scheduled with men who were caregivers, only one was able to make the appointed interview time. The remaining four felt too stressed by caregiving, and took breaks from their responsibilities prior to being interviewed. As a result, they did not return my calls to schedule an interview after these breaks. I do not know if they returned to caregiving or not. Therefore, the data presented here refer to only one actual interview with a male caregiver.

*Which grandchildren care: The Inter-relatedness of Sibling Order and Gender*

The most common situation in which grandchildren provided care was for the
oldest granddaughter to be the one providing care. Several of these granddaughters dismissed their younger siblings solely on the basis of age. Sibling order was a larger predictor of care in grandchildren’s rationale than gender, although granddaughters were certainly more likely than grandsons to be their grandparent’s caregivers.

Sibling order became most relevant when the middle generation was unavailable to provide any care. Often, the middle generation had died, leaving only the grandchildren available to become caregivers. In these cases, the caregiver did not often ask their younger siblings to provide any assistance because of their age.

“I started caring for my grandfather five years ago. Right now, I am thirty years old. My sisters are younger than me. They are much younger, and not in a position to do it (Meagan, 36-year-old caregiver).”

Granddaughters also felt that they could not rely on their brothers because of their gender. It was common for grandsons to not have time to provide care due to work, family obligations, and/or distance.

“I don't know if they (my father and brothers) expected my sister and me to take this on, but they just assumed they wouldn't because they lived out of town. So maybe they did expect it because Patty and I were here. And they don't feel bad that we're doing everything and they're doing squat. I don't know. (Mary, 46-year-old caregiver)”

What was interesting was that the granddaughters had these same obligations, but worked around them to provide the necessary care to their grandparent.

“My brother just -- you know how there's always one in the family who does all the work? That's me. I'm really frustrated with my brother. Actually, we got into a huge fight about it because I was taking care of everything, you know? I wanted him to at least help a little bit. He would say he would, but he never would (Laura, 35-year-old caregiver).”

The brother mentioned in the above quotation resented the power that his sister
had over her grandparents’ finances and will, but did nothing, aside from complaining, to remedy the situation. The siblings currently do not speak, and the tension between them has permanently affected their relationship. Previous research on sibling relationships shows a gendered norm that sisters provide the majority of care, and brothers tend to use geographical proximity and work as reasons why not to provide care. However, the granddaughters in this generation may be more hostile to the fact that brothers are not helping than older generations. This may be due to being taught different gender role expectations than previous generations—the girls are not raised to believe that their brothers will be exempt from providing care on the basis of their gender. As a result, the expectation that brothers will help is followed by a deeper resentment on the part of granddaughters when they do not help.

Two themes emerged in reference to future expectations of care from granddaughters. Some granddaughters felt that it had been established within their extended families that they would be several relatives’ caregivers because of their experiences with their grandparents.

“I think that since everyone knows I am a caregiver to my grandfather, everyone comes to me. They are always calling me to get advice from me. It’s a different level. Um, my aunt is sending me papers about her illness and diagnosis, and what is going to happen, what the prognosis is, and she wants to know what is going to happen to her. In terms of knowledge, they want to know what I know about this. They all come to me. My uncle is also doing the same thing. Even my cousins are doing this to me. Because they remember I’m the one with my grandparents (Dawn, 43-year-old caregiver).”

Other grandchildren were clear in limiting their role as the family caregiver to this one caregiving experience. They felt that taking care of their grandparents was going
beyond the realm of usual expectations, and as a result, providing this help exempted them from having to provide any caregiving to other family members as they aged. As one caregiver claimed:

“Well, it's funny, because one of the last conversations I had with my sister, when it was clear things were falling apart, I said, OK, here's the deal. I'm taking care of Grandma. You get Mom and Dad. We kind of divvied it up. I don't think my parents will fare as well. It's karma, what can I say (Kathy, 39-year-old caregiver)?”

This type of caregiving defiance is not seen in the literature on adult children providing care to a parent. This may be a generational shift of filial obligation—caring for one relative was seen as too much of an expectation from other family members, let alone caring for multiple family members over time. At any rate, the granddaughters I spoke to had less of a socialized sense of self as the permanent caregiver to their various family members than what has been written about previous generations. This is not to say that families had less of a socialized expectation of the granddaughter continuing to provide care, as seen in the quotation from Magda.

The gendered patterns of care seen among adult grandchildren mimic those seen in adult children and even spouses who provide care. The granddaughters, as with daughters and wives, are more likely to be informal caregivers (Finley 1989; Miller and Cafasso 1992; Ingerson-Dayton, Starrels and Dowler 1996; Ron 2009). While Brody (1981) coined the term “women in the middle”, her original terminology referred to an adult daughter caring for a sick parent and a child under the age of eighteen. For several of the women in the study, they were caring not only for a sick parent, but also a sick
grandparent and a child. The stresses seen among women in the middle were multiplied for these caregivers.

If one was to expand the Hierarchy Availability Model (Shanas 1968; Cantor 1979) to include grandchildren, the findings from this study indicate that spouses would be on the inner circle of care, adult daughters on the next ring of that care, and adult granddaughters on the third ring of that care. Often, mothers relied on their adult daughters, rather than male siblings, to help provide care when available.

The types of care grandchildren provide

The types of care that grandchildren provided included both instrumental ADL tasks, such as taking grandparents to doctor’s appointments, cooking meals and paying bills for the grandparents, and the intimate ADL tasks, such as bathing, feeding, toileting, and aspirating the grandparents. Both granddaughters and grandsons spent considerable time on these intimate tasks. The comfort level associated with performing these tasks varied according to the gender of and relationship with the grandparents.

The most common caregiving dyad studied was grandmothers being cared for by granddaughters. And, in several of these cases, granddaughters had very intimate responsibilities in caring for their grandmothers. Three themes emerged: the grandparent refused to allow the grandchild to perform the task, the grandparent paid the grandchild for performing the task, or the grandparent was too sick to object to the grandchild performing the task.

Catheter insertions are an example of a particularly personal task, and
grandparents had a fair level of resistance to allowing grandchildren to perform this task. This was seen as more intimate than bathing.

“She (my grandmother), um, has a condition where she cannot fully empty her bladder, so she has to catharsize herself supposedly three times a day. She will not let us help her do that. And so we're in the process now of getting, you know, an advance home care nurse to come do that. Because she's on a regular basis having bladder infections, and I'm sure it's because, you know, she does the best she can at 92, but every 90-year-old person cannot self-cathe, you know (Sophie, 35-year-old caregiver)?”

When personal care tasks could not be avoided, some grandparents elected to make the relationship between themselves and their grandchildren formal, thus setting up a boundary between their roles as a grandparent versus their relationship as a care recipient.

“And another ritual we have that's kind of weird, is whenever I help her with her shower, she pays me $40. And that's something for a lady who, when we go to church, she won't put more than $1 in the basket. ... (Jennifer, 36-year-old caregiver)”

For the majority of grandchildren, intimate tasks were simply part of a long list of things that they did on a regular basis for their grandparents. The ease with which the grandchildren spoke of such intimate tasks reflected how often they had to perform them, and how ritualized these intimacies had become.

“I was asked to do a stool sample a few months ago by one of her doctors. She could not do it. She kept calling us again and again. Finally, I just had to go over there for hours at a time for days and days, until she had a bowel movement and show her that okay, this is how you put it on the sample. She destroyed one of them, because she put it in the refrigerator, which you are not supposed to do, and she had to start over. And, oh my god, she is doing one right now, and if she screws it up we’ll have to do the same thing over again, which is go over and stay there for a couple of days and deal with it (Colleen, 29-year-old caregiver).”
The exception to the rule was from the grandson providing care to his grandfather. While the grandfather currently resides in an assisted living facility, the grandson recalled several times that he did have to bathe his grandfather. Unlike granddaughters, he was comfortable providing this care and the grandfather was zealous in thanking him for the care, which was not mentioned among granddaughters providing this same care.

“He loved it (when I’d provide personal care). He’d always say, oh wow, you’re such a good grandson and everything. He started calling me his son. I said Grandpa, I’m not your son, I’m your grandson. And, he told me that yeah, I know, but you’re so good to me. You’re more like a son (Tony, 21-year-old caregiver).”

The gender dynamics of what a grandparent (especially a grandfather) would expect a grandson to perform, versus what a grandparent would expect a granddaughter to perform, may explain the effusiveness of the grandfather’s reaction to his grandson providing this care. For a granddaughter to do this would be expected in her gendered role as informal caregiver. For a grandson to take on this responsibility may be seen as going above and beyond the prescribed norms of what a man would be expected to do, and thus, the response was much more grateful.

The granddaughters in the study exhibited the same gender norms as previous generations in regard to the expectation that they would provide care. They took on a myriad of personal caregiving tasks that were intimate, time consuming, and hands-on (Horowitz 1985; Miller and Cafasso 1992; Kramer and Kipnis 1995; Dwyer and Coward 1991; Kaye and Applegate 1990; Dwyer and Seccombe 1991; Seccombe 1992; Ron 2009; Brown & Shu-li 2008).
An interesting intersecting dynamic with gendered caregiving is generational gaps in gender expectations. The grandparents often assumed that the granddaughters would be providing the majority of care, even with male spouses or boyfriends present. The granddaughters recognized this generational difference and made allowances for their grandparents. One aspect that was different for adult grandchildren than other cohorts, however, was that adult granddaughters were much more likely to hire out personal family and cleaning responsibilities in order to provide greater care to their grandparents. This hiring out also came in the form of hiring home health aides to perform personal care for their grandparents, especially if the grandparents were different genders than the grandchildren.
Chapter 5: The Grandparent/Grandchild Relationship and Caregiving

How the dynamics of the existing grandparent/grandchild relationship affect caregiving processes of grandchildren

The grandchildren in the study were largely very close to their grandparents growing up. For several of the grandchildren that I spoke to, the notion of not helping their grandparents in a time of need was not even considered. Usually, grandchildren were close to their grandparents because they spent a lot of time with their grandparents while growing up, their grandparents were seen as a second set of parents, and they felt that they could rely on their grandparents while their own parents were going through turmoil.

Grandchildren usually spent weeks at a time with their grandparents while growing up. Usually, this time was voluntary, and was more common for the grandchildren being interviewed than for their siblings. The arrangement that most grandchildren had was one of preferring to spend their spare time with their grandparents, as opposed to having to spend their spare time growing up with their grandparents.

Patterns of triangulation typically seen in three-generation family dynamics were present for these grandchildren as well. It was unusual for a grandchild to be close to a grandparent if the parent was not also close to the grandparent throughout the grandchild’s childhood. Often, the grandchild cited the parent as the pivotal person to allow so much time to be spent with the grandparent. One exception to this occurred with a step-grandparent. In this scenario, the granddaughter grew up knowing her step-
grandmother as her grandmother (she married her grandfather when the girl was only one). However, the girl’s father never felt close to his step-mother, and resented her marrying his father. Upon the grandfather’s death, the granddaughter felt an allegiance to her grandmother (technically, her step-grandmother) that her own father did not feel. Another exception occurred when the grandparent sided with the grandchild on a life choice, thereby alienating herself from her adult children. Subsequently, when the grandmother later became sick, she was estranged from her adult child, and was taken care of by her granddaughter.

**Intergenerational Family Dynamics**

Four general intergenerational family situations defined grandchildren’s role in the caregiving process. In the first scenario, the grandchild was caregiving for his or her grandparent in conjunction with his or her parent also being a caregiver. In this context, the grandchild usually saw him or herself as a respite for the parent, and didn’t define themselves as a primary caregiver. In the second scenario, the parent was alive, but due to his or her own illness the grandchild was the family member taking on the bulk of caregiving duties. Third, grandchildren were taking care of the grandparents because the parents refused to do so. In the fourth context, the grandchild was caring for the grandparent because his or her own parent had died. Sometimes, this loss was recent and unexpected. These four profiles for grandchildren had very different consequences for intergenerational family dynamics.

**Caregiving in Conjunction with a Parent**
For grandchildren who were ‘helpers’ to their parents, the relationship was usually amicable, with shared responsibilities. Often, these parents were single parents, with no siblings available to help in the care. They relied on their adult children extensively.

“My mother is an only child, and um, so actually between my mother, my sister and myself, we rotate pretty much. (Kim, 33-year-old caregiver)”

Because most grandchildren were helping their parents in an informal context, few of them had had a conversation with their parents regarding who was the ‘primary caregiver’. To this extent, grandchildren often felt that they were providing the majority of care, but the parents may claim themselves to be the primary caregivers if asked.

“He (my father) might consider himself the -- well, I don't know. You know, he's taken on -- we sort of divvied up the duties at home in terms of, he pays the bills and he's, you know, he has the power of attorney and, um, that kind of thing. But I'm the one who's here. You know, we've talked about it, and it kind of depends on the context. If it's -- I think if you're talking about her medical needs, he would consider himself the primary caregiver. If you're talking about day to day needs, I think he would say I'm the primary (Debbie, 38-year-old caregiver).”

For those parents who thanked the grandchildren, and treated them as part of a caregiving team, this designation over who was the primary caregiver was not tension-filled. In talking with the grandchildren, it was rare that they had an actual conversation with their parents about who was the ‘primary’ versus ‘secondary’ caregiver. Grandchildren did, however, work with the parents to discuss what they would be doing, what their respective roles in the care would be, and what others’ roles would be. The
families simply did not define this in terms of ‘primary’ versus ‘secondary’ caregiving roles.

Shared caregiving responsibilities between adult children and grandparents are indicative of strong bonds formed among all three generations. Parents who are close to their own parents are more likely to have children who are also close to their parents, hence the multi-generational caregiving (Rossi and Rossi 1990; King and Elder 1995; Sassler, Cunningham, & Lichter 2009; Fruhauf, Jarrott, & Allen, 2006; Fruhauf and Orel 2008). Researchers consider this type of intergenerational triad ‘connected’, where the grandparent, parent and grandchild are all cohesive (Goodman and Silverstein 2001; Goodman 2007). In families where connectedness occurred throughout the grandchild’s childhood, those grandchildren are invested in being part of the family unit providing care to an ailing grandparent.

Caregiving Because of Parent Refusal to Care

This sense of shared responsibilities and camaraderie was not found with grandchildren who were providing care to grandparents because their parents refused to care for their parents (or in-laws). The triangulations in the intergenerational conflicts were two-directional. In some circumstances, the parents did not have a relationship with their own parents (or step-parents), but the grandchildren had a relationship with both their parents and grandparents. In other cases, the middle generation was estranged from the grandchild, but not from the grandparent. In these cases, although they were
estranged from the parents, the grandchildren still needed to be in contact with the parents because of the grandparents’ condition.

“The funny thing is, I could totally imagine her (my mom) saying that she’s the caregiver. She is constantly talking about how she is so overworked, that she is taking care of her parents, her children and her grandchildren…by living here, she gets to say that she is caring for me, although I am the one who is actually helping her take care of her parents, and I am the one taking care of the grandchildren (Angela, 32-year-old caregiver).”

Some grandchildren acknowledge with frankness that their own parents are simply not fit to be caregivers to their grandparents. These grandchildren recognize that they are taking over the care not because the parent is unavailable, but because the parent is unable to do the work required. Sometimes, being the grandchild, rather than the child, is enough to warrant taking over the care.

“Well, um, my mom is kind of a laid-back person, you know? And, um, she's not really assertive about things, and making life decisions for her mother, I don't think she could really handle. My dad, you know, my dad thought it would be best that I do it. I mean, it's like, um, I take her to all the doctor's appointments, I do all of that. They call me. Now, a couple of times when I couldn't take her and my mom had to take her, they couldn't even, you know, when I get talking, what did he say? They can't even tell me what's going on, you know? I feel because of the removal in generations that sometimes I have an easier time because even though it's difficult for me, I'm not so tied to all the memories of childhood with her and I can just focus on what's happening right here and now and what's the best thing for her and what's the best way to take care of her (Melissa, 29-year-old caregiver).”

These patterns of triangulation are typical of intergenerational dynamics. For some grandchildren, the source of strain was between them and the middle generation (grandmother-linked), and in others, the grandchild had a relationship with both his or her parent and grandparent, but the grandparent did not have a relationship with his or her
adult child (grandchild-linked) (Goodman and Silverstein 2001, Goodman 2007). Past research suggests that these types of links would be more stressful for the varying generations, and the discord seen between the grandchild, grandparent and the absent middle generation were good illustrations of this. Grandchildren resented when their parents were able to provide care, but chose not to.

**Caregiving Because of Parental Death**

In the final situation, the grandchild’s parent died, leaving the grandchild as the sole caregiver. Some grandchildren lost their parents at a young age, and others were still coping with a recent loss. In this scenario, the grandchildren did not grow up with their grandparents as parent figures, and were often still adjusting to the loss of their parents. Subsequently, their grandparents were also still adjusting to the loss of their children. The added burden of having to grieve for a parent while also providing care to the grandparent came in many forms. Some grandchildren resented having to hear stories about their parents, some felt that they could not replace the care their parents gave. Having to relive the grief of loss with the grandparents on a daily basis was an added strain for several grandchildren.

“Um, I think in the beginning it was good (hearing about my mother), but then after a while, I guess you get ... I mean, I guess it becomes weary when everything is always about her perspective and what she's lost. Because that's really what the focus of it is always about (Stephanie, 29-year-old caregiver)”

Rather than being able to rely on the grandparents to help them process the loss of their parents, these grandchildren were put in a role of having to help the grandparents process the loss of their children. The sense that their loss was somehow greater than the
grandchild’s loss was a difficult situation for grandchildren to be in. They often felt that the grandparent did not take into consideration the sacrifices that the grandchild had to make by providing the care to their grandparent in lieu of the parent doing so.

Often in this case, the grandchild had no sure understanding of whether the parent would have wanted them to be providing care for the grandparent. Because these deaths were usually unexpected, the grandchildren often had no legal documentation in place to be the caregivers to their grandparents, and did not have any understanding of the grandparents’ wishes or finances.

“When my mother first passed away, it made me very resentful toward my grandmother. Because, my mother was only 56. And here my grandmother, you know ... And it makes me miss her and sometimes -- I don't feel the resentment as much towards them, but I do ... I do wonder why. Why are they so old and getting more and more dependent everyday, when, you know, my mother's gone (Sarah, 39-year-old caregiver)”

For these grandchildren, the loss of their parent is often rife with confusion and even anger over the burden of having to care for their grandparents. This was a common theme for grandchildren who had recently lost their own parents, and the anger that they exhibited was directed both at the grandparents for outliving their parents, and at their parents for leaving them with such a responsibility.

“To me, I just feel it's something that I'm meant to do, I guess, is the way I can say it. I feel that -- I curse my mother once in a while and say, thanks a lot, Mom, you know (Liz, 31-year-old caregiver)”

This theme of loss as part of the caregiving experience is largely absent from the literature on adult children and spouses. The normalized assumption that an adult child will take on that role is one that prevents the same amount of discord that occurs when the adult child dies and a grandchild is left to care. The absence of that middle generation signifies a much different loss than a spousal loss. Losing one’s child not only is difficult for the grandparent, but also compounds the grief for the adult grandchild.
How Caregiving for a Grandparent Changes the Grandchild/Grandparent Relationship

The grandchildren studied were acutely aware of changes that necessarily had taken place in their relationships with their grandparents as a result of caregiving. Grandchildren often missed the relationship that was present before the grandparent became ill, and felt very sad for their grandparents. The four themes that emerged in regard to how the relationship between the grandchildren and the grandparents changed included role reversal, the grandchildren making the decision making, a crossing of intimate personal space due to caregiving, and the grandparents’ fear of being a burden.

Role Reversal

It was a change in protocol to have to be the one ‘parenting’ grandparents. The grandchildren often had to tell the grandparents sternly what to do, and could not take too much time to think about how that may be hurting the grandparents’ feelings if the grandparents’ safety was at stake. This was a definite change in their relationships.

“Well, um, it's . . how do I want to say it. It's more -- I feel like I have to be more forceful with them. Like, because she won't take her medicine sometimes and I'm like, Grandma, you know -- it would be things that I wouldn't even concern myself with, but if I don't, there's nobody else to concern themselves with it. You know? So I think I have to -- the other day, I had to basically try to bribe her, yell at her, do anything to her, you know, to try to get her to get up out of bed because she didn't even want to get out of bed. That's a new thing we're working on now in the last couple of weeks, so, you know, I have to be, I can't be just their granddaughter, you know? Now I have to be, like I said, I have to be more forceful with her (Heather, 30-year-old caregiver).”

Decision Making Left to Grandchildren
For several grandchildren, a deep change in their relationship with their grandparents was the fact that the grandparents were uncomfortable making decisions about their own care, and left this largely to the grandchildren. This sometimes was due to the grandparent having Alzheimer’s Disease, but even in the absence of this, the grandchildren still made the majority of decisions regarding their grandparents’ care.

“I don't want to ever hurt her feelings, but if came between her being safe or being cared for, like, I would be honest and tell her. Like, with the assisted living stuff, I sort of brought it up over a six-month period and when the day came, I said, you know what? I can't leave you here and that's it. And I just didn't really give her a chance to argue about it. I just said, we're getting a truck and you're moving. ... I actually think she felt relieved because I think it was a decision she hadn't wanted to make. And like I've done a lot of research online, and a lot of -- just reading about different things, and one of the assisted living facilities that I went to look at before I even brought it up to my grandmother, I said, well, you know, she said, well, when does she want to come up? And I said, well, that's kind of difficult because I don't know. And she said, well, sometimes they want somebody to make the decision for them. And I've really found that to be true of my grandmother. If I really am assertive about it, she seems to go with it much easier and be so much more comfortable if I'm comfortable with it. If I kind of go back and forth a little bit, then she's uncomfortable (Karen, 38-year-old caregiver).”

**Intimate Personal Space Barriers**

A major change in the roles of the grandparent/grandchild relationships once caregiving took place was that often, the grandparents needed intimate personal care as a result of their illnesses. This level of personal intimacy was uncomfortable for many grandchildren and grandparents, and it was something that they tried to avoid.

There was a definite gendered norm of behavior for grandchildren and their grandparents’ personal space. While grandmothers were more willing to be personally bathed and cleaned by their granddaughters, granddaughters elected to hire outside help
to bathe their grandfathers. For some granddaughters who were involved in the intimate care of a grandmother, the grandmothers insisted on paying the grandchild specifically for that care, therefore maintaining a personal separation in the roles of grandchild versus caregiver. The grandson who was interviewed did not have this same feeling of taboo, and his grandfather expressed no discomfort over having his grandson bathe him.

Grandparent’s Fear of Being a Burden

Some grandchildren felt that their grandparents felt a burden of responsibility placed on the grandchildren for having to take the care. Grandchildren often spoke of how their grandparents acknowledged the care that they received. While grateful for receiving this acknowledgement, it served as a reminder to grandchildren about how their relationship with their grandparents had changed due to caregiving.

“I help them and, you know, they thank me. And that's the one thing that they just recently started. Grandma not so much lately, but a couple months ago, she was, you know, do you know how much I thank you for doing this, how much you've helped us and everything, you know. And that, not that I expected it, but that was a nice thing for her to say, you know (Tracy, 36-year-old caregiver)?”

This acknowledgement came in two forms: First, as discussed above, thanking the grandchildren. Second, grandparents often apologized to the grandchildren for being such burdens on them. This was both appreciated and dreaded by the grandchildren, who did not want the grandparents to feel like they were a burden. Having to reassure the grandparents was something that grandchildren took seriously, often dismissing their own burdens of caregiving in order to spare the feelings of their grandparents. The grandchildren felt protectiveness toward their grandparents. The following three
quotations illustrate the myriad of ways that the unfairness of the situations, and the guilt that grandparents feel from having to rely on grandchildren is verbalized.

“And another thing is that I try to shield that from my grandmother because I'm afraid that if she thinks that -- she's always worried that she's being a burden, but I think sometimes she doesn't tell me about things that are wrong because she's afraid of being a burden so it ends up being more of an emergency situation later. So I always try to shield that from her. Like, oh, it's no big deal, you know (Kristen, 37-year-old caregiver)?”

“I think in some ways, I think she tries harder than she would with my mother because she knows that it's not a fair position for me to be in. She does recognize that. And there's nothing she can do about it. But, you know, sometimes she says it verbally, but, um, I guess I would just like a little more acknowledgment from her, but she does recognize that I'm the one that's stepped up to the plate and I'm the youngest family member and I'm the one who's been there for her. And so she tries to make it as easy on me as possible sometimes. But then if I don't go see for a week, then she definitely puts on a guilt trip Lisa, 22-year-old caregiver).”

“As a matter of fact, just recently, my grandmother made a comment to me to the fact that she wasn't going to be around too much longer and that kind of thing, "I don't want to be a burden on you" and that kind of thing. I try not to -- I really try not to, when she's around, not to let it out (Jackie, 35-year-old caregiver).”

The grandchildren in the study felt that their relationship with their grandparent changed in a myriad of ways because of having to provide care to them. Similar to the other study which exclusively sampled adult grandchildren (Fruhaut, Jarrott, & Allen, 2006), the biggest change that the grandchildren felt as a result of providing care to a grandparent was role reversal. Regardless of whether it was easy or difficult for grandchildren to take on this responsibility, they actively set limits with their grandparents, told them what needed to be done, and took charge of the minutia of the grandparents’ days.
This role reversal was more pronounced for grandchildren than for adult children because the majority of the grandchild’s life was as a child in the grandchild/grandparent partnership. To have to relinquish that embedded relationship was difficult for grandchildren to do, but a necessary part of providing care. Many grandchildren felt sadness over having to give up the previous child-like qualities of their relationship with their grandparent.

**Chapter 6: Negative and Positive Effects of Providing Care**

*Negative Effects of Providing Care*

The grandchildren in the study experienced a multitude of negative effects of providing care to their grandparents. Interviewees were at an earlier stage of the life course than adult children or spouses who provide care, and this resulted in a number of unique negative stressors for grandchildren. This section will discuss the types/extent that secondary role strains compete with grandchildren’s caregiving responsibilities, the financial/legal responsibilities that grandchildren have toward their grandparent’s care, and the manifestation of stress within adult grandchildren.

*Secondary Role Strains*

*Caregiving and Work*

The interviews that were conducted with grandchildren focused on several work-related questions. The themes regarding work were reflective of the larger caregiving
and work themes prominent in caregiving literature. These themes included whether or not grandchildren disclosed their caregiving status to co-workers, whether or not grandchildren felt supported by others at work in reference to caregiving, formal supports and policies provided to grandchildren at their jobs, issues of job promotion/advancement and caregiving, the balance between work and caregiving, reducing hours or quitting due to caregiving, and caregiving as an alternative to participating in the formal work force.

**Disclosing one’s caregiving responsibilities to co-workers**

Granddaughters providing care to grandparents had mixed feelings about whether to tell co-workers and bosses about their caregiving responsibilities. Often, they felt obligated to tell their boss, even if their other co-workers did not know. The reasons for disclosure to their bosses included accounting for lost time at work, assuring the boss that they were capable of combining these two roles, and to squash rumors that the granddaughter herself was sick.

“My boss knows. Basically I had to tell him just because of, you know, I didn't want him to think that I was being irresponsible, like I'm going to be out every Tuesday afternoon for the next eight weeks. You know, people start to think you're seriously ill. And I'm like, no, it's not me. I'm fine. I just basically felt it was going to hurt me more if I didn't tell him (Rachel, 27-year-old caregiver).”

For many caregiving granddaughters, disclosure to others at work became necessary, because their grandparents often called them during work. This especially presented a challenge to those grandchildren providing care to grandparents with dementia, as they had several interrupted moments due to phone calls. As Denise, one granddaughter, commented:
“Work, well, it conflicts with what my grandfather thinks I should be able to do is one way I could see it. Because he expects me to be able to do, like he called me at work one time, and I was like, if somebody calls me at work, it's gotta be an emergency. But it wasn't. He just called because he knew I was at work and wanted to make sure -- I don't even remember what the case was (Denise, 39-year-old caregiver).”

This occurred both for grandchildren who were in professional jobs, and for grandchildren who were in college. Often, the grandchildren attending college found it very difficult to sit through classes with their grandparents calling. These granddaughters found it necessary to alert their teachers of their caregiving, and if necessary, drop classes if there was a strict cell phone policy.

“My grandfather’s assisted living facility will call me during class and tell me that I have to make a decision, or something like that. Or, just tell me the status of my grandfather. The teachers hate it if a cell phone rings. I keep it on silent or vibrate, but they still hate it. Some teachers will ask in the beginning of the semester if anyone is on health or on call- some of the teachers will ask that (Tony, 21-year-old caregiver).”

Solutions to the disruptions at work and school occurred at the individual level rather than at the larger structural level. No grandchildren asked for accommodations from their bosses for these disruptions, and all considered the conflict between their professional lives (be it a job or as a student) and their grandchild status as personal, and a source of discomfort while performing their jobs.

Work as a Support System Granddaughters providing care to a grandparent felt like they were part of a larger caregiving support system because of their jobs, or felt that they did not want others at their jobs (aside from their supervisors) to know their caregiving status. This correlated with whether they were surrounded by other
caregivers, and whether the granddaughters were comfortable talking about their personal lives. For example, Patty, a 40-year-old state worker, felt supported by co-workers:

“Actually all of the people in my office have some parent or family member they are caring for. Our secretary, her 92-year-old mother lives with her. My immediate boss, her parents are in her 80s and she is one of the two closest family members in the area. One gentleman who works with us—his mother is 72. My boss’s boss has a 92-year-old mother in her home that she cares for. And, her brother has esophageal cancer, and he’s not well, but she’s caring for him, too. With health, everyone gets it, and there is no need to explain. And, it’s not something that I was initially aware of when I made the move, either. It happened to be a random coincidence that we were all in that kind of boat (Patty, 40-year-old caregiver).”

Even when grandchildren did have supportive work environments, it is important to note that they made a distinction between telling trusted friends at work versus publicly defining themselves as caregivers. This disclosure usually came after friendships were made at the office. This selection factor reveals the inherent professional risks that caregivers face when disclosing their caregiving responsibilities at work.

“I have lunch with some girls every day, a couple of the programmers. And so it's like the girls lunch. It's almost like a therapy group in a way because I tell Grandma stories. They're like, oh, have you got any Grandma stories? OK, well, let me tell you this one, you know? And then one of the other ladies, her mother has Alzheimer’s. So she, you know, she'll tell us about leaving her mother at the hospital. So, I mean, it's just sort of a known thing within my closer circle. It's not like I go to meetings and have a badge on or something (Mary, 46-year-old caregiver).”

For other granddaughters who did not disclose, they found the separation between work and caregiving to be a welcome respite. This is consistent with caregiving literature that reveals that caregivers often use their jobs as a break from caregiving (Pearlin et. al, 1990).

“I don't -- I'm not the type of person, I don't like to let my problems affect other aspects of my life, so it's kind of refreshing for me to go to work and not have to
talk about it (Julie, 40-year-old caregiver).”

Formal Supports and Policies Provided at Jobs The formal supports and policies provided at granddaughters’ jobs became their barometers for judging the caregiving friendliness of their work environments. Unfortunately, the majority of caregivers felt further isolated when seeking formal support through their professional jobs, because most formalized programs were aimed at child or spouse caregivers rather than grandchildren providing care.

“You know, like I work for a large corporation, and they offered what they call a ‘lunch and learn’ where they have a speaker come in to talk about, um, caring for your elderly parents. And I mean, I realize that that would reach more people than it would, you know -- but I think at some point you start to feel so isolated because they’re no support for you (Marybeth, 48-year-old caregiver).”

This isolation was also apparent with the lack of leave time available for grandchildren to take off from work in order to provide care to their grandparents. No granddaughters in the study were able to rely on any formal benefits or leave time for the purpose of taking care of their grandparents. Most grandchildren were not even aware of leave time as an option. The following was a typical exchange that I had with interviewees:

“Me: At work, have you ever tried to receive legal benefits because of taking care of your grandparent?
Interviewee: No.
Me: Okay, so you have never, for example, had them listed as a dependent on your health insurance; used family sick leave to care for them; used your flex-benefits to have tax deductions based on care for them?
Interviewee: No.
Me: Is that because it is not available, or because you didn’t think you needed it?
Interviewee: Because it is not available.”
This exchange is particularly revealing because it indicates the rigidity of workplace policies that address family issues. The workplace policies that exclude grandchildren as protected individuals in caregiving realms are a reflection of the federal Family Medical Leave Act of 1996, which extends coverage to children providing care to parents, parents providing care to children, grandparents providing care to grandchildren, but which does not provide coverage for grandchildren caring for grandparents.

*Job Promotion/Advancement and Caregiving* Caregiving literature focuses on the fact that caregivers are often forced to take time off from work to provide care, and those who return to work are more likely to earn lower wages, have a “benefits-poor” job, and reduced retirement benefits (Dettinger and Clarksburg 2002). This impact is seen more dramatically for women than for men. Women are more likely to state that their supervisors make it more difficult for them to manage their work and caregiving responsibilities (Scharlach and Fredriksen 1994), and therefore find caregiving to be more stressful, and are more likely to quit a job due to caregiving responsibilities. Female caregivers are more likely to decrease their work hours to provide care. They are more likely to be passed up for a promotion, training or assignment. Further, caregivers are more likely than their non-caring counterparts to take a leave of absence from work, switch from full-time to part-time status, quit their jobs or retire early (Health and Human Services 1998). This pattern was visible with the grandchildren who were caregivers in this study. For the most part, grandchildren tried not to turn down promotions, but it was a struggle to accept or compete for promotions while caring for grandparents. The end
result is that these caregivers were under-performing at their job.

“I was given an incredible opportunity at the beginning of this year, um ... it was part of a nationwide leadership program and I was selected for my leadership potential. And, um ...at the same time, you know, my grandmother's needs really increased. So ... I haven't done as much as I wanted to. I feel like I’ve really wasted a fabulous opportunity, and my professional reputation is at stake (Colleen, 29-year-old caregiver). “

**Balance Between Work and Caregiving**

Because grandchildren were in the beginning stages of their careers, quitting full-time work was often not an option. Not only did grandchildren not wish to quit their jobs, they also stated that they could not afford to quit. However, this is not to say that the grandchildren did not feel the stress of trying to balance work and caregiving.

“Um, the responsibility of it, um, the ... feeling like there's -- I don't know. Always having to choose, um, you know, if I do the caregiving the way I want to do it, then I'm falling behind at work. And if I'm, you know, not falling behind at work, then I feel like I'm neglecting my grandmother. And so, just that wanting. I mean, I really love caregiving in many ways and, um, if I could, I would do more of it because it's very satisfying. But, financially, I have to work, and so, um, in some ways I can't do as much of it (Laura, 35-year-old caregiver).”

Strategies that grandchildren employed included hiring out domestic responsibilities, hiring out caregiving responsibilities, working on weekends, and relying on friends and family members to help with the care of their grandparents. These strategies were often utilized for job security and to appear competent for job promotions:

“I have not had to turn down any promotions, but the reason that I hired somebody to take her to the doctor was I was concerned that I wouldn't get a promotion if I was going to be out of the office as much as I was at the time. Even though no one said anything to me about it, I just felt that, you know, if you're going to give a promotion, you're not going to give it to the girl who's leaving early every week (Debbie, 38-year-old caregiver).”
The amount of hiring out grandchildren had to do in order to maintain normalcy at work was notable. Grandchildren hired drivers to take their grandparents to doctors’ appointments, they hired housekeepers to care for their homes, they hired companions for their grandparents on days that they would be working late, and they even hired gardeners so that they would have more time to spend with their grandparents after work. The expense of this care often fell to the grandchildren, and was seen as a cost incurred by them, rather than the grandparents, because it was their ‘choice’ to work. This often compromised family budgets.

“I spend so much money paying other people to take care of what I need to do—it’s just…sometimes, I wonder why I work at all, you know (Sue, 34-year-old caregiver)?”

When grandchildren were forced to rely on other family members to help care for their grandparents, it was most often their spouses that they asked to help. This was an interesting dilemma, as most of the spouses were male, were not skilled at nursing, and did not know how to care for the grandparents in the same way. Also, the grandparents preferred the care of the granddaughters, not the granddaughters’ spouses, and the gendered generation differential for grandparents and granddaughters made this demand a source of stress for granddaughters.

“There are many times in the year that I need to be there (at work). For example, last Thursday, I was at work until 1 in the morning. But, at 5:00, my husband and I met up, switched cars, he took my son and grandfather home, and I went back to work. You know, so when I have to, I do. When I can, I do. And, there are some weeks when we’re doing 80-90 hours, and it can get crazy. It’s an expectation. My grandfather cannot understand this, and cannot believe that I would be working until the middle of the night (Meagan, 36-year-old caregiver).”

Reducing Hours or Quitting Due to Caregiving

Grandchildren who reduced
hours or quit their jobs due to caregiving responsibilities usually did so as a last resort. This was often done without a lot of preparation, and the stress and financial strain that the granddaughters (and their families) felt was immediate.

“I was working part time at a law firm and, uh, with all their doctor's appointments I brought them to, it conflicted with work. Because a lot of times, the doctor could only see them on a Friday, and that's all I worked was Thursdays and Fridays. So it got to the point where I had to quit (Tracy, 36-year-old caregiver).”

The above quotation relays the frustration that several grandchildren stated with the geriatric professionals caring for their grandparents. Doctors’ offices were often unwilling or unable to juggle appointments to accommodate the schedules of grandchildren who were working. For some grandchildren, quitting work became their only option. Quitting a job, however, was not the norm for most grandchildren- this was a costly and usually reactionary measure for grandchildren to take.

The patterns for grandchildren having to reduce their hours to part-time or quit their jobs due to caregiving responsibilities mimics the patterns seen with older cohorts. Women who are caregivers are often likely to feel that their supervisors make it difficult for them to balance work and caregiving (Scharlach and Fredriksen 1994), they are likely to have to take time out of their career to provide care (Family Caregiver Alliance 2003; Masuy 2009) and were overlooked for promotions because of their caregiving responsibilities (Dellman-Jenkins, Blankemeyer, and Pinkard 2000).

*Caregiving as an Alternative to Participating in the Formal Workforce Some*
grandchildren were working as the family caregivers and accepting pay from their families to provide this help. This was a fascinating paradox, because these grandchildren often left lucrative careers to become caregivers. In these cases, the grandchildren often regretted their decisions, and the long-term ramifications of dropping out of the workforce at a young age provided an additional level of strain and worry.

“I had gotten laid off from my job, and for personal and financial reasons, had to move back home. I wasn’t working, and I found that my grandfather needed the help, and didn’t trust someone he didn’t know to help. He pays me $300/week to be the caregiver to my grandmother. Truly, $300 is not a lot of money. It’s barely enough to live on. And, my grandfather acts like the $300 is so much money. He wouldn’t even dream of giving me a raise. And, since he is paying me, I really am stuck doing this all the time. I just feel like day in, day out, I am doing the same thing, and sometimes it is hard to see everyone else getting to go out, have their breaks, and then come back- and I am here all the time. I am worried about my long-term career. I don’t have any benefits with this job, no retirement, no health insurance- and, it’ll look like I’ve been out of work for a very long time. You know, this sounds horrible, but I already know that when she dies, I won’t have time to sit back and feel sad and grieve- I will be out of work. My grandfather won’t give me $300 for any time after she dies, so it could happen at any time. She could die tomorrow, she could die a year from now- but, when she does die, I will have no income. Period (Sophie, 35-year-old caregiver).”

Long-term ramifications, as shown through the previous quotation, included the grandchildren’s health coverage, retirement benefit accruals, a lack of unemployment coverage if the grandparents died, and having large gaps in formal work careers. Granddaughters being paid for caring for their grandparents felt especially taken advantage of. The combination of no paid vacations, no respite from caregiving, no job security and low wages made caregiving for grandparents extremely stressful. At the same time, because informal arrangements were made with family members, these grandchildren often found it difficult to impossible to remove themselves from being the
paid primary caregivers for their grandparents.

The precariousness of this situation for grandchildren was different from the choice for spouses to retire early from work to care for their spouses. Grandchildren are at a younger age, have fewer savings to help supplement the pay given by family members to provide care, and have more long-term consequences of taking time out of the formal work force than do older caregivers who choose to retire early (Dettinger and Clarksburg 2002).

_Caregiving and Romantic Relationships_

The grandchildren who were interviewed were engaged in a broad spectrum of romantic relationships. Themes that emerged included: 1) grandchildren who were consciously avoiding romantic involvement because of their caregiving; 2) grandchildren who were trying to date (but not in a formal relationship) while caregiving; 3) grandchildren who had started caregiving while in a formal romantic relationship that had since dissolved, 4) grandchildren who had started caregiving while single and since had started a serious romantic relationship, and 5) grandchildren who were in a formal romantic relationship prior to the start of caregiving, and were still in that relationship. All grandchildren, regardless of their relationship status, agree that their caregiving responsibilities compete greatly with their ability to be active participants in romantic relationships.

_Avoiding Romantic Involvement While Caregiving_ There were several grandchildren who made a conscious decision that this part of their lives would be
devoted to caregiving, not relationships. Grandchildren often felt limited in the amount of time they could give a new relationship, and/or embarrassed by the family dynamics due to their grandparents being sick. These grandchildren acknowledged that they may be altering their future life courses by deciding not to date at all, but did not see any alternatives.

One caregiver moved to a rural location to accommodate living closer to her grandmother’s house. This move has restricted her abilities to date:

“I mean, I still see some guys sometimes, but nobody's like -- I kind of live in the sticks, so nobody comes by. So it's different. And it's different moving to an area that you're not used to, being a rural area, and not having a lot of social opportunity other than, you know, like the local bar. I'm not a big drinker and a lot of the people in the area -- demographics in general, it's a higher environment. There are not a lot of single guys that are worth hanging out with. I know that sounds mean (Kristen, 37-year-old caregiver).”

Grandchildren were surprisingly candid about the embarrassment they felt from their grandparents. Often, grandparents needing care had mental health issues, and inappropriate comments from grandparents were frequent. A way to deal with this was to either avoid bringing dates home, or avoiding dating altogether.

“Well, I'm just not comfortable bringing people I date home. I mean, I've done it in the past and, um, my grandmother sometimes says really inappropriate things. And you know, it's just not overly comfortable and it's not comfortable for me, so I just tend to do avoidance (Michelle, 19-year-old caregiver).”

The following quotation is another example of a granddaughter who was not actively seeking someone to date, due to the overwhelming job of taking care of her grandmother. While her grandmother was not the direct reason this granddaughter was not dating, she still expressed thanks that she was not trying to combine these two roles.
“I’m really glad that I’m not looking for anyone. She’s not the reason, but if I was looking for someone, she would be a really big deal, and a big pain to deal with if I wanted to be looking for someone. Because, whoever it was would have to put up with the fact that I have no free time, that I am with her constantly, that I talk about her constantly and I bitch about her constantly. They’d have to be somebody that would be nice to her and be able to deal with her on a regular basis. So, that’s not the reason, but I am really glad that I am not dating anyone or looking for anyone because she would make it a heck of a lot harder. I cannot imagine what would happen if I had a boyfriend! I’m thinking I wouldn’t tell her about it (Christine, 22-year-old caregiver)!”

Grandchildren who were avoiding dating were resentful of their caregiving roles, and felt that they literally had to make a choice between their own social lives and their grandparents’ needs. As a result, they often felt that they were not going to find anyone, and this served as a source of depression for them.

The isolation that these grandchildren felt as a result of their caregiving parallels the role engulfment that occurs with spouses. When a grandchild isolates themselves from finding new relationships, along with isolating themselves from friends, the encompassing nature of caregiving can be overwhelming (Dautzenburg et. Al. 2000; Neal et.al. 1997). Unlike adult children or spouses who feel that they do not have time to provide care to grandchildren and children because of caregiving (Campbell and Martin-Matthews 2000), these grandchildren miss the opportunities to forge new relationships.

**Dating While Caregiving** Not all grandchildren who were single chose not to date at all. Some grandchildren did actively date while also caring for their grandparents, although their availability for dating was very limited. A consistent theme was that grandchildren who were dating did make it clear to prospective mates that their
grandparents were not a negotiable part of their lives, and that to date them essentially meant to also put up with the time restrictions that caregiving caused.

“I just make it clear up front, this is what I have to do, you know, before any kinds of feelings and emotions get involved. And if you can't handle it, then there's no use to me in taking it any further. Because this is where I am right now. You have a choice to decide whether you want to be here with me or not. And if you don't then that's, you know, I have to respect it (Liz, 31-year-old caregiver).”

The means of communication while dating are qualitatively different for caregivers. Grandchildren freely admit that they do not have a lot of time for face-to-face dating, but do manage to converse in the absence of face-to-face contact. Unfortunately, for beginning relationships, this mode of communication, while keeping the relationship going, does not appear to move the relationship to a more serious level. The following quotation exemplifies the truncated time that grandchildren are able to devote to new relationships:

“I have not seen him since -- I got together with him about a month ago. I mean, we emailed a couple of times. We talk once in a while on the phone, but he's living his life, and I'm taking care of my grandmother (Patty, 40-year-old caregiver).”

Other grandchildren were able to maintain serious monogamous relationships with others, but because of their caregiving responsibilities, had very limited time to devote to the relationship. The grandchildren knew that this was a lot to ask of new partners, but did not have any power to change their schedules or find respite from caregiving in order to spend more time dating.

“My boyfriend knows that the only time I have to spend with him is on Saturdays, IF my sister comes in. And, he just has to know that is my only time for him. I would really like to have more time to spend the night at his house, things like
that— it doesn’t really happen that he can come here because I am with my parents and grandparents (Angela, 32-year-old caregiver).”

This is not to say that romantic relationships never move to a more intimate level due to caregiving responsibilities. Several grandchildren did solidify romantic relationships that started while caregiving. Their explanations of how their relationships fit in their lives, in conjunction with caregiving, are very structured. Systems for making time for their significant others, as well as dividing the time that they must spend caring for their grandparents, become part of caregivers’ realities when moving to the next relationship level. Almost all caregivers conveyed a wish to have more time to devote to relationships.

“So, I never said it in so many words, but it was clear from the beginning of our relationship what a big part of my life she was and how important she was to me and how much I love and respect her, and if he wasn't going to love and respect her in the same way, then there wasn't going to be a relationship. So, yeah, I think that was there from the beginning. And then, once he moved in, um, you know, I think we handled things in a systematic in terms of, we didn't always have all those things split up as nicely as we do now (Karen, 38-year-old caregiver).”

Perhaps the starkest example of this clash between caregiving and being in a romantic relationship was revealed during an interview with a caregiver who married her boyfriend once she was already a caregiver for her grandmother. At the time of her marriage, she had already been caring for her grandmother for a number of years. Stress between her brother and parents had mounted during this time, and she was estranged from them. She had to make a decision of whether to include her grandmother in her wedding plans.

“My family was not there (at my wedding). I mean, I had a ceremony and all that.
Because my husband's family really wanted that. So I mean, I walked myself down the aisle. My brother wasn't there. Nobody was there from my family out of 35 people. Not only that, but that (talking care of my grandmother) was one of the reasons why I decided to go far away, because otherwise she would have wanted me to go pick her up and drive her. Because at the time she didn't live near me. And it's kind of like, that's not fair. Like, it's my wedding day. I can't worry about getting married and be worried about you and how you're going to get home. That was just like too much for me (Laura, 35-year-old caregiver)."

Previous research on role strains and caregiving fails to address the formation of new relationships, and the strain that providing care puts on this aspect of one’s social life. For many grandchildren, the strain is not from established relationships, or that they don’t have time for current family members. Their time crunch comes in the form of fewer dates, fewer opportunities to nurture new relationships, and fewer opportunities to be intimate with a dating partner. The combination of stage of the life course and intergenerational norms of how much intimacy during dating is appropriate all lead this topic to be relatively unstudied with older caregivers.

*Breaking Up Due to Caregiving* It was more common for grandchildren to feel very strained in their relationships, and on the verge of breaking up, than to actually have had a break-up due to caregiving responsibilities. One caregiver who did break up with someone explained that she could not end her caregiving responsibilities simply because her grandmother’s ‘caregiving crisis’ had passed.

“When I was with somebody at first, and they were with us during the time when she was really sick and everything. And as a matter of fact helped me with her. We were staying at her house and everything. Grandma's house. And, you know, when she got a little better, he was putting the pressure on me. Well, you need to do this, you need to do this. So, you know, that was the end of the relationship (Kim, 33-year-old caregiver).”
Changes in Long-term Relationships Due to Caregiving

The resounding theme in the changes in long-term relationships due to caregiving was not having as much time to do things independently as a couple. Grandchildren who provided care to their grandparents missed the camaraderie and friendship that once defined their relationships. Caregiving took the spontaneity out of relationships. The following quotations are from various grandchildren, and collectively, they speak to the theme of the loss of leisure time with others.

“Well, it's (caregiving) definitely stressed it (our relationship). Yeah. For sure. Time. Uh, freedom. You know, the ability to just go off and do what we want. One of the two of us has to stay. I mean, it sounds stupid, but I'm like, oh, you want to go grocery shopping with me? It would just be an excuse to spend time. Now it's not really an option. Somebody has to be around. And so that gets a little tiresome. Like, oh, we might go over to Costco or something, the big warehouse store. And now we can't really do that, you know? So it's felt a lot restrictive. (Julie, 40-year-old caregiver)”

“Well, you do have to give up a lot. My husband and I used to play volleyball together sometimes and I had to give that up (Karen, 38-year-old caregiver).”

“I miss the ability to go out on a moment’s notice, the idea that you have to put someone else’s needs before your own, that you have to consider someone else’s schedule before you plan your own schedule, that kind of thing. I miss going out to restaurants more frequently. We used to that more before my grandfather was with us (Jennifer, 36-year-old caregiver).”

“Well, I mean, in some ways, we've grown much closer, but in other ways, like, you know, my husband has said he feels like we never get a fair chance to just do our own thing (Sue, 34-year-old caregiver).”

“Like I went out of town for my anniversary, just three days, and I think I had five messages on my voicemail from her (Lynn, 44-year-old caregiver).”
Several grandchildren who had their grandparents living with them and their partners had to adjust to the lack of privacy within their households. This resulted in a combination of awkward moments and halted sexuality for the grandchildren.

“We decided to put a lock on the bedroom door because it's a little weird having your grandma walk in. And I'll joke, if we don't move, she can't see us. So we laugh about it, but it is sort of awful. Like we were taking a shower together and all of a sudden I hear a clunk, and I'm like, what was that? And he goes, I think it was Grandma. Next thing you know, the bathroom door flies open. And we're in the shower together. And I'm like, oh! And Grandma's like, have you called your boss and said you're not going to work tomorrow? Because I was kind of under the weather. I said, Grandma -- I peek out the door of the shower and say, tomorrow is Saturday. And she goes, oh. And leaves. I like pulled the shower door and we're just standing in there, and I'm like, I'm sorry about that. He's like, what! What! And I go, you know what's really sad? This is normal. These are the things that stress a marriage. Even though that was kind of funny. I laugh about it because it was just so horrible (Sarah, 39-year-old caregiver).”

For granddaughters, living with their grandparent revealed the grandchildren’s gender tasks within their households versus the gendered expectations that the grandparents held. The granddaughters did not appear to have any outward resentment toward their grandparents for expecting different things from them and their spouses—anything, they were amused at how much praise their spouses (who did relatively little) received in comparison to them.

“When I went away to college, I, um, you know, was talking about doing my laundry in college and my grandmother very seriously said, well, who does the boys' laundry? And I said, well, they do their laundry! (laughter) So, she, you know ... she's much more progressive in terms of her views in some ways, in terms of it doesn't bother her that we're not married and living together, but, um, she still expects me to do everything in the house and doesn't expect my boyfriend to do anything (Colleen, 29-year-old caregiver).”

These gender role expectations also manifested themselves for grandchildren,
through the limited tasks that caregivers (female) felt that they could assign to their spouses (males). This further illustrated the gap between the praise that the men received from the grandparents, compared to the actual work done. This next quotation exemplifies the extra work that women typically had to do with the planning of the caregiving, because of the men’s lack of caregiving experience:

“He supports me 100 percent. But he is not very good at caregiving. So I had to leave Paul in charge one day because I couldn't work from the home the whole week. And that sort of made me nervous. I was like, come on, I'm counting on you, you have to remember to feed her, you have to cruise through the house and make sure she's OK, that kind of stuff. So when I came home, I said, what'd you have to eat today Grandma? And she had like a piece of pie and ice cream. And I'm like, Paul, you're no good. He said, that's what she wanted. I wasn't going to argue with her. And I'm like, OK, she's 96, who cares. But you know, you want a little nutrition. ...(Mary, 46-year-old caregiver).”

In spite of the stresses that caregiving created in romantic relationships, those who had been with their partners for a long duration did find a lot of comfort in the reliability and caring of their spouses. They relied on their spouses to be objective and supportive. Grandchildren often praised their spouses for supporting them, and said they felt their spouses were good people.

“He's really superb. If I were him, I think I'd complain all the time. But he doesn't say one word. If anything, he's very supportive, which is so nice (Karen, 38-year-old caregiver).”

This served as a buffer for grandchildren who were committed for the majority of time to caregiving. Ironically, it was the support of the grandchildren’s decisions, rather than the amount of actual caregiving performed by the spouses, that resulted in the greatest relief of burden for grandchildren.
“I had been married to my husband for 3 years when my grandfather got sick, and actually had been together since high school. He is very much the same way that I am, in that it’s family. There is no question. The question is what can we do, what is feasible? When it got to the point where my grandfather had run out of money, I said to him, this is where I’m at. And he said, well, he’s coming here. That was a relief to me. I didn’t actually ever think that he would say no, but that is a pretty heavy question to ask. And, he beat me to the punch, which was just fine. That is just the expectation, understanding that some day we may have to put him in a nursing home, but today is not that day (Julie, 40-year-old caregiver).

Caregivers who were in long-term relationships did find their spouses/partners to be a source of support, but in general, had a lot more to say about how caregiving affected their friendships than how caregiving affected their romantic relationships. This may be due to being able to take their relationships, and the support they provided, for granted. It seemed that many caregivers did little to nurture their romantic relationships, either due to caregiving responsibilities or due to too many other competing responsibilities along with caregiving. In rare instances, the combination of caregiving and the relationship itself was a source of frustration and resentment for caregivers.

“It’s been a very difficult adjustment for us. A very difficult adjustment. But, he-I am lucky that he is very good to me, and he helps out as much as possible (Karen, 38-year-old caregiver).”

These glimpses into marital discord were difficult to ascertain, and came out more as laughing comments. The stress in the situation is palatable, but caregivers’ ability to discuss this stress, or the ability to address how to remedy it, was absent.

“So when I say he lives in the garage, I mean, I laugh, but it's kind an unfortunate truth. He'll go out there and he will stay out all night. Like an all-nighter. He will never come to bed. And I think it's just for him to be away from the stress of the walker in the middle of the hallway and Grandma bumping in the bedroom (Amy, 34-year-old caregiver).”
I was left with the impression that the grandchildren who missed their pre-caregiving relationships depended on the support that such long-term relationships provided, and lacked the ability (or time) to reflect on how to improve those relationships. At the same time, perhaps the loyalty they felt to their significant others because of the additional burden that their grandparents were putting on their relationships prevented these grandchildren from discussing their relationship discord further.

The relative newness of the spouse relationships for adult grandchildren who provide care places them in a different position than adult children who report less time with their spouses and families as a result of the caregiving (Harper and Lund 1990). As a result, the grandchildren in the study seemed grateful for any assistance that their spouses provided, and were ill equipped to ‘fix’ marital problems that arose from caregiving. Notably, very few spouses suggested marital counseling, but several suggested that the caregiving grandchild attend counseling on their own because of the stress of caregiving. Similar to patterns found in the adult child caregiving literature, the stress associated with caregiving and its impact on long-term marital/partner relationships for the caregivers was greater as the amount of time in the caregiver role lengthened (Bookwala 2009)

*Caregiving and Friendships*

The grandchildren that were interviewed experienced a tremendous amount of change in friendships due to their caregiving responsibilities. These changes spanned
from having to abandon friendships due to a lack of support, to positive changes in friendships and additional support from friends. Grandchildren’s schedules, emotional availability, and closeness to friends were all affected by caregiving duties.

The ease of support from friends is a gradual one, preceded by a shift in the dynamics of friendships. Grandchildren usually first limited the amount of time that they were available to go out with friends.

“I mean, you know, I just am in the stage now that I don't plan anything Sunday, Monday, Tuesday. And most of my friends know that those times are not available. If they can't handle it, then I think it's their problem. Because I have to do what I have to do for my grandmother (Liz, 31-year-old caregiver).”

This type of sentiment was repeated often by grandchildren- the subsequent changes in their friendships, and their lack of availability, was something that caregivers assumed their friends would have to put up with, and often phrased it as ultimatums. The lack of control that grandchildren felt in suddenly becoming caregivers was often transferred to the lack of control these grandchildren in turn gave to their friends in having to adjust to a lack of availability.

For grandchildren who were in stable locations, with local friends, this ultimatum was less severe. These grandchildren also attempted to combine their friendship time with their caregiving time, and often had friends to their houses (or to their grandparents’ house) and socialized with friends in the presence of their grandparents. While this was a solution to not being at all available, the presence of the grandparents often did create stress for friendships.
“Part of it is that my friends have had to get used to the idea that Grandma is going to be a part of pretty much everything. And, some of them deal with it really really well, and some of them not so well. One of my friends, one of my best friends in the whole world, she understands that my grandmother is losing it. Her only comment every time that we have to deal with my grandmother is ‘I love your grandma!’ But, she is making a face that she would rather be dead.
(Michelle, 19-year-old caregiver) ”

What was so interesting about these exchanges was the power dynamics that ensued. Friends often had to adjust their expectations of the grandchildren, and share the grandchildren’s time with their grandparents. However, in exchange for this, the grandchildren had to listen to friends’ complaints.

“My friend hates it. My grandmother drives him crazy. Everything she does drives him crazy. He goes, “Can’t we go places without your grandmother?” And, I go, “you know, if you want to schedule something three months in advance, sure. If you want to call me and say that you want to get together this week, my schedule is full. If you’d like to join me at my grandmother’s house for dinner, go ahead. Otherwise, you’re not seeing me. End of conversation, you know?”
(Christine, 22 -year-old caregiver)”

Some grandchildren mourned the loss of friendships because they just didn’t have the same things in common anymore. Often, this was revealed in the topics of conversation that had become so diverse between friends. The responsibilities and stress of caregiving were compounded for several grandchildren because their friends, who they were used to going to for advice on other issues, were unable to help or even relate to caregiving issues.

“Um, (caregiving)it's definitely affected my ability to maintain friendships because one, I don't have the time, and two, I've just, I'm in such a different -- I mean, my problems are so different than my friends'. My friends are like, well, where are we going to dinner tonight? And I'm like, well, how's Grandma going to pay for this assisted living facility? You know, it's a little bit different and they don't understand and so I feel a little isolated. (Sue, 34 -year-old caregiver)”

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The friendships that were fraught with tension due to caregiving were often ones that were long-distance. The inability to travel to friends, combined with the uneven amount of work that the other friends had to do to maintain the friendships, often strained ties.

“She's (my friend) been here several times since my grandmother's been here. You know, it's one of those things where you feel bad. I can't go there. And she invites me, or he invites me. And I can't go. It's too far away. (Debbie, 38-year-old caregiver)”

Grandchildren felt both torn and stressed by invitations to travel to friends’ homes with their grandparents. Acceptance of the invitations included several considerations that the grandchildren had to take into account, and often, it was too cumbersome to imagine the work that it would take to travel to another person’s house. This resulted in further isolation for grandchildren, who did not even attempt to make these trips.

“I have a girlfriend who lives way far away from here, and I have to tell her, you're just too far away. You know, I would never be comfortable leaving my grandmother alone. It's almost an hour drive from here. So that's too far away. I wouldn't be comfortable with that at all. So she wants my grandmother to come out there. She wants my grandmother to see her house and she doesn't understand that, you know, my grandmother would sleep the whole time because the ride would exhaust her. An hour ride is a lot when you're 92. Not to mention, with her hip and everything, that would be a difficult trip. And not to mention, if I took her there, she would be so confused about where she was. You know, she wouldn't, you know -- it's like, I look at things and think my grandmother would enjoy and I think, you know what? It would not be enjoyable for her. (Sophie, 35-year-old caregiver)”

Some grandchildren moved in with their grandparents to help provide care. As a result, these grandchildren were geographically separated from friends. The amount of effort that it takes to provide respite care, combined with the physical exhaustion of
caregiving, caused several grandchildren to drop out of the social scene, especially if it was a long-distance scene.

“And a lot of that has been living in (grandparent’s town) and all my friends are in (my hometown). So ... and then, yeah. Um, so -- yeah. It's a lot of friendships are not as close as they once were or even meaningful anymore because it was just so hard to make it to events. You know, driving an hour to get there and just not having the time or, even if I could make the time, having the energy to go. Um, so, yeah. I don't know. I never -- I've always been a person who's had a smaller circle of friends. But even that small circle has gotten smaller. (Jennifer, 36-year-old caregiver)”

Grandchildren who geographically move to be with grandparents lack the history with their peers to help them ease into new friendships easily. For several grandchildren, their own decisions to have children were delayed or put off because of caregiving. Their local peers were in the midst of family life, and they did not have a lot in common with them as a result. These grandchildren swayed between adjusting to a social life with young families, or hanging on to their previous social life that existed before caregiving. The end result was that the grandchildren straddled these two worlds, and their ties to either group were lessened. Social outings occurred once every few months, as opposed to daily or even weekly.

“Well, see, since I moved here as an adult, I know some people. But I'm probably only friendly with a couple. They're like married with children and it's definitely different being single with no kids. And then I also have, I grew up probably about 45 minutes from here, and there's probably a group of like five of us that went to high school who stay in touch. And what we tend to do is like we'll go out to lunch or we'll meet and go shopping and we'll do that like once every couple of months. (Meagan, 36-year-old caregiver)”

The grandchildren who felt distant from previous friends and who did not know any other caregivers seemed to be the ones that were most distraught about the state of
their friendships as a result of caregiving. There were a lot of grandchildren who did make efforts to find friends with similar caregiving responsibilities. No grandchildren found other grandchildren providing care, but some did find others who were caring for family members, and they found these friendships to be a source of support and encouragement.

“I have found that I have some really good friends because they've been awesome with me. I do talk about it all the time because I just need to get it out there. I'm always bouncing stuff off of them, and at least they listen. It’s nice to have someone understand. (Laura, 35-year-old caregiver)”

Friendships definitely changed when grandchildren became consumed with caregiving. It is important to note that for several grandchildren, their friends also grew up with their grandparents as a presence in their lives, and even with the stress associated with the friendships, caregivers did report that they could count on friends to help with emergency care and respite when needed.

“Basically, a lot of my friends are really good to her (my grandmother). Part of it is that a lot of my friends knew her before, because I was super close to her even before she lived here...So, a lot of friends knew she was around, knew her before my grandma was totally going crazy, and they really like her. So, they really put up with her. One of my friends would give my mom and I a break from caregiving by coming over and hanging out with my grandmother for a few hours. The other thing is that I have a lot less time. But in terms of just socially, it’s mostly just how my friends deal with her. (Michelle, 19-year-old caregiver)”

The focus for the grandchildren in regard to friendships most often focused on how THEY were affected in their friendships as a result of caregiving. There was not a lot of examination of how their caregiving may have affected their friends. It leads me to wonder whether the grandchildren were unaware of the effects their caregiving had on
friends, or if they were unable to closely examine their shortcomings as a result of the care they provided grandparents.

Compared to adult children providing care and spouses providing care, adult grandchildren are at a younger phase of life, and the activities which constitute friendships are qualitatively different than those of older cohorts. Clubbing, going to bars, and ‘hanging out’ were activities that the grandchildren were unable to participate in, which alienated them from their friends. In addition, their caregiving was such an off-time event that very few had friends who could truly empathize with what they were going through. Adult children and spouses usually can find camaraderie in other friends who are experiencing their own levels of caregiving. The uniqueness of this status for grandchildren was an isolating factor for them, and as a result, almost all grandchildren saw a decrease in their circle of friends.

*Caregiving and Children*

Regardless of whether the grandchildren had their own children, the presence of grandparents and the intensity of the care that the grandparents needed intersected with this aspect of grandchildren’s lives. Several grandchildren were delaying relationships and childbearing due to their caregiving responsibilities. The majority of the grandchildren who had children of their own were raising toddlers while providing care to their grandparents. For some older grandchildren, their own children were teenagers, and therefore were relied on as additional support in caregiving.
Part of the stress for grandchildren who did not yet have their own children was the uncertainty of how much longer they would be providing care for their grandparents. This served as a barrier for family planning, and these grandchildren were left in a limbo state regarding parenthood.

“There are times when I feel like I should stay here, um, because the home that my grandmother is in is the most comfortable for her, um, so I should just stay here as long as she's alive. Um, but then other times, I feel like I want to start my own family and I, with her care as it is right now, it doesn't seem like that would be possible. At least not preferable. And so, it's an ongoing discussion with my parents, with my boyfriend and in my own head. Um, we're talking anywhere from three months from now or until, you know, however long my grandmother's here. (Melissa, 29-year-old caregiver)"

The grandchildren interested in having children simply could not see how they could handle any more responsibilities. They were aware of the time constraints that caregiving produced, and could not see themselves adding to their already full schedules.

“I worry about how having children would impact my ability to do caregiving. My husband and I have talked very much about getting a dog, but we probably would have if it wasn't for taking care of my grandmother, but I honestly feel that I can't handle any more responsibility than I already have. Again, pretty much maxed out. (Jennifer, 36-year-old caregiver)"

The discussion of children, and whether childless grandchildren could afford the time to have children of their own, was a sensitive topic for many. The stress associated with not only caregiving, but also their biological clocks, led several granddaughters to tears in the interview.

“I mean, I just, yeah. I don't know. I kind of just -- I try not to use that as an excuse, because I'm young, but at the same time, I really just ... I'm like, this is too much and it's not fair. I should be worried about when I'm going to have kids, not how Grandma's going to go to the doctor. (Stephanie, 29-year-old caregiver)"
Grandchildren with small children at home were extremely stressed out over their conflicting responsibilities. They had a difficult time managing their time as well as managing their emotions regarding caring for toddlers and their grandparents.

“My kids get upset that I go to Grandpa’s. Sometimes I bring them during the day. I just hug them and tell them I love them and tell them I'll be home soon but I have to help Grandpa because he can't walk. They know because they know him because I've brought them there. That's a good thing for the 5-year-old. In between my 5-year-old and 3-year-old I lost a baby, and I really honestly think it was because of stress from my grandparents. Because that was the exact time I was planning on taking away their cars and moving them up here. So, yeah, we've thought about that and when's the best time to have a baby. (Julie, 40-year-old caregiver)”

For grandchildren who were working, caring for a grandparents, and caring for children, decisions needed to be made about whose care was going to be hired out. Does the mother in this instance hire a nanny for their child, or a caregiver for their grandparent?

“It's hard to find a baby-sitter sometimes when (my husband) isn't around. I had a baby-sitter that I hired for Monday and Tuesday that comes at like 1:30 and she stays for a couple of hours while I go during the day because the kids are too active to be at my grandparent’s house right now. It's not fun for them. But, then I don't have time to have my whole family together. (Karen, 38-year-old caregiver)”

It was often more practical for the grandchildren to hire additional assistance to help with their children, rather than with grandparents. It was a struggle to get children to daycare providers, but it did provide stable environments for the grandchild.

“I think that the biggest thing I struggle with is trying to maintain some schedule with my son, particularly on days where I’m trying to take my grandpa to the doctor...sometimes I go out of my way to schedule thing in such a way so that we can go down, drop him off at daycare, and then go to the appointment. That way,
my son’s schedule is minimally impacted, Grandpa gets what he needs. It’s a lot of driving (Meagan, 36-year-old caregiver).”

Grandchildren cited the need to drive grandparents to multiple appointments, the grandparents’ anxiety over being cared for by strangers, and finances as reasons why the children often were the ones who were cared for by non-family members. The relatively simple needs of young children also made them more realistic candidates for outside care.

“I hire a nanny to care for my daughter. I just can’t do it. And, she’s young—she’s only 10 months- so I like having her at home and in one place. (Jackie, 35-year-old caregiver)"

The juggling of the needs of grandparents and grandchildren was all-consuming for grandchildren who spent time at home with both their children and their grandparents. And, this occurred both during the workday and at other times, making the care literally 24-hour care. The generational differences in parenting styles as well as the competing needs of their children and grandparents both resulted in increased stress for grandchildren.

“My daughter is ten months old. It’s, if I put her down to go the bathroom, or to get her bottle to go into the other room or something, she starts crazy crying. If I’m in the other room because of my grandfather...I don’t handle it very well. I get angry, I get upset, I get stressed, I get frustrated...I don’t handle it very well. (Jackie, 35-year-old caregiver)”

The pressure associated with providing care to grandparents and providing for the needs of children lessened as children got older. Those grandchildren with teenagers reported less stress with their own children, and more opportunities to have their children learn life lessons from the example they were setting.
“Yeah, she's very good about helping. She understands it. She's not a problem. I just do -- I try to see them and take care of them so it doesn't interfere with her, you know, that I don't have to take time away from her. She's busy working now anyway. If I'm going to go over, she comes over with me a lot to visit with them. She hears the same stories over and over again, God bless her. (Marybeth, 48-year-old caregiver)”

Grandchildren with older children are both grateful for the additional care that their own children provided, and felt fortunate that their children were able to get to know their great-grandparents. This is not to say that any of the grandchildren who were studied indicated that they hoped that their own children would one day become caregivers. If anything, they felt the opposite.

“I would never want to see my daughter do this. I think that my daughter is proud of me, and sees what I am doing, even if nobody else does. I think she’s proud that I am able to help my grandmother. But, I do not tell her that this is because of my mom that I am doing this. It’s because my grandparents needed me. (Debbie, 38-year-old caregiver)”

The above quotation was from a grandchild whose relationship with her own mother had become strained due to the pressures of caregiving. The recognition of efforts were important for grandchildren, and often, even when nobody else in the families were cognizant of the sacrifices that the grandchildren made to provide this care, their own children were knowledgeable and proud of their parents.

Past studies on the role of children when a person is providing care to an elderly relative focus on the pull factors that divide families- the parents have less time to go to extra-curricular activities, attend college events, or drive children to part-time jobs. Not having time for these things is indicative of the varying ages of adult children who provide care, with the majority of them being past the point of caring for young children.
by the time they care for parents (Spitze and Logan, 1990; Loomis and Booth 1995). The presence of very small children does in fact indicate a ‘club sandwich’ effect, where younger caregivers, particularly grandchildren, are caring not only for parents and grandparents, but also young children (Abaya 2000). What is interesting about the findings on grandchildren raising their own children while caring for grandparents is the ‘substitution of care’ effects. Rather than substituting the care for their grandparent with outside services, these grandchildren often tasked out the care of their children to non-kin, creating a different substitution model than other generations. This may be a generational difference in the acceptance of placing children in childcare, in addition to the relative ease of finding childcare versus finding eldercare.

Financial Strain Due to Caregiving

The financial aspect of providing care for grandparents was often fraught with indecision, tension, and conflict for grandchildren. Often, the grandchildren had the formal role of being the grandparents’ power of attorney. This section will discuss the various budget constraints that grandchildren felt as a result of providing care, the strain with family members as a result of financial interests, and the reasons why some grandchildren did not want any formalized financial control over their grandparents’ money.

Budget Constraints

The budgetary impact of caregiving on grandchildren was difficult to pinpoint because they often did not keep accurate accounts of the costs of providing care. The
majority of grandchildren had separate accounts and funds for their grandparents, due to the grandparents’ Social Security income, pension, savings, etc.

“My grandfather gets social security, he gets his pension, and a monthly pension from the VA. It’s not a lot of money, but it is enough to disqualify him from Medicaid, but not enough to really make a comfortable nest-egg. He did have some savings that we have been eating through when we sold his house and paid off the reverse mortgage, there were some proceeds from that, but the move, and his going out to lunch, it’s kind of eating away at that, and that’s why we’re cutting it off his lunch allowance (Dawn, 43-year-old caregiver).”

Most grandchildren began caring for their grandparents in an unplanned fashion, and did not have full understanding of the extent of their grandparents’ finances when they began taking care of them. As a result, the most financially difficult time for several grandchildren were the first months of caregiving, when they did not have parameters set for whether it was appropriate to ask their grandparents to pay for goods and services. Many grandchildren were financially disorganized themselves, so they did not have a good idea of how much of their own money they had spent on caregiving costs.

“She does have funds. Um, her -- you know, she owns her home and has Social Security, and she pays for insurance, and so she has just barely been able to, um, cover her expenses. And so it's been possible for all of that to be covered. Um, you know, at times, just through my own disorganization, that I've bought things and then not asked to be reimburses, or, you know. Um, I don't know. I mean, there are certain things that I have spent my own money on, but for the most part, I mean, at least the possibility for all of it to be covered has been there. (Jackie, 35-year-old caregiver)”

In addition, most caregiving situations began with the grandparents living at home, so many grandchildren bore the cost of visiting them. They did not consider asking their grandparents for transportation costs. The rationale for this was multi-layered.
Interviewee: “When I was going to visit her (my grandmother) all the time, that was always out of my own pocket and that sort of thing. But now that she's in assisted living and that sort of thing, most of the expenses that I incur are paid for by her.”

Me: “Do you think she was aware when you were going out there how much it was costing you to have to do those trips? Did it ever come up?”

Interviewee: “It came up sometimes, but, um, like, she would offer me money, but I always felt I had to turn it down or I would be just another person who was after her money. And I didn't want her to think she had to buy my love or, you know, pay me to go see her. So I felt more like I had to prove to her that I wasn't after any money. So I would always turn it down.” (Heather, 30-year-old caregiver)

Ironically, many grandchildren were comforted that their grandparents were financially independent, and would go to great lengths to proclaim that the grandparents were in no way a financial burden, but they did not factor in the hiring out of their own duties to make the time to care for their grandparents in that equation. The following exchange reflects this disconnect on the part of grandchildren:

Tamara: “How has caregiving affected your family budget?”
Amy: “Oh, you have to understand, I mean- I spend so much money paying other people to take care of what I need to do- it’s just…sometimes, I wonder why I work at all, you know?”
Tamara: “Yeah, yeah. What kinds of things do you end up hiring people for? I know that you said you have a nanny for your daughter…”
Amy: “And, just taking care of housekeeping, things like, you know, washing bottles, doing the laundry, doing the dishes- things like that. Just little things that I don’t have time for.”
T: “Right. So, for your grandfather’s care, does he have independent funds, or are you financially responsible for his care?”
A: “Yes, there are independent funds, and they go to pay for his stuff. And, you know, I do my best to keep it separate, but it’s hard.” (Meagan, 36-year-old caregiver)

Strain with Family Members over Financial Aspects of Providing Care

For some grandchildren, an added stress to the caregiving process was the conflicts with other family members over the financial aspects of providing care.
Grandchildren often were asked by the grandparents to take on this responsibility, often at odds with the wishes of the grandparent’s own children. This put the grandchildren in the position of having to defend their financial decisions, or even defending their motivations for providing that care.

“I'm not crazy about it because I think it's caused -- I think the other side of the family probably thinks that I'm taking advantage of her, which I don't like. But then the other side of me says, well, the only way to prevent her from being taken advantage of is to handle it yourself. So part of me is happy that it is my full responsibility because I don't have to worry about anybody else. Basically the way I feel is if it came down to her running out of money, my husband and I are the only ones who would step in. And because of that, I feel like I have a right to manage her money, if you will. (Lynn, 44-year-old caregiver) ”

Refusing formalized financial control

With the exception of those grandchildren caring for grandparents because their own parents had died, and therefore there was no ‘middle generation’ to take financial responsibility, grandchildren preferred to have their parents and their parents’ siblings taking care of the financial aspects of care. The combination of the grandchildren’s age, the over-stepping of generational boundaries, and general inexperience with money all contributed to making this the preferred arrangement.

“Monetarily, it is my uncle primary and my mother secondary, because I really have no interest or understanding of any of that financial stuff. My interest in financial is trying to pay my credit card bill every month. That’s as far as I want to go with financial. (Lisa, 22-year-old caregiver)”

The combination of having few legal avenues through which to apply for monetary assistance or tax breaks, as well as the fact that grandparents usually had independent funds to use for their care, made the financial aspects of care a murky
situation for grandchildren. Many were at a stage in their life course where they had yet to even manage their own budgets, let alone manage the various costs of providing care for another person. Taking over legal responsibility was a daunting task, and several grandchildren eschewed the responsibility for fear that it would cause rifts in the larger family structure. There exists no norms for grandparents and grandchildren being open and sharing regarding finances, and the grandchildren usually were piecing together what they thought worked best without any outside assistance.

Stress and Burden Associated with Caregiving

The grandchildren in the study have had a multitude of physical, emotional and mental complications as a result of providing care to their grandparents. The manifestation of this stress was apparent through the injuries, depression, and anxiety that the grandchildren exhibited. This section will discuss the causes of stress and burden, the effects of this stress and burden, and the mediating factors that alleviate the negative consequences of providing care to elderly relatives. This grandchild’s quotation is an illustration of the melding of the physical, emotional and mental stress that grandchildren went through:

“This work is heart breaking, and back breaking and mind bending, and my family has absolutely no gratitude in terms of ‘oh, look at how good you are, and I have confidence that you will take care of me in my old age.’ No, ‘I’m so proud of you for stepping up and taking this responsibility, which is really quite a lot for a young woman your age…” None of that. I get none of that. It’s irrelevant whether it SHOULD be their problem. If it lands in their lap and they do it, they deserve your praise and your thanks, they deserve your pride. They definitely don’t deserve to be made to feel like they’re wasting their time and it’s not something that they should be doing. Trust me, I am not doing this for fun (Lisa, 22-year-old caregiver)! ”
Stress and Demographic Factors

Caregiving stress is particularly hard for grandchildren because they are younger, and the socialized norms for grandparent/grandchild relationships do not include this component of providing care to grandparents. This is compounded by the relatively few resources that grandchildren draw upon, the stress of their relationships with the middle generation, caregiving being an off-time event in their lives, and competing demands.

Primary Stressors

Primary stressors refer to those stresses that are embedded in providing care. They include the objective conditions of providing care, activities of daily living dependencies, patient resistance, and the subjective reactions to caregiving role overload, role capacity, and the loss of intimate exchange both with the care recipient and with others as a result of intensive caregiving (Pearlin 1990).

Objective Conditions of Providing Care/Activities of Daily Living Dependencies

For several grandchildren, the objective conditions of providing care were overwhelming simply because their grandparents needed so much assistance. The types of caregiving tasks that they had to perform often were stressful, including physical labor with very dire consequences for not doing it right. This granddaughter’s experiences with her grandmother’s trachea tube shows the severity of failing in providing care:

“She is in the end stage of Alzheimer’s disease. She is at the stage where she keeps choking on her own spit, food, anything. I’m the only one who knows how to aspirate her. I am the only one doing it- my grandfather is there, but he is too sick himself to actually be caring for my grandmother (Angela, 32-year-old caregiver).”
For this granddaughter, the stress of not accurately clearing her grandmother’s airway, combined with the inability to get away for any amount of time because she is the only one capable of aspirating her, provided a very stressful reality for her. Her situation exemplifies the objective stress that caregivers feel from providing care.

*Care Recipient Resistance* The stress felt by grandchildren because of the resistance on the part of their grandparents was qualitatively different than that stress reported by adult children or spouses. Because grandparents do not anticipate having to be cared for by grandchildren, several felt guilty for asking for their assistance, and the care recipient resistance came in the form of not asking for help when they needed it. In turn, the grandchildren would not let the grandparents know that they were overwhelmed by their caregiving duties, in fear of further putting guilt on the grandparents. Straddling these two needs was a precarious situation for grandchildren to be in, and not taking their grandparents’ physical situations seriously enough because the grandparents were not telling them how dire they were usually was the end result.

“When she came home from the hospital, I was so ignorant. I kick myself now how ignorant I was. Because, you know, I was still the granddaughter and she's the grandma, right? Role thing. And, um, she's like, oh, I'll be fine, honey. You just leave me here overnight. I'm like, OK, and I go home. I was so stupid. I had no idea that she was just out of the hospital and -- I was an idiot. OK, Grandma, I'll go home. And then the next morning, I go over there to visit her, and she's looking a little grainy now because this was a big event, and she says, oh, I just left the front door unlocked in case I had to call 9-1-1. I was appalled, like oh my gosh! I should have stayed, I'm an idiot! That really kind of got me, you know? I just realized that wow, I have to be the grownup now. You know? Which was -- I still struggle with that sometimes, trying to be the grownup (Stephanie, 29-year-old caregiver).”

This type of skirting around the issue of how severe one’s physical situation is
seems to be a situation that is unique to grandchild/grandparent dyads. This is different from the types of problematic behaviors usually exhibited by child and spouse caregivers, such as crying, hitting, yelling, or exhibiting socially inappropriate behaviors on the part of the care recipient (Sheehan and Nutall 1988; Chappell and Reid 2002).

Subjective Reactions to Caregiving

Subjective reactions to caregiving are the experiences of role captivity, role overload and the loss of intimate exchange. The combination of the objective conditions of caregiving combined with these subjective reactions serve to create stress for caregivers. The stress that results from these two factors (the objective conditions of caregiving combined with the caregiver’s subjective reactions to these objective conditions) serves to create secondary stressors. These secondary stressors are exhibited through secondary role strains, intrapsychic strains, and the manifestation of stress. The previous section has dealt exhaustively with secondary role strains; this section will discuss both intrapsychic strains and the manifestation of stress for grandchildren in a caregiving role.

Intrapsychic Strains Intrapsychic strains refer to the dimensions of self concept and overall well-being that are diminished as a result of caregiving. Grandchildren exhibit this through questioning their levels of self-esteem. While grandchild caregivers cite an increase in overall self-esteem, several felt that they were not doing enough for their grandparents, they doubted their abilities, and questioned their role as caregivers. As a result, caregiving was an intense emotional rollercoaster for several grandchildren.
They were aware that the stress from caregiving interrupted their emotional well-being, but seemed unable to control this aspect of their experiences. For some grandchildren, the emotional stress resulted from other family members criticizing their caregiving or assuming that they were providing care to financially benefit. For others, the emotional toll of dealing with the personality traits of their grandparent on any given day was burdensome. Finally, for some grandchildren, their lack of preparation for this role, combined with the intensity of the caregiving situations, resulted in additional emotional burden for them. They were frank in expressing their inability to appropriately deal with this facet of providing care.

“I just want to scream. I mean, the overall feeling of sadness has to do with her losing it- but that’s not so much because I’m the caregiver. Even if I was just watching it, that would still be the case. It’s incredible frustration, it’s incredible having to bite my tongue and not scream. Occasionally it’s a feeling of failure, because sometimes I just cannot deal with her, and I call my mother and I say, ‘Deal with her, she’s your mother!’ (Kim, 33-year-old caregiver)”

This candid quotation illustrates the lack of emotional coping skills that the grandchild has, the crushing weight of failure that can come with caregiving, and the propensity to fight with other family members as a result of the stress that caring for a grandparent creates. This grandchild had frequent disagreements not only with her grandmother, but also with her parents, and the emotional toll was great. She was very aware that her strategies to deal with these burdens were not entirely healthy.

Sometimes the emotional immaturity of grandchildren providing care to grandparents was exhibited through the responses that the grandchildren gave to questions. The following quotation is an example of this. The grandchild exhibits an
almost sibling-like relationship with her grandmother, and has very few resources from which to draw when the grandmother is upsetting her. What is interesting about this particular case is that the grandmother has been diagnosed with early Alzheimer’s disease, and the granddaughter, although she is aware of this, cannot separate out the effects of the disease versus her grandmother deliberately being hurtful to her.

“Um, there are certain things that I am a lot better at than my mom, but there are certain things that will drive me up the wall way faster. When my grandmother lies through her face, and knows that is lying, rather than telling her that she is not being truthful, I will call her a liar to her face, because I do not have the emotional ability to withhold that. And then, she gets really mad at me, understandably (Rachel, 27-year-old caregiver).”

The above quotations speak to the relatively young age of the grandchildren providing care, and the lack of experience that they typically have in dealing with such extreme needs. This is a unique characteristic to grandchildren who are caregivers. They are providing intensive care at a time during their own life cycle where they have few additional experiences from which to draw. Their own ‘caregiving career’ is in its beginning stages.

The ‘loss of self’ is another dimension of intrapsychic strain. Several grandchildren had very few breaks in their caregiving, had nobody they could rely on for respite from caregiving, and were actively delaying relationships, childbearing, and making new friends (or nurturing existing friendships) in order to provide care. The end result of this isolation was a ‘loss of self’. Several grandchildren had been providing care literally for years, and had yet to have a twenty-four hour break from that care. The isolation that the grandchildren felt was more resonant of the engulfment that spouse
caregivers go through than child caregivers. This was especially pronounced for adult grandchildren who no longer had a parent in their support network, and were also single. This simple, yet telling, quotation exemplifies this engulfment.

“I feel kind of like the walls are closing in. And, um, I had tried to figure out a way to get away even like overnight. I just felt like I can't even do that (Tracy, 36-year-old caregiver).”

Manifestation of Stress

Mental Illness and Depression Several grandchildren went beyond being emotionally worn out due to caregiving, and actually had diagnosed mental illness. What is interesting is that often, it was their mental illness that drove them to provide care in the first place. For some grandchildren, their mental illness (such as depression, bipolar, and/or OCD) had previously cost them their jobs, their homes, or even custody of their children. These grandchildren used their ability to caregive for their grandparents as their saving grace, the one role in which they were useful again, helpful again, and at times, part of their families again. The combination of caregiving and mental illness made the stakes of succeeding in this role that much more important for these grandchildren. Ironically, this same combination of factors also made providing care that much more difficult for grandchildren.

“It’s a few different things- the big ones are an anxiety disorder and bipolar disorder. There is also ADD, OCD, Oppositional Defiance Disorder- basically if you tell me to do something, I won’t, but if you ask me to do something, I will. There’s all of these things all mixed together, and all of those things combined with the fact that my dad has a very short temper and I take after him, I have a very short temper but I get over it quickly. So, I’ll call her a liar to her face, which is really inappropriate. But, at the same time, there are certain things that I am able to let go and I am able to be ignored (Georgia, 28-year-old caregiver).”
The grandchild here was caring for her grandparent because she had the time to do so. She was unable to hold down a job full-time because of her emotional needs, and was unable to go to school because of anxiety. Several grandchildren had been previously hospitalized for their mental illness, and this was a daily challenge in being able to provide care to their grandparents. Negotiating their limits both emotionally and mentally was something that grandchildren had a hard time doing, and often, their support systems to help mediate this were weak. They relied on other family members to help them to draw limits with how much time and effort they were putting into their caregiving efforts.

“What happened, is that I was hospitalized for…like I said, I have severe emotional disabilities. So, I was hospitalized for that. And, one of the things that I said to my mother was that I said, ‘I cannot keep doing what I am doing. Not in terms of dealing with my grandmother, so much as the command performance thing. I mean, I am pretty much nocturnal. I said, ‘When I go to sleep at 7:00 in the morning, I cannot go with her at 10:00 in the morning because she feels like getting a cup of coffee.’ I can’t keep doing that, and you need to be getting me off the hook. And my mom said, ‘Absolutely, I didn’t realize how hard it was for you.’ And, now, she’ll get me out of anything, including Shabas lunch which theoretically I should go to, because it means a lot to my grandmother, but my attitude is that when I just spent the last four days with her, I’m not going. My mom will pretty much get me out of doing anything at this point, even if it means lying to my grandmother (Christine, 22-year-old caregiver).”

Several grandchildren had undiagnosed depression, but were told by their closest family and friends that they should consider seeking professional help. Many of them did not actually seek such help, but were actively considering seeking counseling or anti-depression medications.
Finally, grandchildren were aware of the depression and anxiety that result from caregiving, and the grandchildren in the study acknowledged that they would benefit from seeking individual counseling, anti-depression and anxiety medications, and acknowledging the emotional tolls that caregiving takes on their mental status. Usually, their primary care physicians were also aware that there were mental health issues, but some caregivers were resistant to a dependency on medication or counseling to feel better.

“Well, my doctor tried to give me some medication for it, but I'm not big on taking drugs for depression or anxiety. I don't want to do that. Once you get started, it's hard to get off those (Dawn, 43-year-old caregiver).”

*Physical Stress* Several grandchildren had physical illnesses of their own that coincided with the care that they provided. As a result, the physical toll that caregiving took was severe. They were concerned over their ability to provide care over the long run because of their own failing health. For some grandchildren, their own medical needs made them better caregivers. They were able to empathize with their grandparents’ condition because they were sick themselves.

“Yes. Yeah. Well, I actually have had a lot of medical problems myself. I have a blood disease (can't hear). I'm pretty much out of disposable parts. But, so, you know, it's like, I think I've ... I have a lot of experience in being not well. So I have a unique empathy for someone who's not well (Lynn, 44-year-old caregiver).”

Ironically, several grandchildren who did have their own physical problems did little to care for themselves- it was rare for them to go to the doctor, to take time to exercise, or to educate themselves on how to lift in ways that would not be hurtful to them. They were aware that their grandparents needed more physical help than they
could provide, but finding substitute support for their grandparents to take care of their physical needs was sometimes difficult.

“I have MS myself, so I, it's physically impossible for me to do their house, to keep their stuff going. So, um, that's why I'm trying to find somebody that will come in at a reasonable, you know .. it's expensive and they don't have the resources to do it (Patty, 40-year-old caregiver).”

Other physical ailments that grandchildren complained about were constant tension headaches, weight gain, and general fatigue as a result of caregiving. The sheer amount of time and effort it took to provide care, combined with the lack of respite cares on most days, made their physical symptoms worse. These factors also made the physical negative effects of caregiving something that most grandchildren simply accepted as part of their situation. Many caregivers noted that it was the lack of self-care that was wearing them down physically.

“Obviously one of the side effects of the stress of caregiving has been weight gain. Oh my God. I've gained 30 pounds in the last year. That's terrible. And I feel like that's all stress related. Because the last person you think of is yourself, that sort of thing (Liz, 31-year old caregiver).”

Mediators of Stress

Mediators of stress refer to the coping mechanisms, roles outside of being a caregiver, positive affect, and social support that caregivers seek in order to assuage stress and burden of caregiving. The mediators that adult grandchildren drew upon to help them with their strain as a result of caregiving were both similar and different to those tactics used by adult children and spouses.
It has been argued in previous research that women often exhibit better coping mechanisms as caregivers because they have been socialized into the role of being a caregiver because of their gender (Chappell and Reid 2002; Spaid and Barush 1991; Miller and Cafasso 1992). Some granddaughters readily admitted that they were known within their families as a take-charge, caregiver type of person.

“I've always been a kind of person that, um, what word do I want to use. I've always kind of had that caregiving thing, you know? Not only with my grandmother -- I have a cousin, you know, she works with me at the coliseum, and one day a week, you know, sat down and she was talking to me and telling me she didn't feel good. And I was like -- because she just recently turned 60, I think. So she's quite a few years older than me. And you know, she's telling me she didn't feel good. I said, well, you need to go to the doctor. Well, I don't have no insurance. I was like, look, I'm calling Medicaid for you because you need to get yourself checked out. So I got everything set up, called the doctor, told them what was happening. She said, can you get her in here? I said, I'll have her in there. And her daughter says to me, I don't know what you did to get my mom to go to the doctor. I've been trying to get my mom to go to the doctor for 10 years, and she will not go. I don't know what you said or what you did. I said, I told her she's going, she's got no choice (Debbie, 38-year-old caregiver).”

Other granddaughters acknowledged that they did have experience with being a caregiver because they had younger siblings and their parent had died young. For these caregivers, the care for grandparents was not the first caregiving role within their lives, and they were already used to looking out for others.

“My younger brother -- my youngest brother is eight years younger than me -- and there were some bad times in the family and I ended up taking care of him. My parents separated twice and he got left at home with my father. My mother moved out. My father doesn't know how to take care of a house or do dishes or take care of a child. The first time they were separated, I was (can't hear). You know? So, I ended up doing everything at 12 years old. We lived in a 13-room house. So it wasn't a small task to go to school, take care of my little brother, make dinner, clean the house and be a kid (Mary, 46-year-old caregiver).”
Even when granddaughters did have experience with providing care in other capacities in their life, they often felt overwhelmed and unprepared for the role of being caregivers to their grandparents. The type of care it entails, and the consuming nature of the care, made it very different from caring for young children.

Another mediator of stress is the ability to do things outside of the caregiving role. The grandchildren interviewed had varying degrees of whether they were able to fulfill their hobbies and interests in addition to caregiving. For those who were able to find time for themselves, the ability to get away was a useful tool in coping. Some caregivers found work to be their respite, and others found that outings with friends and family provided these moments. Yet, even with breaks from caregiving, the grandchildren were still accountable to the grandparents, and never felt that they had a true ‘clean break’ from their caregiving.

“So, I go away with my friends for these weekends, and they’re usually pretty cheap- they’re usually about 30 bucks, plus the cost of the hotel room. But, I’m gone from Friday til Sunday night. She just cannot get it in her head that I am not available. I tell my grandmother that I’m at this convention, and she tells me that this person needs to say hi to me, etc. So, I tell her, “Grandma, are you planning on dying before Sunday?” She will say no, so I go, “Then, tell me on Sunday! Better yet, tell Mom. Mom will tell me on Sunday. She can’t get it through her head that if I’m doing this- and I only do it a few times a year- I do not want to be chatting with her. And, I cannot deal with that, cannot get it through her head. So, everyone at conventions basically know there will be at least some point in the day that I am going to be in a really rotten mood because I was stuck talking to my grandmother for half an hour. So, it’s not that I don’t do things- it’s that it gets interrupted constantly, and it can put me in a really rotten mood about that (Christine, 22-year-old caregiver).”

Positive affect is another tool that several grandchildren actively used to help them with the caregiving burden. Feeling good about being a caregiver, knowing that
they were providing their grandparents with a better ending, and even getting to know the grandparents better were all effects of positive affect. This will be discussed at length in Chapter 9.

One last tool that grandchildren used to their advantage when caring for a grandparent was social supports. This is dealt with extensively in Chapter 10. Interestingly, the social supports that grandchildren draw upon are different from those supports that adult children and spouses tend to utilize. The grandchildren were likely to lean on siblings, their own parents, and friends as social supports. Leaning on support groups as a method of seeking social support was almost non-existent for adult grandchildren.

The negative effects of providing care to grandparents both mimic and differ from the themes present in past research. Grandchildren in a caregiving role experience role strain and financial burden, suffer from caregiver stress, and use strategies to alleviate that stress. Their position both within their intergenerational family dynamics and within their broader life course create a different set of both advantages and obstacles for grandchildren providing care.

The role strains that are most deeply felt for grandchildren are those stemming from being in the beginning phases of their careers and dealing with the burden of being caregivers while working, and from relationship changes due to their responsibilities. The changes in romantic relationships and friendships were particularly difficult for grandchildren to deal with. Largely, many of these roles were relatively new for
grandchildren because they were younger, and therefore had less time invested in their other relationships prior to caregiving. The stability of relationships experienced by older caregivers simply hadn’t had the same amount of time to be nurtured prior to the grandparent becoming sick.

As with other generations who provide care, grandchildren did suffer from additional physical and depressive and anxious symptoms (Wallsten, 2000; Haug et al. 1999; Sheehan and Nutall 1988; Call, Finch, Huck and Kane 1999). Grandchildren were aware of the physical and mental strain that caregiving brought, and many were active in trying to take steps to take care of themselves. This may be because they were receiving outside advice from partners, friends, and even doctors in regard to paying attention to the physical and mental tolls that caregiving took. This may be because others were more in-tune with the added stress that caregiving presents as an off-time event. Alternatively, this is the first generation within the United States that grew up with a lessened stigma of mental illness and depression, and their acknowledgement that they were suffering from these effects may be a reflection of that decreased stigma.

Positive Effects of Providing Care

The grandchildren in the study had many positive things to say about providing care to their grandparents. Caregiving, as stressful as it was, was also an enriching experience that allowed grandchildren to know their grandparents as people, and feel like they were providing invaluable support to their families. Getting to know the grandparents better, enjoying their grandparents’ company, bringing meaning to their
grandparents’ final days, giving back to the grandparents, learning about death and dying issues, and feeling a sense of purpose from caregiving were all factors that mediated adult grandchildren’s stress levels. Several good things had also come from the caregiving. The grandchildren felt that their caregiving experiences had raised their self-esteem. Caregiving benefitted grandchildren by preparing them for future challenges within their lives.

Getting to know grandparent

Prior to caregiving, many of the grandchildren felt that their relationship with their grandparents was very much based in a child-adult context. The opportunity to get to know their grandparents on such an intimate level as adults was an often unexpected bonus of providing care. The grandchildren were able to establish better senses of family histories, understand the nuances of their grandparents, and have their grandparents be a bigger part of their lives than they would have been without illness. The following quotations from a variety of caregivers exemplify this theme.

“I guess I've gained a relationship with her that I didn't have. I've gained a lot of knowledge about my family that I didn't know. You know, even in a positive light, things I didn't know about people and history and that sort of thing (Meagan, 36-year-old caregiver).”

“I learn a lot from him, though, that’s for sure. My family has all of these stories about him, but I never knew a lot of things about him (Denise, 39-year-old caregiver).”

“Um, I probably see them more than I would, you know. Um, we see them at family events. I mean, I would see them once in a while, but I wouldn't see them as often as I do now (Tracy, 36-year-old caregiver).”
The grandparents as the keepers of family information, and having access to that information through caregiving, was an important theme for several grandchildren. They recognized that the moments with their grandparents, learning family histories and stories, were moments that they may not have received without being the caregivers to their grandparents.

Previous research refers to the positive return that caregivers feel as a result of caregiving as ‘caregiver gain’ (Kramer 1997). Taking the time to get to know their grandparents better, and realizing that they were able to gain from those experiences exemplifies this notion. Like adult children, grandchildren also report that their relationship with their grandparents has strengthened due to providing care to them (Gerstel and Gallagher 2000).

*Enjoying grandparent’s company*

When the grandchildren that were interviewed were asked what the positive aspects of caregiving were, several grandchildren just felt happy to be in their grandparents’ company. It was apparent that they liked their grandparents, and the opportunity to give care to them also equated to more time spent with them.

“It’s nice spending time with her, because as a person I really do like her. But, I really like her as a person. She’s funny, sometimes she’s really witty and sharp, she’s nice, she’s a really nice and a good person, she likes a lot of the same things that I like, she’ll try to like the same things I like…One thing that’s really fun, is that the more downhill she goes, the better she becomes at watching baseball. My mom and I call her the baseball savant. It’s interesting and annoying, because why can’t she remember anything else? But, it’s something we can do together as a family, because while she is watching the game, she’s not driving anyone else crazy. There are really parts of being able to spend time with her that are really fun. It’s nice being able to spend time with her (Kim, 33-year-old caregiver).”
Grandchildren who were having time to spend with their grandparents recognized that they were benefitting from relationships that few of their peers had. While the grandchildren were frustrated that many of their friends couldn’t relate to wanting to care for grandparents to such an extent, they were aware that they were benefitting from these relationships in ways that their friends never would. This served as a mediator of stress for the grandchildren.

“I just like her, you know. I just like her as a person. Because you know how many people will talk about grandmother stories and how horrible their grandmother was and how their grandmother didn't like them. And I just couldn't even think of that! I mean, just the thought of that just really shocks me. Because we have always had such good relationships with both of our grandparents, even my dad's mom (Jackie, 35-year-old caregiver).”

For the grandchildren who had grandparents with Alzheimer’s Disease, an added sense of relief that they were getting to spend time with their grandparents before the disease made interaction more difficult was apparent. The grandchildren took both pride and pleasure from being able to help their grandparents.

“I've changed the end of her life. You know? I mean, isn't that a wonderful thing, to be able to be there and share in the end of life of somebody you love dearly? To, to ... to be there not just to meet her needs. That's not all there is about caregiving. Even with the dementia, I mean there are what I refer to as "sparkle moments." And, you know, it might be months in between one to the next. But one sparkle moment can keep you going through those months. And that's just so wonderful to have those moments with her. If she was still languishing on her own in Florida, it never would have happened. Not only do I get to share in them, but hey, I am part of creating them for her. You know, gosh, what could be better (Mary, 46-year-old caregiver).”

The ability to recognize that the grandchildren were able to help their grandparents, and took this as a source of pride, has previously been described in the
caregiver literature as ‘caregiver satisfaction’ (Lawton et al. 1989; Latwon et al. 1991). The amount of satisfaction that a caregiver feels from helping change a care recipient’s life is a strong mediating effect against the stresses of caregiving.

**Bringing Meaning to their Grandparent’s Final Days**

Several grandchildren saw the decision to take care of their grandparent as the better alternative to placing their grandparents in institutionalized settings. The pride that grandchildren took in not having to place their grandparent into a nursing home was palatable. Their comments reflected how much they valued the opportunities to create positive change at this phase of their grandparents’ lives:

“Um, yeah, the other day … my grandmother was answering a card that she'd gotten, and, um, when I really have the time -- or take the time -- to devote to doing something with her or helping her with something, um, it's really very satisfying. Um, and it kind of reminds me of why, and, you know, seeing her be able to be in her own home and not be in a nursing home and all those kinds of things. When I feel like me being here is, you know, make her life a little better or happier, yeah, then I see why I go through the hard stuff, too (Melissa, 29-year-old caregiver).”

Grandchildren took pride in being the one to provide this meaning to their grandparents’ final days, and recognized that these deeper reasons for caregiving mediated the stress of their days. This was an important aspect for grandchildren to realize. There were many times that these comments were spoken amid their frustrations of caregiving- the grandchildren used these positive moments as an anchoring point to remember why they were doing the job.

The notion that being taken care of at home brings more comfort to grandparents than being placed in a nursing home or other long-term care facility has also been
reported by spouse and adult child caregivers. (Toseland, Smith and McCallion, 2001; Schalach, 1994; Dellman and Brittian 2003). This source of pride and accomplishment is an important aspect of the positive aspects of providing care. It helps grandchildren find a deeper meaning and sense of purpose in their lives as a result of their caregiving.

_Giving Back to the Grandparent_

For grandchildren who received a lot of help and love from their grandparents growing up, a positive aspect to providing care to their grandparents was that they had received so much help from them growing up. Being able to reciprocate this care was an important function of caregiving for several grandchildren.

“I feel like taking care of another person is one of the meaningful things you can do. And -- I don't know, it's such a big thing, I don't know how to put it in just a few words. Like, you know, well, part of it is giving back. Feeling like I'm repaying what my grandmother did for me when I was young. You know, she was really there for me when I needed her, and so, it's fulfilling to be here now when she needs someone. Um, and, just there's deep satisfaction in -- you know, when the first time she wasn't able to take a bath for herself and give herself a bath, and I was able to help her with that, she was sooo happy and so grateful. And it just, you know, it's satisfying on a deeper level (Kathy, 39-year-old caregiver).”

Sometimes this notion of giving back to grandparents was a mantra that grandchildren repeated to themselves when they were having difficult caregiving days. The perception of reciprocity certainly helped mediate the stress of caring.

“Well, there's no use in having a pity party for myself, you know? I'm certainly mad about it on some days. But, no, I am convinced that I, you know, well, am I going respect my grandmother who cared for me? You know. She did a heck of a lot for me. She did a lot for me as a child and growing up. You know? And it's like, how could I possibly resent doing something for her when she needs me (Marybeth, 48-year-old caregiver)?”
Notions of reciprocity and the ability to give back to care recipients is a theme within research on spouse caregivers and adult child caregivers. (Dellman-Jenkins, Blankemeyer, and Pinkard, 2000). Adult grandchildren also feel the benefits of reciprocity when delivering care to their grandparents. The majority of grandchildren grew up with the presence of their grandparents, and while in most cases the care was not custodial, the grandparents were a consistent presence in the grandchildren’s lives. As a result, the grandchildren felt pride in being able to give back to their grandparents during their time of need.

*Learning about Death and Dying*

An interesting facet of caregiving at such a relatively young stage of the life cycle is that several grandchildren had no prior experiences with death and dying. Caring for elderly relatives who were in the process of dying de-mystified the experience for grandchildren, and made them more aware of their own life course processes. The grandchildren received a sense of peace in recognizing that they would be able to handle death and dying issues better in the future because of their grandparents.

“Uh, I would say an amazing perspective on life. You know? Like end of life issues. And I never thought I would be facing at this point. You know, I feel like I'm getting it early than most people get. So, I think that's one of the gifts that I'm learning to accept that this is a natural part of life. And so, I would say that's been difficult but I also think it's a benefit. Because my family has always kind of run from death and dying and nobody wants to say anything. We don't do funerals well at all and that kind of stuff. But, um, I'm learning that it's not all that terrible, that it'll be all right (Laura, 35-year-old caregiver).”

Learning more about the death and dying process is a theme that is not present in the previous literature on the positive aspects of caregiving. This may be because of the
life course position that adult grandchildren are in versus their older parents and grandparents. Grandchildren were less likely to have experienced death within their lifetime, particularly as an adult. Older persons are more familiar with this aspect of life and dying.

Sense of Purpose from Caregiving

Grandchildren came into the role of being their grandparents’ caregivers through many routes. Some grandchildren had to provide care because there was nobody else to do it. Some shared in the care because they felt a feeling of responsibility toward their grandparents. For some grandchildren in the study, however, they provided care because it was helping them recapture their sense of self-worth. Caregiving to these grandchildren became their identities, and the one thing that they were good at in life. For these grandchildren, the purpose of their life was defined through their accomplishments in providing care.

“My grandmother is the only place in the real world where I can really feel that I am good at something, and I am making a difference, and I am doing something with my life. It’s kind of the first time that I can feel like I’m really useful. That’s really special to me, because I don’t get to feel that way very often. Another thing that is useful is that she has dragged me out from living behind my computer screen. There are days when my behind does not move itself from my computer screen. Now, it’s like, “Do you want to go out to dinner?” I’ll be like, “Grandma, I’m doing something!” Then, she’ll say please, and we’ll go. My favorite thing is that even when she is driving me crazy, I really am being helpful, and I really am necessary, and right now, the way the situation is, it really doesn’t matter what my dad things, and what my idiot friends think. I need to be doing this, it’s my higher responsibility. It’s good. I feel really good that I’m doing this. There are times that it’s a complete pain in the ass, and there are days that I hate it, but I’m doing this because it needs to get done, and I love her (Lisa, 22-year-old caregiver).”
**Self-Esteem**

All grandchildren found that providing care to their grandparent helped raise their self-esteem. Having to take on caregiving with relatively little experience, and navigating their way through the myriad of channels to determine how to best meet the needs of their grandparents, served as a self-esteem boost for grandchildren.

“It (my self esteem) has gone up quite a bit. It’s always been up there, but now, I don’t know, you’re just not afraid of certain things. Talking to lawyers, things like that, you know? And, sometimes you learn to be a little bit diplomatic (Tony, 21-year-old caregiver).”

The self-esteem that grandchildren felt was reinforced by the people in their lives who recognized that they were taking on an extraordinary duty for someone their age. The grandchildren reveled in these comments, and found them to be a source of pride.

“There are benefits to it- I mean, it’s like how my dad and other people- family, and those who know about this- they’ll tell me that they know this is difficult for you, but we are sure it will pay off in the end. My dad keeps telling me that too, he’s like you know, you are learning so much right now. Actually, I have had a lot of people tell me that! And, people that I have spoken to at the health facility, they are like, ‘wow, you are handling all of this?’ Even the guy at the bank asked me how come I haven’t had a heart attack dealing with all of this. Like, I never realized that this was all really that big of a deal (Sue, 34-year-old caregiver).”

Even with the lift in self-esteem, grandchildren were quick to say that their caregiving was something that was overwhelming, and something they hoped would not last for the rest of their lives. It was interesting that even during the moments of the interviews when they were talking about the positive aspects of care, the notion of how overwhelming it all was apparent.

“And I’ve gained a lot more self-confidence in my abilities of what I can handle. Um, I just hope that my whole life isn’t like this. I mean, yeah, I've gained a lot
more confidence. If somebody had told me that I would have to do this, I would have said, there's no way I can do it. And, I mean, there are definitely days where emotionally I couldn't do it, but I would just kind of fake it through, you know, to get through the day (Cecilia, 43-year-old caregiver).

*Parenting Skills*

For grandchildren who had their own children, or even who were contemplating having children, a benefit of being the caregiver to their grandparents was that it prepared them to be better parents as well. This is in direct contrast to older cohorts who begin their caregiving career with infants, and end their caregiving career with assisting an older person. For the majority of the grandchildren, caring for the older person came first.

“In a good sense, I think I feel like I've learned that I'm capable of doing more than I thought I might be able to. Um, because I grew up in kind of a chaotic household, I sort of questioned my own ability to have my own kids and be able to be a good parent. And so, caregiving for my grandmother has kind of been a way to practice that and actually do it. And, while I haven't been perfect, I think that I've been enough that I feel like I could actually be a parent (Georgia, 28-year-old caregiver).”

The granddaughters often equated caregiving to being a mom, and that the tasks of caregiving made them feel more capable as parents. They noted that as a person provides care for longer periods of time, they become more used to it, less scared of it, and better able to handle the stress associated with it.
Chapter 7: Available Supports and Needs of Adult Grandchildren

A central component of this research is to determine the available supports and needs of grandchildren providing care for grandparents. Past research shows that adult children and spouse caregivers utilize a variety of given supports. They seek information from friends and colleagues, use a variety of formal services and attend support groups to help ease the burden of caregiving. This section will discuss the social supports that grandchildren rely on, the formal supports that they utilize, and finally, the role of support groups in their caregiving efforts.

Social Support for Grandchildren Providing Care to Grandparents

Past research has shown that social support is an integral part of buffering caregiver stress. Having a network of support mediates the stress that caregivers experience, increases the quality of care that caregivers provide, and decreases overall caregiver burden. Grandchildren usually rely on siblings, friends, parents and even their grandparents for this social support.

Sibling as Support

There are a myriad of people who recognize the efforts that grandchildren put into their caregiving. Because grandchildren are part of three generations, the support that they receive also comes from three generational layers: their siblings and friends, their parents, and finally, their grandparents themselves. The acknowledgement of a job well-
done does not automatically transfer into additional support for the grandchildren, but they do realize that people see their efforts.

For several grandchildren, they were the grandchild that was either chosen, or volunteered, to provide care for a grandparent. Their siblings often were minimally involved with that care, and while the grandchildren were grateful that their efforts were recognized, it was also frustrating for some to not be provided with more support by their siblings.

“Well, it's funny, because one of the last conversations I had with my sister, when it was clear things were falling apart, I said, OK, here's the deal. I'm taking care of Grandma. You get Mom and Dad. We kind of divvied it up. I don't think my parents will fare as well. It's karma, what can I say (Heather, 30-year-old caregiver)?”

What is striking in the above quotation is how solitary the granddaughter is in her caregiving, and while the sister acknowledges that yes, she is providing care, there is a definitive divide between the sisters. The subtle dig at the sister’s caregiving abilities is actually very common for the grandchildren providing the care- they recognize that the reason they are the ones doing this job is that they are a better fit for their grandparents than their siblings. This struck me as a sort of sibling rivalry/resentment. For some grandchildren, this further alienated them from their siblings because of expectations of inheritance.

“So I have a brother and my dad, but because my dad remarried, he wasn't really much of a fixture. Only kind of to drop us off. My brother just -- you know how there's always one in the family who does all the work? That's me. My brother is resentful of all of the legal designations and financial arrangements being controlled by me. He's mad because he's worried that the will is not divided equally. I don't think he's mad that he doesn't have control of their bills, you
know, paying them, stuff like that. But yeah, that's what he's mad at (Laura, 35-year-old caregiver).”

The stress in the sibling relationship as a result of one grandchild doing the bulk of the caregiving was apparent with almost all grandchildren who had brothers and sisters. The reasons why they were the ones helping and not their siblings varied—geographical distance, age, and even gender. The end result was that siblings were available to vent to, and were supportive overall of the choices that the grandchildren made, but grandchildren usually did not go to their siblings as a preferred mode of support. And, for most grandchildren, the ability to make decisions for their grandparents, without having to pass their decisions through their siblings, was the extent of support from brothers and sisters.

“My oldest brother moved to Florida with his family. But he's not about to try to help out. He's not one of those siblings that tries to pretend he is. Fortunately, I don't have any siblings telling me what I'm doing wrong. And that's something—they aren’t criticizing me (Patty, 40-year-old caregiver).”

This perception that siblings are available as people to vent to and to provide support in the events of an emergencies mirrors the importance of the perception of available support from past research (Chappell and Reid 2002; Gold, Cohen, Shulman, Zucchero, Andres & Etezadi 1995).

Friends as Support

Friends play a crucial role in supporting the caregiving efforts of grandchildren. They often sought out friends to provide respite, talk through their situation with, and also utilized their friendship networks as a way to take a break from caregiving. The
complexities of the way friendships change as a result of caregiving have been discussed; however, the way that grandchildren rely on their peers for support deserves mention.

An interesting aspect of the friendships of grandchildren who provided care was that the oldest friends were usually the ones who were the most reliable in terms of helping provide substitute care for the grandparents. This was an important aspect to friendships, because the friends who had been in the grandchildren’s lives the longest were also the friends who most likely knew the grandparents prior to their illness. As such, they were able to provide support to the grandchildren by giving them breaks in their caregiving.

“A lot of friends knew she was around, knew her before my grandma was totally going crazy, and they really like her. So, they really put up with her. One of my friends would give my mom and I a break from caregiving by coming over and hanging out with my grandmother for a few hours (Lisa, 22-year-old caregiver).”

The presence of friends allows grandchildren to vent about their caregiving situation without the conflict of interest that family members present. They would often take time to call friends to complain about their grandparents, seek advice for situations, and simply ask for support.

“I have found that I have some really good friends because they've been awesome with me. I do talk about it all the time because I just need to get it out there. I'm always bouncing stuff off of them, and at least they listen (Meagan, 36-year-old caregiver).”

Even with having friends willing to provide breaks from caregiving, it is astounding that most caregivers had very little time off from the pressures daily life with their grandparents. For those who did get away, they often relied on day trips with
friends to help give them respite. These served both as important sources of support and as important links to friends.

“I had one day where my best friend came. I had a caregiver come into the house and my best friend came and she and I went for a day and hit the spa for a day and had a little facial, pedicures, manicures and massage, you know? So we did those, but that was my only day off (Stephanie, 29-year-old caregiver).”

Because friends who were not caregiving could sometimes not relate to the issues associated with caring for grandparents, grandchildren actively sought out friend groups, both in person and online, to create networks of friendship support. Feeling needed, and offering advice and support to others, was a constant theme with the grandchildren in the study. This, in turn, provided sources of support for the grandchildren.

“I have friends online. The great thing about being involved with the things I’m involved in is that the majority of them are women between their 40s and 50s, so what I have is like a built-in support group, because what I have is all of these women who are dealing with the same stuff with their parents. I can post comments like, “I am hugging you, I am thinking about you, I know how hard it is, I’ve been there, I’ve done that, and I am here.” And, I get the same responses from my online friends (Liz, 31-year-old caregiver).”

Patterns of reliance on friends to ease caregiver burden were different for adult grandchildren than for other cohorts for two reasons. First, grandchildren typically had current friends who knew the grandparent when they were children. As such, they were able to better identify and relate to the changes that the grandparent had gone through because of their illness and the aging process. Second, adult child caregivers are older than are adult grandchildren who provide care. As such, the space of time between their own childhood and caregiving is greater, and their friends who may currently know the aging parent were less likely to have known them growing up. The second difference in
friendships for adult grandchildren is that they are from a generation that is more likely to use the internet for social networking. This provides adult grandchildren with more alternative ways to keep in touch with outside friends and to make new friends than we have seen with other cohorts of caregivers. The grandchildren had to find alternative friendship networks to provide them with a commonality to draw upon for helping them provide care to their grandparent. For adult child caregivers, those friends are more likely to be embedded in every day acquaintances because more of their friends are going through similar phases (Bainbridge, Krueger, Lohfeld & Brazil, 2009). Friendships made over the internet were unique sources of friends to fill this void for adult grandchildren.

Parents as Support

For the grandchildren who had parents present, their support and approval was an important asset for the grandchildren to have. Several parents shared the caregiving load with the grandchildren, and others, unable to care themselves for the grandparents, took strides to make sure their children understood how appreciated they were. This recognition of efforts and thanks was enough ‘support’ for grandchildren. The hoping for the recognition of their efforts reflected grandchildren’s need for their parents’ approval and love. While most grandchildren did not partake in caregiving because their parents forced them to, they did enjoy hearing these comments.

“My mom thanks me constantly. The thing is, sometimes, occasionally, she won’t realize it, but she does say thank you all the time. Or, we’ll be talking about something and she’ll go, “You know, I really don’t say it enough, but I cannot do this without you. I know that she will eventually get and aide and I won’t rely on you so much. But, until then, I want you to know that I really do rely, and that you are doing this job and not getting paid and are really not getting
any recognition for it, and I am very grateful, and I recognize that you are doing all of this work. It’s great, she is really good about that (Kim, 33-year-old caregiver).”

The role of parental support for adult grandchildren who assist grandparents is qualitatively different from parental support to adult children providing support to their own parent because of the intergenerational component. For grandchildren, parent’s support/approval is for the care of their own parent rather than for their spouse, and because of this, the need for their acknowledgement is higher for adult grandchildren than it seems to be for adult children providing care to a parent.

*Grandparents as Support*

For several grandchildren, the acknowledgement and support they received from their actual grandparents was an immense source of pride and well-being for them. Grandchildren were grateful for the praise of their grandparents, and often, this was the only acknowledgement of their efforts that they received. Because of this, it is necessary to list grandparents as the last source of social support for grandchildren.

“My Grandma thanks me everyday. I mean, bless her heart. I am one of the fortunate ones. Because some people, I’ve heard their stories that the older they get, the nastier they get. And that hasn't happened with my grandma. She's a glimmer of the person she used to be, but she's still the person she was and just very accommodating and she tries to be a trouper and everything. So, and she thanks me a lot. And I get -- she actually embarrasses me. Because we'll be at some event and she'll say, oh, this is my granddaughter, she does everything for me! She works so hard, blah blah blah. You know? It's sweet, but this is getting embarrassing. I'm like, oh, Grandma, that's OK. You know, you're my grandma. That's my thing. You know, I do this because you're my grandma. That's all you have to do is be my grandma (Jackie, 35-year-old caregiver).”
This quotation exemplifies both the strong bond between the grandchild and the grandmother, as well as the acknowledgement that it is unusual for granddaughters to be taking on this amount of care for grandparents. The grandchildren reveled in such adoration, and were grateful for the support and acknowledgement of efforts by their grandparents.

The Use of Formal Support

Adult children tend to use formal supports such as respite care, and home health aides and even assisted living communities in conjunction with their caregiving from the outset, whereas spouses tend to use these supports as a last resort, when the burden of care is overwhelming and they have to utilize them. The grandchildren that were interviewed did not feel inadequate as caregivers because of the use of alternative caretakers; if anything, they accepted this as part of their strategy. This may be because they were born during a social era when the stigma of outsourced care was lessened—many of the grandchildren grew up receiving childcare from daycare centers, and saw their own parents use a complementary model of support. The fact that they were younger and therefore less likely to be expected to solely provide care is another factor involved in why grandchildren used a complementary model of formal support. An example of this would be the conflict of working full time and providing care. The majority of grandchildren did not forgo a professional career to provide care, rather, they hired help for their grandparents when they were not able to physically be there. Because
grandchildren were at the beginning of their professional careers, opting out of the formal employment sector was usually not an option.

“Well, I share my caregiving responsibilities with a lot of other people. Um, I also work full time and so, when I'm at work, there is someone coming to -- there's a local service agency called Catholic Community Services, and it started out with just the four hours a week of respite. But then we added because her needs increased -- she can no longer be left home alone -- we started getting people more and more often. And right now we have people coming in six days a week (Debbie, 38-year-old caregiver).”

Grandchildren readily use adult day care, companion services for their grandparents, and home health aides. Often, these are a bridge between the grandparents being able to live either independently or stay for the day in the house without the grandchild’s presence or moving into assisted living facilities. The daily preparation that the grandchildren went through in order to execute and facilitate this care was immense.

“Yeah, she goes to day care. I work full time. I work out of the house. Outside of the house. She really can't be left alone. I get up, we get up between 6:30 and 7, usually. We get her into the bathroom, get her started, you know, I've got her into the regiment of; you know, even though she has no teeth, she has full upper and lower dentures. We have a very soft baby brush, brushing her tongue and cleaning all the bacteria. So we do that and she rinses with a mouthwash and puts her teeth in, get her face washed, put her face cream on, go to the bathroom, take off her panties. We use, um, you know, adult protective undergarments. So we take off her dirty panties, put a clean one on. She cleans herself -- that's a big thing, making sure she cleans herself properly. And, um, then back into the bedroom and get the pajamas off, pick out what she's going to wear for the day, get her dressed. She has a specialized device that I have to put on her leg that prevents the inflammation or swelling from the ademia. So we have to get her leg into that. So I get that on her, get some shoes on her. And we go downstairs and get her coffee, breakfast, all that good stuff. Then we, um, the daycare she goes to has a transport van. They pick her up. It does take a big load off of me to have them pick her up. They come to the house and pick her up. They're usually here about 8:30. And then she goes on into the daycare and I go to work and then they, the bus drops her off at my office about 5 o'clock (Julie, 40-year-old caregiver).”
Even in cases where the grandparents did stay home alone during the day while the grandchildren worked, they usually did not spend the entire day in isolation. Grandchildren took great steps to be sure that the social and physical needs of their grandparents were being met while they were at work. The following quotation exemplifies the wide array of services most grandchildren used in order to facilitate smooth days for their grandparents while they are at work.

“Right now, the situation is such that we have home meals delivered three days a week. That is really for my piece of mind that a) he’s getting something to eat during the day, because otherwise he’d just eat cereal, and b) there is a second person checking in on him. Because usually, my husband and I have left for the day, and I am down Albany for the day, and it’s human contact, it’s someone else for him, and it makes him get up, get dressed, forces him to get up and do things that he wouldn’t do if he didn’t have to. Two days a week, there is a home health aide that comes in. Once a week, he gives him a bath, but he vacuums up his room, changes his bed, does some personal care- lotion, that type of thing. What I also have set up is twice a week, someone from a respite agency comes and takes him to lunch. So, he’s getting out. Because, we’ve tried, do you want to go to the senior center, and no, he doesn’t want to be around those old people (Dawn, 43-year-old caregiver).”

The grandchildren who had their grandparents at home during the day while they were at work had to deal with concerns about the grandparents’ safety, comfort, and the level of care provided for them in the grandchildren’s absence. At times, this came with risk to the grandchildren’s reputations as competent caregivers.

“Once we got my grandfather home, it was a patchwork of people coming in, aides coming in. I had hired some aides. And, that was not going well. Particularly in the beginning, because it was different aides, and he is not really forthcoming with people, so you have gotta have the same person all the time in order to catch the nuances of his behavior, to see what he is doing and not doing, and at one point, because someone had not placed a phone call to me to say he needed money- because they were doing grocery shopping for him, and doing a lot of things for him. I tried not to rely on his neighbors too much, because I
knew…they had offered to help, but I wanted them as a back-up. So, what ended up happening is that I did not send money quickly enough, and someone called the office of aging to say that I was stealing his money, and it was a whole big thing, and I get this phone call that you need to be there. In the meantime, there was a whole financial mess (Julie, 40-year-old caregiver).

It was astounding that grandchildren were so quickly accused of mismanaging their grandparents’ finances when obtaining formal support services for them. Most grandchildren had never navigated these channels, and were doing so without the benefit of having the legal Power of Attorney. This was a stressful part of utilizing formal services that adult grandchildren suffered through that older caregivers seemed to be able to avoid. Their age, their distant relationship, and the fact that they did not have legalized financial control of their grandparents’ assets all served to discredit their abilities in setting up formal care.

The cost of this formal care was a burden for several grandchildren. For many, whether the services available were covered through formal channels dictated whether the grandparents would be the recipient of such services. This was particularly hard on grandchildren, and in the absence of formal care, they had to make drastic changes to their own schedules in order to fulfill these needs. The following quotation is an illustration of this.

“The way that Medicare works, you’ll only give you an aide if you are homebound, except for doctor’s visits- and the thing was, she wasn’t homebound, she just couldn’t use her arm. So, she just wound up being stranded in her house for like 8 hours a day. Which certainly didn’t help the cognitive decline. So, we now usually spend time with her usually about 5 days a week, and of that, I usually see her at least 4 days a week, and I usually spend about 10 hours a week alone (Kim, 33-year-old caregiver).”
Grandchildren lamented the possibility of having to decrease the amount of care that their grandparents received because of budgetary reasons. This served as a source of strain for them. Coordinating these services, and the people coming in and out of the grandparents’ houses served as sources of stress for grandchildren. Few grandchildren utilized free formal services— they were unaware that they existed, or felt that it was too burdensome to set up.

Sometimes, providing care for grandparents was too overwhelming to provide either within the grandparents’ homes or in the grandchildren’s homes. For these grandchildren, finding more comprehensive models of formal support was a necessity. Several grandchildren moved their grandparents into assisted living facilities because the grandchildren were aware that they could not emotionally and/or physically provide for the grandparents fully on their own.

“Well, my grandfather passed away in 2004 and up until that point, I wasn't providing any care. And then after he passed away, we made a family agreement that one of us—meaning me, my father or my brother—would come to visit my grandmother every weekend. We would take turns. So once a month, we would drive the three and a half hours to her house to make sure she was doing OK. And then over the course of a year, a lot of things changed. My dad got remarried and that caused some turmoil. And basically everyone stopped going but me. And, um, I did that until July of 2006, when she fell and broke her ribs and I realized she couldn't stay by herself. And then I had -- I had been in the process of investigating assisted living communities near my home, and so I had gone down there to see how she was doing and I realized we couldn't move her, so we just packed up her stuff and moved her into an assisted living place by me Kathy, 39-year-old caregiver).”

Grandchildren whose grandparents had moved into assisted living facilities were still very much involved in the day to day care of their grandparents. They were still
accountable for their grandparents’ finances, and any physical care that the grandparents needed that was not routinely taken care of by the facility.

“I'm over there pretty much every day. Um, even though it's assisted living, he doesn't get the care that I would like to give him. Um, I go over and I change his clothes. I spend about an hour every day there. As a matter of fact, that's why I just walked in the door. I came from helping him out. Um, he has skin cancer, and certain living facilities don't do certain things because of state regulations. He has open wounds from skin cancer and so I have to go change his bandages. I go to see him pretty much every day (Dawn, 43-year-old caregiver).”

Almost every grandchild interviewed used some sort of formalized support. The sources of this support varied, from home health aides, respite care, companions, to more inclusive formal support from assisted living facilities. Regardless of the type of formalized care that grandchildren utilized, the general theme was that grandchildren do not utilize a substitution model of formal support usage when caring for grandparents. Their experiences much more mimic the usage patterns seen by adult children, who are also at younger points of their own lives, and unable to drop everything to become full-time caregivers.

*Support Groups for Caregiving*

Unlike spouses with elderly husbands or wives that are ill, or even adult children who are caring for a sick parents, adult grandchildren do not utilize available formal channels of support to help them emotionally deal with the negative effects of providing care. The reasons that grandchildren shy away from this support are nuanced and multi-layered. Most grandchildren are either unaware that such supports exist, find that they do not have time to utilize these supports, or find that existing supports designed for
caregivers are aimed at the life event/balance issues of older caregivers, and do not apply to their needs.

The majority of grandchildren had not tried to access any formal support groups for caregiving. They were unaware that caregiving support groups existed, and did not know what a support group could even offer. As a result, their caregiving experiences seemed to be that of isolation and having relatively few outlets to discuss their burdens.

Some grandchildren did attend support groups for caregivers. There were two kinds of support groups- face-to-face groups and online groups. Overwhelmingly, the grandchildren who attended face-to-face groups felt out of place there, and did not feel that the content met their expectations.

“I started out going to a support group for a while, but that was not very helpful. Um, so, I guess I just sort of plan it as I go along. The moderator was awful. She like, she was judgmental, she…I wanted to talk about thing like life-balance issues, she made it out like I was the only one in the group who had that concern, and it just wasn’t for me. It just wasn’t a good fit (Denise, 39-year old caregiver).”

This observation was very typical of grandchildren. Their experiences were compared to others’ experiences within the support groups, and because their relationship was a generation removed, they often felt that their issues were very different, and sometimes minimal, compared to the other attendees.

“We go and we talk about what's going on in our lives and that's been very enlightening for me. Because when I got there the first night and they went around the table, you know, I was feeling really overwhelmed and everything. By the time they got to me and I listened to all these ladies' stories, I was like, oh my God. I don't think I even qualify to be here. I said, you know, I'm taking care of my really sweet grandma. And I'm a little tired. I mean, relative to what some of these women were going through, you know, I felt like perspective was very
valuable (Sue, 34-year-old caregiver).”

The experiences of face-to-face support groups being inapplicable to the experiences of adult grandchildren, feeling out of place, or that the content did not meet their needs are different from the reasons for support group dissatisfaction typically exhibited by adult children or spouses. These two groups more often cite accessibility, personal factors, concern for confidentiality, and not knowing group members as primary reasons for dissatisfaction with face-to-face support groups (Toseland et al. 2001; Mittleman et al. 1993). In fact, the overwhelming reason that grandchildren felt alienated from support groups was due to a mismatch between the grandchildren and the target populations for the support groups, namely, adult children and spouses who provided care. This notion of compatibility has been noted in previous research (Monohan 1994).

While face to face support groups were not met with satisfaction from grandchildren providing care, they did have more success utilizing online support groups. Unlike face-to-face groups which were not aimed at the needs of younger caregivers, there were online support groups completely aimed at the younger caregivers. The grandchildren that I spoke with were more likely to utilize this form of support, and found that the bonds that they made with caregivers here were often their only link to outside peers who understood the unique challenges of caregiving at a younger stage of life. The online groups were aimed at a young caregiver, not solely at young caregivers providing care to a grandparent.

“I am online checking messages with my friends in that group every day. I’ve really gotten to know the people there, and they know the most about my
grandmother. I don’t have to start over each time something happens, and they remind me to take care of me (Liz, 31-year-old caregiver).”

Some grandchildren never actually utilized the message boards to post their own concerns, but used them to garner support just by reading. The availability of that support, and knowing that it was there if they did ever need to use it, provided a sense of well-being for grandchildren. This practice was referred to as ‘lurking’. Another practice was to enter chat rooms. The chat rooms were not as popular with the grandchildren, simply because it was difficult to find people to chat with in ‘real time’.

“I keep kind of looking for like chat rooms or something. I’ve been to a lot of caregiving sites that have chat rooms, and you go in and nobody's there. It's humorous. One of the things I noticed is that I hadn't gone to the caregiver group in like four weeks, and it was because I was so busy caregiving. I just couldn't go, you know? And so it's sort of a cyclical thing where you can't really help yourself because you're in the middle of it. But sometimes you have to jump out of that loop and try something different. So, yeah, I do look at the Web sites (Stephanie, 29-year old caregiver).”

The grandchildren I spoke to were very technologically savvy, and were experienced with a variety of online resources not only for garnering support from others, but also to learn more about the illness that their grandparents had. These information networks were preferred to asking doctors questions, reading books on illness, or even going to local support centers, such as the Alzheimer’s Association, for disease-specific support. As a result, the search for both emotional support and information on disease often were solitary activities that caregivers performed on their own, when they had time, which was usually at night. This is not to say that grandchildren relied on nobody else to
provide them with emotional support and acknowledgement of their caregiving. Rather, the bulk of this support was through informal, rather than formal, channels.
Chapter 8: Conclusion

Grandchildren provide an integral role of support for grandparents in today’s society. This research project reflects the complexities of the situation for grandchildren who provide intensive care to grandparents. They are active in their roles in supporting both their parents and their grandparents through this service, and as a result, our understanding of both what grandchildren do, and who encompasses the role of caregiver, deserves expansion. The six themes that this research specifically examined will be discussed, and the implications of these findings will follow.

Why/Under what circumstances adult grandchildren provide care for their grandparents

There are several circumstances through which adult children end up providing care to grandparents. Grandchildren feel intense feelings of reciprocity toward their grandparents, even if the grandparents were peripheral to the nuclear families while the grandchildren were growing up. These feelings of reciprocity often were developed out of having a life-long close relationships with the grandparents. The grandchildren who stepped in to help grandparents during their times of need were usually the ones who also could claim the closest relationship with their grandparents. These feelings of reciprocity usually were to the grandparents for being a presence in the grandchildren’s lives, rather than providing help to grandparents as a feeling of reciprocity toward the grandchildren’s own parents. This theme of reciprocity was similar for adult children and spouses who provided care.
Some grandchildren took on care due to locational proximity. Like their older contemporaries, grandchildren closest to the grandparents physically often were the ones who were helping in their care. Interestingly, the grandchildren physically closest to the grandparents were also the ones who had chosen to live physically closest to the grandparents because of life-long relationships with those grandparents. Some grandchildren who were the caregivers to their grandparents were closest in locational proximity to them only because the grandparents had no spouses, children, or other grandchildren living to provide them with care.

Grandchildren also exhibited strong feelings of responsibility as a reason for why they provided care to their grandparents. For several of the grandchildren in the study, nursing home placement was something to avoid at all costs, and this was a value that had been instilled in them from a young age. Unlike older generations, however, adult grandchildren did not provide care and keep their grandparents out of nursing homes with the hopes that they too would be provided care by family members. This is a theme that resonates with adult child and spouse caregivers, but was not one that was mentioned among adult grandchild caregivers. For those grandchildren who provided care because of a sense of responsibility, the fact that they sometimes did not get along with the grandparents did not excuse them from providing this care. This usually occurred when grandparents were sick, and the middle generation was either too sick to provide care, absent because of intergenerational conflict, or deceased. In these instances, the feelings
of responsibilities were stronger facilitators of providing care than were feelings of reciprocity.

Similar to gender dynamics which dictate that adult daughters are more likely to provide care to parents than are adult sons, adult granddaughters were more likely than adult grandsons to be in the position of being caregivers to their grandparents. Gender and sibling order were interrelated for adult grandchildren; if the caregivers had siblings, they usually were the oldest siblings except in cases of having older brothers. Older brothers, unlike older sisters, felt excused from providing care for several reasons according to the granddaughters in the study. They cited that grandsons usually felt they couldn’t do the job, had family and work responsibilities, or lived too far away to provide additional help to their grandparents.

The grandchildren who were involved in providing care were usually providing very intimate hands-on care, except in cases where they hired professionals to bathe their grandparents. They typically helped their grandparents with a great number of activities of daily living, coordinated all doctor appointments, managed the grandparents’ finances, and provided social support to their grandparents as part of their roles as caregivers.

*How the dynamics of the existing grandparent/grandchild relationship affects caregiving processes of grandchildren*

The most common intergenerational triangular dynamics that existed prior to grandchildren providing care to grandparents were that all three generations were connected and close. This inter-connectedness provided the necessary background for
the grandchildren to be close to the grandparents throughout childhood and into adulthood. For families with intergenerational connectedness, caregiving was most often characterized by frequent exchanges with all three generations, and a caregiving team approach.

A second theme was intergenerational disconnect. For some grandchildren/grandparent dyads, their relationships had flourished earlier in life because the middle generation was estranged from either the grandchildren or the grandparents. Within these caregiving dyads, the care was usually supplemented by fictional kin or neighbors, and the grandchildren had more resentment toward the middle generation for not fulfilling a filial role to their grandparents.

The final theme in intergenerational triangulation which was present was the actual absence of this triangulation because the middle generation was not present due to death. In cases where the middle generation deceased, a strong intergenerational bond from earlier in life allowed connections to grandparents to continue even when the middle generation could not contribute in the same way. The feelings of loss that grandchildren felt when their parents were deceased was a theme that is not present in previous literature on caregiving. The anger and resentment toward parents for dying, even if the grandchildren loved their grandparents and were willing to take care of them, are things that is simply were not present in two-generation caregiver dyads.

*How Caregiving for a Grandparent Affects the Grandchild/Grandparent Relationship*
There are several changes to the grandchild/grandparent relationship that occur as a result of having to take physical care of grandparents. These changes are largely undocumented in current literature on grandparent/grandchild relationships, largely because the existing literature focuses on healthy grandparents. The grandchildren in the study had difficult times with the role reversals that occurred once they were providing care to their grandparents. Grandchildren found that they had to be assertive with their grandparents, had to be the ones to set boundaries and rules, and even had to upset the grandparents at times if they disagreed with a grandparent’s course of action.

Grandchildren found themselves having to make the majority of decisions on behalf of their grandparents. Medical decisions, financial decisions, and even end-of-life decisions were left to the grandchildren the majority of the time. While the grandchildren appreciated the amount of trust that their grandparents exhibited in them, they also felt burdened by the sheer responsibility of having to make all of the decisions.

A very difficult part of caregiving for several grandchildren was the necessary crossing of physical boundaries in order to provide intimate care to their grandparents. These grandchildren had not had to see their grandparents naked before, and exhibited hesitation in bathing or helping their grandparents with the bathroom. Granddaughters were likely to hire outside professional home health aides to help bathe their grandparents rather than have to break that social norm. In instances where the grandparents did have to be cared for by the grandchildren on such an intimate level, they tried to arrange
monetary compensation as a way to deal with the intrusion for both the grandchild and the grandparent.

A major change in the relationships between the grandchildren and grandparents as a result of providing care to the grandparents were the notions of guilt and burden that grandparents felt for having to be cared for by their grandchildren. This was difficult terrain for grandchildren to navigate, because they either were uncomfortable with too much praise, or were having to reassure the grandparents that they were not a burden, when in fact, they were. This interplay between grandchildren and their grandparents is different than what is typically seen with caregiver dyads who are parent/child or spouse partners. The acknowledgement that the grandchildren were in stages of life where caregiving was overwhelming and an off-time event was a salient concern of grandparents, and while the grandchildren appreciated the acknowledgement, they were unable to truly confide to the grandparents the extent of their burden.

The Negative Effects of Providing Care

The grandchildren in the study were forthcoming about the various negative effects of providing care. Caregiving came at a time in their lives where they were juggling many other responsibilities, and the strains that the caregiving created were vast. These strains included disruptions in caregivers’ roles as workers, romantic partners, friends, and parents.

Caregiving created role strain for grandchildren because many of them were at the beginning stages of their careers. Because these grandchildren did not have a lot of
seniority or a lot of vacation/sick days to use, and were not eligible for FMLA coverage, they had to seriously consider whether to even disclose to coworkers that they were providing care to grandparents. Often, the grandparents, or the necessities of providing care to grandparents, were invasive enough that grandchildren did disclose their caregiving status so that their job performance would not be seen as negligent. Sometimes, grandchildren found additional support in work settings, because coworkers were also caregiving for their own family members. No grandchildren were able to use any formal support or policies provided at jobs. The grandchildren studied either did not know if any formal supports existed, or they were excluded from these formal policies because the relationship status between a grandparent and a grandchild was considered too distant to merit accommodations. Grandchildren were often overlooked for promotions, or had to outsource care to their grandparents during work hours in order to still be considered for advancement at work. The balance between work and caregiving was a precarious one and for some grandchildren, working full-time and providing care to their grandparents became feasibly impossible as the grandparents became sicker over time. As a result, for a subset of the grandchildren, the stress associated with work and caregiving came from disrupting their careers to provide care, and the long-term consequences that decision would have on both their career advancement and retirement savings.

Grandchildren had varying degrees of romantic relationships which were strained because of their caregiving duties. In general, these degrees included avoiding romantic
involvement while caregiving, dating while caregiving, dissolving relationships because of conflicts with caregiving, starting romantic relationships while being a caregiver, and grandchildren who were in long-term relationships which pre-existed their caregiving duties. All grandchildren, regardless of their relationship statuses, felt the strain that caregiving put on their romantic involvements. The stresses of caregiving challenged their abilities to fully give to relationships, and unless that relationship was pre-existing and secure, several grandchildren found that they were unable to participate fully as a partner. Further, even those grandchildren in long-term relationships felt that the spontaneity was removed because they could not find time away from caring for their grandparents. This theme was consistent with other caregivers.

Grandchildren were similarly strained in their friendships. Many of the grandchildren felt out of synch with their friends, as their caregiving duties took both time and commonality away from them. Other grandchildren noted that their friendships were an important source of support for them, and that their friends could be a sounding board for grandchildren especially when topics were too sensitive for other family members to hear. The uniqueness of the relatively young age of grandchildren who provided care resulted in a dilemma with friends that older generations do not experience. Grandchildren’s peers were at a phase of life where they were either very busy socially, going out at night and socializing at bars/clubs, or in the beginning stages of child rearing. For those grandchildren who were single, they resented not being able to also go out with their friends. Not having children for some grandchildren posed a serious
disconnect between them and their friends, especially when the grandchildren were
delaying childbearing because of their caregiving responsibilities. The disconnect
between friends was less stressful for grandchildren who were parents- this may have had
to do with having less overall time to commit to friendships because of their children, not
because of their grandparents.

Caregiving for grandparents had serious consequences for both the planning for,
and the time and attention given to existing children. For some grandchildren, the
decision to have children was one that they could not even contemplate because they
were so overwhelmed with caregiving responsibilities. These caregivers were typically
in their late twenties and early thirties, and the competition between needing to spend
their time providing care and their own biological clocks was something that was
stressful for them. For grandchildren with children, a major conflict was the attention
needed to provide their grandparents with adequate care competing with the attention
needed to raise children. A common strategy for these grandchildren was to hire out the
care of their children while performing the majority of grandparental care themselves. As
the children of grandchildren became older, they were likely to become assistants to the
grandchildren, helping with the caregiving tasks. These grandchildren were thankful that
the opportunity to have their children see them providing assistance to grandparents, but
were adamant that they never wanted to see their own children take on the same levels of
care. The general theme of the competing needs of children and their grandparents is a
discussion that is not commonly seen for adult children who provide care. This may be
because the children are typically older in these families, or because the grandparents (rather than the great-grandparents) have a closer, more well-defined, relationships with their grandchildren.

Financial concerns were plentiful for adult children providing care to grandparents. The majority of grandchildren did take some role in the financial management of their grandparents’ incomes, and all grandparents did have independent funds to help with the cost of the care. However, this money was often not enough, and the majority of grandchildren had untold personal expenses that they did not account for in their reyling of the costs of providing care. Grandchildren felt the budgetary restraints of caregiving, and often had to supplement the costs of the care with their own family budgets. Strain with other family members was a common theme among grandchildren, and the grandchildren’s role in being financially responsible for their grandparents’ funds often was in conflict with the wishes of other family members. Grandchildren were accused of mismanaging funds, caregiving for the sole purpose of receiving bigger inheritances, and not having enough life experience to make appropriate financial decisions. At times, this pressure was so great that grandchildren refused to partake in the financial management of their grandparents’ assets. This was particularly pronounced for grandchildren who had the middle generation still living and involved with the care.

Caregiving for grandparents caused grandchildren to have a variety of physical, emotional and mental complications. The primary stressors that the grandchildren cited
as problematic included being overwhelmed with the amount of care their grandparent needed, and feeling stressed because the grandparent felt that they were being burdensome to the grandchild. As a result of the overwhelming tasks of caregiving, several grandchildren felt intrapsychic strains, mental illness and depression, and physical stress. Often, these grandchildren were concerned that they were not doing enough for their grandparent, and that they had few previous life experiences from which to draw to help them with caregiving. This pattern was different from previous generations, who are more likely to have started caregiving at a later point in their lives when they had already taken on other caregiving responsibilities. The vulnerability that the off-time event of caregiving had for grandchildren often left them seeking counseling or medication to help them deal with the stress. Others were caregiving precisely because they were mentally ill, and while the tasks of caregiving were overwhelming for these grandchildren, they were comforted by the notion that by providing this care, they were in a sense being worthwhile. Physical stress as a result of caregiving came in the form of complicating existing medical conditions, or creating new ones such as weight gain. Mediators of stress for adult grandchildren providing care included feeling a sense of mastery due to one’s gender (particularly for women), taking time to do other things outside of caregiving, positive affect, and confiding in others when caregiving because too stressful.

*Positive Effects of Providing Care*

Grandchildren cited many positive outcomes for providing care. Some of these outcomes mimicked what adult children and spouses claim are the positive effects of
providing care, and some were exclusive to grandchildren. Among the positive effects, grandchildren felt grateful to be able to get to know their grandparent on a different level, they enjoyed their grandparent’s company, they were proud that they were able to bring meaning to their grandparent’s final days, they were cognizant that they were able to give back to the grandparent through caring for them, they learned more about death and dying, they gained a sense of purpose from their caregiving, and experienced lifts in self-esteem due to their caregiving. Finally, some grandchildren noted that their own parenting skills were enhanced by providing care to their grandparent, and that this would serve them well as they became mothers themselves.

Available Supports and Needs of Adult Grandchildren

Grandchildren relied on a variety of social supports to help them buffer the strain of caregiving. Namely, they were likely to seek advice and vent to their siblings, their friends, their parents, and were even able to gain support from their grandparents themselves. The extent that grandchildren used the internet as a source of social support was notable, and this form of keeping in touch with friends allowed them some flexibility in keeping in touch with them while also providing care. Likewise, several grandchildren found support through online friends who were also caregivers.

The extensive use of formal services was a necessary combination for adult grandchildren providing care. They utilized a variety of formal resources to help provide care for the grandparents who were living independently or with them, and often utilized this support while working. This was in line with the way that adult children use a
complementary model of social support to ease the burden of caregiving. Grandchildren, while resistant to placing grandparents in nursing homes, did not have a social stigma associated with placing them in assisted living facilities. For several grandchildren, this setting allowed them to maintain an active role in providing care, but also allowed others to formally step in to help the grandparent when they could not. Restrictions to formal care came from budgetary constraints, not from a negative association with asking for help from formal channels.

Grandchildren rarely used support groups as a mean of support for themselves. For grandchildren who tried attending these groups, they often felt that they had little in common with the other participants, who were usually adult children or spouses of care recipients. The end result was that most grandchildren used them sporadically, and did not return. A more common source of support groups for grandchildren was through online support chat rooms and discussion boards. This was a medium that grandchildren were comfortable using, and the likelihood of finding another grandchild or young adult caregiver was greater through this channel. As a result, the grandchildren in the study had a wide array of supports that they had never met face-to-face, but with whom they were comfortable sharing intimate details of their caregiving experiences.

Implications of Research

Contrary to the absence of research which would imply otherwise, grandchildren are actively participating in providing care to the elderly population within the United States. This care often comes at the costs of a grandchild’s own life course direction.
There is no one solidifying family form that makes caregiving a more likely pursuit for some grandchildren—regardless of family type, it is a venture that grandchildren are actively participating in. These grandchildren often find themselves ill prepared for the caregiving role, and have to navigate channels of both formal and informal support without practice. Grandchildren providing care to grandparents have a likelihood of being in the caregiving role without time to prepare for such an endeavor, and remain in the role for long periods of time, often years.

This research uncovered a multitude of caregiving patterns within the adult grandchild population that both reflect and differ from those patterns seen among adult children and spouses who provide care. The themes summarized above have key theoretical implications for what we do know about adult grandchildren based on observations of other caregivers, but as importantly, reveal absences within the caregiving literature because existing studies have focused on adult children and/or spouses providing care. This section will reveal these patterns and absences within the literature, compared to the findings from this study.

*Why/Under what circumstances adult grandchildren provide care to their grandparents*

Similar to adult children who feel reciprocity toward their own parents and use this as a rationale for providing care, adult grandchildren also have these same feelings of reciprocity. A key difference to grandchildren’s feelings of reciprocity is the reason why adult grandchildren feel a need to ‘pay back’ their grandparents. Very seldom were the grandchildren in the study raised by their grandparents, which would indicate the
grandparent as a substitute parent deserving of that reciprocity role. Rather, the
grandchildren in the study cited feelings of closeness to their grandparent, feelings of
closeness throughout their childhood, and being taken care of by their grandparents in
addition to (rather than in replacement of) being cared for by their own parents. The
grandchildren in the study were reciprocating the feelings of being cared for above and
beyond the traditional roles that a grandparent typically plays in contemporary society.

The addition of a middle generation makes this reciprocity different than other
caregiver/care recipient dyads. When considering how their relationship with the
grandparent lent itself to wanting to care for the grandparent at this point in time,
grandchildren relied on their feelings of closeness, and their gratitude from having the
closest relationship to their grandparents among all the grandchildren. Previous studies
which examine the role of reciprocity between adult children and their frail parents reveal
different trends. These adult children had a feeling of reciprocity due to societal
pressures that one should care for a parent when they are ill, and the actual ‘tasks’ that
adult children cite that their parents did for them are much more aligned with needing to
pay back the parent by caring for them. Adult children recognized that the parent raised
them, helped them to pay for their education, helped financially, and even helped in the
raising of their own children (Bliezner and Hamon 1992, Lee 1992, Haraven 1994,
Horowitz and Shindelman 1983, Arber and Ginn 1990, Wallsten 2000). In addition,
adult children cited societal expectations that they would provide care to a parent if they
needed it. Adult grandchildren do not face the same societal pressures if they are unable
to provide such care. The reciprocity that grandchildren feel is somewhat optional for grandchildren, in a way that the reciprocity between adult children and their parents is not.

The addition of the middle generation also brings forth a key difference in feelings of reciprocity that is unique to multi-intergenerational family ties. The grandchildren did not cite their parents as the source of reciprocity for them. Even when a grandchild was caring for the grandparent because their own parent was physically unable to do so, or because they had died, the grandchildren in the study did not cite their feelings of reciprocity toward their own parent as a rationale for taking care of their grandparent. This theme brings up the important question of whom that reciprocity rests with, and whether having a close relationship with a parent, but not a close relationship with a grandparent, would reveal similar trends.

This research revealed that grandchildren make conscious decisions to remain geographically close to their grandparents. In addition, grandchildren are willing to geographically move closer to their grandparents when their assistance is needed due to illness or frailty. The literature has examined the role of geographic closeness as a determinant of care for adult children, but the choices that grandchildren make to be close or away from their grandparents are largely unexamined. This may be because often, the physical location of grandparents are assumed to mirror the physical location of parents. However, this is an outdated concept- today’s families are spread apart more widely than previous generations, and it is a fallacy to assume that the choice to live close to a
grandparent automatically coincides with living close to one’s own parent. This is particularly revealing because adult grandchildren are typically at a point within their own lives where geographic mobility is feasible and even expected of them. While the literature has focused on the costs and benefits of adult children living close to or far apart from their own parents during times of caregiving crisis, this remains a gap in the adult grandchild/grandparent literature. This is only addressed in childhood studies of grandchild/grandparent closeness. Further studies need to examine the rationale behind decisions of adult grandchildren to remain geographically close to their grandparents, the costs and benefits of such decisions, and whether that puts any additional expectations on grandchildren, both from their parents and from their grandparents, of fulfilling an eventual caregiver role to the grandparent.

The grandchildren in the study had strong feelings about the stigma associated with placing a grandparent into a nursing home. What remains unknown is why a grandchild would feel this burden, especially if they were not feeling pressure from their own parent to care for the grandparent in lieu of nursing home placement. The literature shows that adult children who have to place their parent in a nursing home go through a period of personal disappointment, feelings of being an inadequate child, and disappointing their parents. Grandchildren are one generation removed from this responsibility- why would they too feel the stigma associated with not being able to provide care to a parent in a private home? We do not know if the stigma associated with this is pressure put on the grandchildren from their parents and/or grandparents, or
whether they have been socialized to assume that nursing homes are bad. It is important to note that the grandchildren in the study were often born amid the 1980s nursing home reform, so their personal experiences with nursing homes may have been minimal, and/or after broad reforms were made within nursing homes. The grandchild’s image of a nursing home and the possible abuse that could occur there are likely to be qualitatively different from the images that their parents’ generation would conjure. This notion of stigma from putting the grandparent in a nursing home, and the sources of this stigma deserve further study.

*Gender Dynamics*

This study revealed that grandchildren experience similar gendered expectations and taboos of providing care that adult children portray. It is certainly worth noting that with the exception of one male, all of respondents were granddaughters, and not grandsons. Interestingly, the granddaughters in the study had few insights for why they were the ones providing care to the grandparent rather than their brothers or even other sisters, other than that they were the ones who were able to do so. Caregiving teams with other siblings always included other sisters providing care, rather than brothers contributing. Granddaughters in a caregiving role reenact the same gendered patterns that adult children typically follow.

What is missing from the current literature on gendered patterns of care is a discussion of the decisions adult daughters make when enacting a caregiving ‘team’ to help them care for parents. Is it normative to ask a grown child to help with this care, or
is it more likely that an adult child in a caregiving role to their parent would ask their own siblings? For those parents who do enact the help of their adult children, is it due to being only children, having only brothers as siblings, or do other factors such as geographic distance and/or tension between the adult siblings that contributes to the grandchild maintaining a key role in providing care to a grandparent? These questions are beyond the scope of this study, but further research needs to be directed at the complex intergenerational ties that contribute to, and result from, adult grandchildren providing care to a grandparent.

How the dynamics of the existing grandparent/grandchild relationship affects caregiving processes of grandchildren

The intergenerational triangular dynamics that were experienced by adult grandchildren providing care to a grandparent have been minimized in both caregiving and grandchild/grandparent literature. Whether the grandchildren were providing care in conjunction with a parent, due to an intergenerational disconnect between themselves and their own parents, or even because their own parent had died, a key theme is that the grandchild felt the effects of this middle generation with their own relationships with, and caregiving for, their grandparents. The decision to play such an integral role within the care of a grandparent was never made in absence of considering the intergenerational dynamics within the larger family. While we know that grandchildren do fall into caregiving roles regardless of these dynamics, further studies need to more fully examine the support and the stress of maintaining three generations of relationships while
providing such care. What is missing from this analysis is the reactions from both the parental generation and the grandparent generation of the grandchild being a source of care. Does this in turn entail feelings of pride for the parent? Do parents who cannot independently provide care to their own parent feel that they are putting undue stress on their child? Do parents who ask their own children to help provide care feel greater disappointment in their own siblings for not helping? In the cases of the parental generation being deceased, why is it that the grandchild, rather than the parent’s siblings, taking over with this care? Previous studies that examine the intergenerational dynamics in caregiving treat grandchildren as ‘children’ rather than adults, and as a result, this is a serious gap within the caregiving literature. Accordingly, the care recipient literature mentions nothing about whether a grandparent would prefer a grandchild to a child for providing care, especially in cases where there is tension within the middle generation and the grandparent generation, or when the gender of the middle generation children tends to be male. This warrants further exploration.

*How caregiving affects the grandchild/grandparent relationship*

It is clear that providing care to a grandparent in turn affects the relationship. This research displayed many ways that this is illustrated- the role reversal that occurs with grandparents when a grandchild is making major decisions on behalf of that grandparent, the crossing of physical boundaries that is a necessary part of providing intimate care to a person, and guilt expressed by grandparents for having to rely on a grandchild. These themes are all explored within the adult child/parent caregiving
literature, and it follows that societal norms on privacy would be compounded among these caregiving dyads.

A theme that this research uncovered, but only topically, was the guilt that grandparents exhibit from disrupting the daily lives of grandchildren. Rather than feeling entitled that they should be cared for, grandparents often exhibited great stress from having to rely on their grandchildren. Sources of this stress included worrying that they were taking away from the grandchild’s social time, placing too much responsibility in the hands of their grandchildren, and even minimizing their own illnesses in order to create less stress for their grandchildren. This minimization of illness is not illustrated in the caregiving literature, and warrants further investigation. What we do not know from interviewing adult grandchildren are the internal processes that the grandparents go through as a result of relying on their grandchild to care for them. Do grandparents resent their own children for not providing such care? Do they feel stigmatized that they have fewer members of the middle or spousal generation who are willing to help them during these moments? Do these grandparents exhibit closer ties with the grandchildren who are helping them, as compared to their other grandchildren or even their own children? This study was able to capture the reasons why grandchildren take on this care, and the effects of doing so; what still needs to be investigated is why grandparents accept this care from their grandchildren, and the subsequent effects that this has for the grandparent.

The Negative Effects of Providing Care
The scope of this research was an exploratory study into the effects that providing care to a grandparent has on an adult grandchild. Since the interviews that were conducted were based on a single point in time, the research leads to several themes that should be explored longitudinally. We know that the decision to provide care to a grandparent has a profound impact on the working lives of adult grandchildren. The long-term implications of this decision are unknown. Do adult grandchildren suffer professionally in the long run from taking time out of their careers to provide care to a grandparent? Are grandchildren penalized in the same way that adult children and spouses are for having to balance caregiving and work? The obvious life course position of grandchildren necessitates that they are making these decisions at the beginning of, rather than in the middle, or even at the end, of their careers.

While we do know that friendships are important sources of both relief and stress for caregivers, what is unique about adult grandchildren providing care to grandparents is the importance that these friendships have in their lives. Most grandchildren were in the early stages of their lifecourse, and were either just starting families or still socializing primarily with friends. The long-term effects that caregiving earlier in life have on friendships has not been examined. Studies based on the friendship circles of adult children who are caregivers are not adequate to describe the stresses felt within grandchildren’s friendship networks for several reasons. The length and the intensity of friendships outside of the nuclear family are qualitatively different for a younger caregiver. The off-time event of caregiving has a negative impact on the grandchild’s
ability to rely on these friends. Likewise, middle-aged adults tend to have other friends who are experiencing similar caregiving responsibilities with their own parents. This absence of kinship with other friends is a stark comparison of the importance, and failing, of friendships for adult grandchildren versus the emotions and intensity placed on friendships for adult children. Simply relying on the current literature on caregiving and social ties, which places the caregiver at a later point of the life course, are simply inadequate to describe the triumphs and struggles that adult grandchildren face with their own social networks.

Similarly, the role of spouses and/or romantic partners is qualitatively different for adult grandchildren than it is for adult children who are providing care to an elderly parent. Often, the absence of a partner for adult children is a result of divorce or even spousal death. None of the grandchildren studied were divorced, and only one grandchild was widowed. As a result, the stresses associated with spouses and/or partners stems from a relatively immature relationship. Adult children cite the long history that they have with their own spouse as sources of strength for dealing with these stressful moments. The collection of time spent together, having and raising children together, and dealing with deaths, relocations, and even career changes are sources of bonding for adult children that mediate the stress felt when a caregiver is unable to perform as well within their relationship role. This history is largely absent for adult grandchildren providing care. They are either dating or in the beginning of long-term relationships rather than within the middle of them, and therefore, the consequences of providing care
may have different long-term effects for this generation. A longitudinal study of adult
grandchild caregivers would uncover whether taking care of a grandparent leads to more
incidences of divorce, singlehood, and serial dating for adult grandchildren. These
themes within relationships are qualitatively different than the topics that are discussed
for older couples who have had a longer time together.

Past research reveals that the majority of adult child caregiving tends to occur
when their own children are already grown. As such, the stresses of caring for a young
child or children in conjunction with caring for an elderly family member has been
underscored in current literature on caregiver family decisions. In addition, the difficult
decisions for hiring out care to children may be more ‘acceptable’ for doing this because
one’s parent needs them, rather than one’s grandparent needing them.

Positive effects of providing care

The grandchildren studied had a variety of positive effects stemming from the
care that they provided. Current literature which reviews the positive aspects of
providing care relies on a child’s perspective or a spouse’s perspective. This is limiting,
because the age issues is not addressed. For older caregivers, it is likely that death and
dying are issues that they previously have dealt with. For grandchildren, the concept that
their grandparent will die, and that they have the ability to aid them in that dying process,
is a very positive thing. While some grandchildren feared this eventual ending, they were
aware that they knew more about death and dying than their peers, and were not scared of
the process of death. This is a unique positive effect of caregiving to this generation. In
addition, grandchildren cite the increased confidence when raising their own children as a major benefit of providing care. It is important to note that for several grandchildren, their leap into caring for a grandparent was their first official role as a caregiver, and subsequently, this group experienced a lot of self-esteem lifts, value from their role as caregivers, and joy in getting to know their grandparent in a way that they otherwise would not have been able to do.

Available supports and needs of Adult Grandchildren

Current methods of supporting caregivers neglects the intergenerational and life course position of grandchildren. The layered conflicts which come from multiple generations have been minimized in caregiving literature, and the amount of planning, re-planning, and delaying personal relationships and goals as a result of caregiving merits further consideration.

Grandchildren providing care to a grandparent need further recognition both within the workplace and in larger society. The lack of formal policies and formal supports which address the needs of grandchildren is outdated. As our elderly population continues to age, we need to consider the realistic ramifications that will have not only for spouse and adult child caregivers, but also for adult grandchildren who are meeting the challenge of providing care to their elderly grandparents.

Limitations of Research

Sampling
The sampling design of this research, combined with the language used within the recruitment materials, certainly resulted in a small, narrowly drawn sample. The majority of participants in the study were largely women, white, well educated, employed, and often co-residing with their grandparents. The caregiving role usually lasted for years rather than months, and the participants were investing several hours per week providing care for their grandparent. This section will discuss the reasons why this particular sample was drawn from the recruitment process, and the key effects that this bias in sampling may have had on the results of the study.

As noted in the research methods section, the vast majority of participants for this study were female. The recruitment materials used in the study did not specify that granddaughters, rather than grandsons, were being considered for the study; however, the socialization that occurs with the gendered impact of caregiving may have led the study to appear more applicable to women rather than men. While I did not use the term ‘caregiver’ in my advertising to direct individuals (in the form of fliers and advertisements), I did use the term caregiver in the recruitment letters sent to geriatric professionals across New York State. This in turn may have led to a bias in these professionals considering women as more eligible for the research than men. This definition also resulted in a sample of people who typically lived with the grandparent and who experienced major negative consequences from their care. In the recruitment fliers which were posted both in local venues and in online forums, I specified that I was seeking grandchildren who “were providing at least four hours of assistance per week to a
grandparent because of their illness (examples: driving to appointments, cooking, cleaning, providing personal care)” . Perhaps the examples that were provided indicated gender-specific tasks, and these tasks were more catered to the typical caregiving tasks that a woman, rather than a man, would perform (Lawrence et al. 2002) It is unknown whether including more examples, such as balancing a budget, taking care of lawn work, managing medical affairs, and other male-oriented tasks would have resulted in a more balanced sample. Future studies which examine adult grandchildren providing care to their grandparents need to consider the wording of these recruitment materials in order to make an effort to capture not only adult granddaughters, but also adult grandsons.

The sample that was drawn for the study resulted in a white, educated, employed sample. This pattern was unexpected, and again, the recruitment materials and the places that were focused on for recruitment, may have led to an oversampling of these demographics. The recruitment strategies that I used necessitated gatekeepers to help recruit a sample. Relying on geriatric professionals to identify caregivers eligible for the study may have influenced the patterns of respondents. In order to be contacted by a ‘gate keeper’, a grandchild must have exhibited enough of a burdensome situation to stand out to that professional. As a result, grandchildren who were combining careers or education with their caregiving, those grandchildren who were experiencing higher levels of stress (and therefore, visibility to professionals) because they were co-residing with their grandparents, and those grandchildren who were members of extended families with conflict as a result of caregiving needs may have been more visible, and therefore, more
heavily recruited, for the study by the various geriatric practitioners, social workers, doctors, and community agency liaisons. The grandchildren who may have been overlooked through this methodology included those grandchildren who had minimal caregiving responsibilities, were caregiving largely in conjunction with other family members, and those grandchildren who had not sought out assistance from any professionals. As research has isolated these biases for which caregivers do seek formal assistance with their caregiving needs, it follows that efforts in future studies need to focus on capturing the grandchildren who are not receiving formal services, and who have less perceived stress and burden associated with their caregiving experiences.

This study did attempt to recruit grandchildren who were not affiliated with receiving any formal services. The additional non-internet methods included tabling, public service announcements to radio stations, posting flyers, listing on the Time Warner Channel 18 Bulletin Board, and placing advertisements in newspapers throughout New York State. Several of these methods were more likely to draw an educated caregiver. All of these venues necessitate access to the advertisements, and those individuals with access to them may have likely been higher educated, whiter, and more likely to be working than the general grandchild caregiving population. In addition, because many of the fliers were mailed to local businesses to post, there is no guarantee that the fliers were posted in visible areas, or even in gender-neutral areas. Future research needs to consider the implications that sampling design will have on the demographics the sample. The recruitment methodology for adult grandchildren is particularly daunting because unlike
other caregivers, adult grandchildren tend to be less linked with other caregivers, formal services, or employee programs that target caregiving populations.

The most successful strategy for recruiting grandchildren for the study was through internet postings. This may have also contributed to the bias within the sample. Craigslist served as a thriving source for finding adult grandchildren who were providing care. As someone who is familiar with Craigslist, however, it is important to note where on the website the ads were placed. They were located within the ‘community volunteers’ section of Craigslist, which is not as heavily utilized as the ‘for sale’ or ‘personal’ sections of the website. All material posted on the website must be approved prior to posting, so I was unable to locate the advertisement in these sections of the website. Using Craigslist for such a large proportion of participants had its own implications for sample bias. Access to, and familiarity with, the internet and specifically to Craigslist was one such implication. Those who use the internet regularly tend to be highly educated, white, and middle class. (Pew Research Company 2010). Similarly, those caregivers who found out about the study from YoungCaregiver.com were biased because they were actively seeking support from others who were providing care. To be at a point of needing additional support logically necessitates a stressed caregiver who is in need of these additional resources. Likewise, those caregivers who were recruited from YoungCaregiver.com had to be familiar enough with the internet to access this site, so the possibility of a biased sample on the basis of their computer skills and accessibility may have resulted.
The recruitment of a sample was the most daunting task of this research. I chose to use the term ‘illness’ rather than ‘frail’ for the sample because I was concerned that too many grandchildren who did not identify their grandparent as ‘frail’ would self select out of the study prior to even talking to me. In retrospect, a combination of these two terms, rather than the inclusion of only ‘illness’ may have resulted in a broader spectrum of the types of grandchildren who actively provide support to their grandparents. The above sampling characteristics did result in a distinctive caregiver population. Those grandchildren that were depressed due to their caregiving responsibilities, were more likely to have connections to formal services, those co-residing with the grandparent and those grandchildren who were providing the bulk of care to their grandparent were the ones most likely to respond. Future research needs to expand upon these sampling techniques to capture more adult grandchildren who are caregivers to their grandparents. The limitations of the sampling design chosen include not being able to address the ways that grandsons experience the caregiving role, how uneducated grandchildren with limited resources experience this role, or how those who are not in contact with any formal services may experience caregiving differently from those caregivers included here. In addition, this study cannot make general conclusions about how grandchildren living with a grandparent differ from those not living with a grandparent, or the effects that race may have on individuals’ experiences with caregiving. A study which examines the similarities and differences between these demographic subpopulations of caregivers is warranted.
Interviewing Methodology

The format for conducting interviews for this study was a face-to-face intensive interview design. Traditionally, this has been a sound methodology when researching populations on whom we have little information (Glasser and Strauss 1967; Strauss and Corbin 1990; Weiss 1994). Ironically, such an intensive method may have also resulted in a skewed research population. To participate in the interview, the respondents had to be willing to meet face to face with me in order to conduct an interview. Given the technological savvy of this generation, alternative interview methods, such as using Skype (a computer assisted program which transmits live images of webcams to each participant) for an interview, allowing respondents to answer open ended questions via an internet survey tool such as Survey Monkey, or having an instant online chat with participants may have resulted in more participants. The advantages of face-to-face interviews, such as the ability to read facial cues and to establish trust, were not so great that these would create insurmountable obstacles within the research project. The research methodology used within this research design was established prior to the explosion of online social networking spaces that have digitalized the world. Future research with this population should consider posting ads on Facebook, utilizing Skype to conduct interviews, and utilizing online chat Instant Messaging for conducting research interviews.

Existing Literature on Caregiving
Another area of limitation embedded in my research design is the saturation of theoretical concepts available within the sociological literature on caregiving which focus on only adult children who provide care, or spousal caregivers. The pioneering studies on caregivers in the 1980s and 1990s relied on the concept that one person exists as the ‘primary’ caregiver, and all others are considered ‘secondary’ caregivers. This has been illustrated as a Hierarchy of Availability model of care, where a person only steps in to help in the care when the person closest in relationship to the sick person is unavailable. According to this model, a spouse would be the closest person in this hierarchy, followed by an adult child (Shanas 1968; Cantor 1979), and finally, other family members. This theoretical implication has framed much of the existing literature. The concept that a family can have many equal partners in the caregiving team, and the notion that one caregiver may not be more important to the caregiving team than another is one that has not been reflected in the literature. Because this is an exploratory study to examine the roles that grandchildren play in the caregiving processes of their grandparents, the extent that these patterned relationships do exist within these families was largely unexamined, but warrants further research.

Future research on intergenerational family relationships and how they are affected when the third generation (the adult grandchild) steps in to provide assistance in providing care to a grandparent needs to be further developed. The perspectives of the grandparent or the adult child in these scenarios were beyond the scope of this study. In the same vein that intervention research involving caregiver dyads recommends that the
care recipient, in addition to the caregiver, be included in the research (Lingler et al. 2008; Lyons et al. 2002), further research needs to examine the complexity of intergenerational relationships and how caregiving changes them, not only from the grandchild’s perspective, but also from both the grandparental and adult child’s perspective. This research is unable to provide insight to whether the grandchild’s role is one that is creating conflict or peace within families, save for anecdotal evidence from the grandchildren themselves.

In addition to there being a lack of discussion in the existing literature about the limitations of labeling one person in a family as the ‘primary caregiver’, the sociologically based literature regarding caregivers employs a two-generation dichotomy which is inadequate to explain the complexities present with three generations providing care. For example, this study could not fully discuss the feelings of competitiveness or ambivalence among the siblings of the grandchildren, or further, the stresses that may be exhibited among the siblings of the middle generation as a result of a grandchild providing care to a grandparent. Future studies need to examine these intergenerational sibling/aunt and uncle/grandparent dynamics.

The role of the internet in caregiving as a role of support has received little recognition in the wider caregiving literature. Because the grandchildren in the study relied so heavily on the internet as both a source of information and as a source of support, the impetus for focusing more attention on the role of the internet with caregiving needs to be examined in future research studies.
Certainly, the lack of inclusion of grandchildren in caregiver demographic studies and the lack of overall research on adult grandchildren providing care to a grandparent creates a limitation for this study. Because grandchildren as caregivers are still seen as such anomalies within the caregiving community, the lack of demographics which could measure how many grandchildren provide care, the lack of studies which discuss the unique positive and negative consequences of providing this care, and the ways that grandchildren differ in their caregiving experiences from other generations have simply been not examined. This leads to a very isolated group of caregivers which are both difficult to identify, and strenuous to recruit. Future studies need to consider how the existing literature serves as an obstacle for learning more about the experiences of adult grandchildren.

Future Directions

This research was an exploratory doctoral study examining the role of adult grandchildren serving as caregivers to their grandparents. As such, this project served to examine the key areas where adult grandchildren both mimic and differ from other groups of caregivers who have traditionally studied. This research should be viewed as a starting point for subsequent studies, rather than an end point of knowing all that we need to about the unique situation grandchildren find themselves in when caring for a grandparent.

Further research examining adult grandchildren needs to incorporate an intergenerational approach which includes both the insights of these caregivers, but also
the reactions of and feelings that this caregiving provokes among both their siblings, parents and their grandparents. Such a study design will help capture several key components which are still missing within the research. For example, the tension or cooperation felt between the grandchild and parent generation is absent in the literature thus far. Future studies need to examine why a grandchild is put into a caregiving situation, whether this is expected or rewarded by either their parents or grandparent, as well as whether this is a stigma or celebration for these intergenerational triads. The possible feelings of resentment or gratitude on the part of the siblings of both the grandchildren’s and the adult children’s grandchildren are other intergenerational areas that deserves exploration. Because no grandchild was caring for their grandparent because there was no other family at all to turn to, further research into these complex family dynamics, both from the perspective of the adult grandchildren and from the other members of the family involved (or not involved) in this care is warranted. The perspectives of grandchildren’s friends and partners are also possible future directions with which to take this research. By conducting such studies, our society will be better equipped to support both grandchildren and their grandparents who find themselves in the unfamiliar role of caring for, and being cared by, one another.

Several of the key findings of this study lead to longitudinal studies that will capture the long-term effects for adult grandchildren who care to a grandparent. We know that grandchildren leave their residences, geographically move to be with their grandparents, and suffer serious consequences professionally for doing so. This study
captured the immediate consequences of such decisions; however, a longitudinal design will determine whether the effects of these decisions are temporary or long-lasting. We do not know whether caregiving causes long-term negative or positive effects over the lifecourse, in areas such as relationship formation and maintenance, family formation, and the subsequent relationship intergenerational relationship dynamics that follow.

Another area of focus that a long-term study would be able to capture will be the effects of the grandparent’s death on the grandchild. Because this study included only grandchildren who still were caring for their grandparents, it cannot provide insight into the grieving process that grandchildren go through. The study results indicated that these grandchildren were fearful of their grandparent’s deaths, were worried that the grandparent’s death and dying wishes would be overruled because of the grandchild’s place within the broader family context, and that some grandchildren would be removed from the informal workplace for an extended period of time upon the grandparent’s death. Future studies should consider the coping mechanisms that these grandchildren rely upon in the event of death, their ability to find work if they were out of the formal workforce due to their caregiving, and whether the grandparent’s death caused an increase or decrease in tension with other family members.

Current interventions aimed at caregiver support are based on the adult child and/or spouse caregiver model. These interventions and support groups tend to be localized, require face-to-face attendance, and are largely comprised of older caregivers. This study provides the impetus for creating a web-based caregiver support group aimed
at the unique stressors that grandchildren, who are younger, face as a result of their roles. Such support needs to specifically deal with the life course position of adult grandchildren, and the uniqueness of their situation. The overlaying complexities of multiple generations involved (or not involved) in the care, the adjustments that such care necessitates on both friendships and family relationships, and the balance of caring for a grandparent while either forfeiting childbearing or raising small children in conjunction with that care are all sources of stress that the grandchildren studied exhibited. Any interventions aimed at this population need to address these stressors. In addition, these interventions need to be web-based rather than face-to-face, due to the geographic isolation of adult grandchildren who are caregiving for a grandparent. Further, the technologically savvy of this generation lends itself to a successful online format. Adult grandchildren would likely be less stressed with the format of an online support forum than their parents or grandparents would feel.

This research will become a springboard for further examination into the unique characteristics of grandchildren who are caregivers to their grandparents. My immediate agenda includes publishing this research as a book, and creating a documentary which illustrates several of the themes discussed throughout this research. One obstacle to providing additional support to grandchildren who are caregivers is an absence of the recognition of this role in our mainstream media. Bringing this to light through a documentary will serve to assign a face and story to the countless grandchildren who are taking care of their grandparents. Next, I plan to partner with the National Caregiver
Alliance to provide them with the narratives necessary to lobby Congress to amend the current Federal Family Leave Medical Act to include adult grandchildren who are the caregivers to their grandparents. The same policies which enable other family members to provide quality care to their elderly relatives without fear of losing their job security should be made available to the grandchildren who provide similar care. Finally, I hope to help establish online caregiver support groups which are aimed at the unique stressors that adult grandchildren face. These support groups make sense to be conducted online rather than in-person because a) grandchildren are familiar and comfortable with online modes of retrieving information and networking, and b) the geographical diffusion of adult grandchildren who are caregivers makes an online community more feasible than a face-to-face community.
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APPENDIXES

A. Interview Guide
B. Demographic Questionnaire
C. Letter to Agencies
D. Recruitment Flyer
E. Newspaper Advertisement
F. Consent Form
G. Available Services for Grandchildren
Appendix A: Interview Guide

I. Introductory Questions

1. How/why did you become a caregiver for your grandparent?

2. When did you first start providing care for your grandparent?

3. How much time (in hours/days) do you devote to caring for your grandparent each week?
   a. Has this amount of care changed over time?

4. Can you tell me how many people provide care to your grandparent?
   a. What types of care do they perform?

5. Who provides the most care to your grandparent?

6. Can you describe the level of care that you give? What typical things do you do in a given week to help out?
   a. Has this level of care changed over time?
   b. Have you taken over any tasks that used to be someone else’s responsibility?

II. Family Background Questions: History of Relationship with Grandparent

In order to understand your relationship with your grandparent today, it will be helpful to get some information of how your relationship has been throughout your life.

1. Is the care recipient your maternal or paternal grandparent?

2. How would you describe your relationship with your grandparent as you were growing up?

3. Did you live close to your grandparent during your childhood?
   a. How close? Living together?

4. How often did you see your grandparent while growing up?
   a. How did this change over time?

5. While you were growing up, how was the relationship between your parents and
your grandparents?
   a. Is this still the same today?
   b. How did their relationship dynamics affect your relationship with your grandparents?

6. Was your grandparent ever called upon to help your family, either economically or emotionally, throughout your childhood (ex: parental divorce, unemployment)?
   a. How did this affect your relationship?

III. Questions about becoming a caregiver

I’d like to know a little more about why you are the one caring for your grandparent.

1. Are you the closest person geographically to your grandparent?
   -If yes: Do you think this is part of the reason you are caring for them?
   -If no: why isn’t that person caring for your grandparent instead of you?

2. Were you asked to provide the care by someone?
   -if yes, who asked you?
   -was anybody else asked as well?
   -if yes, do they help in the care? Why or why not? Have they helped in the past?

3. Do you feel that others expected you to provide this care?
   -why or why not?

IV. Negative and positive aspects of caregiving

   Other Responsibilities

1. Are you caring for anyone other than your grandparent?
   - if so, who?
   - how do you juggle these responsibilities?

3. If you have children: Do you have any issues of daycare? Schooling? Children’s’ activities?

   Caregiving and Work

1. What do you do as a profession? (are you still in school? Working? Both?)

2. Can you tell me about your job? (How long you’ve worked there, your status,
responsibilities, benefits)
   a. Where are you in your career?
   b. What type of job do you have? What are your hours?

3. Do people in your professional life realize that you are a caregiver? Why or why not?

4. How has caregiving affected your work life?
   - How supportive/non-supportive is your boss/co-workers of your role as a caregiver?

5. Into which income category does your household income fall (before taxes)?
   Household income is the sum of money income received in the previous calendar year by all household members 15 years old and over, including household members not related to the householder, people living alone, and others in nonfamily households.
   i. 0-20,000
   ii. 20,001-50,000
   iii. 50,001-75,000
   iv. 75,001-100,000
   v. 100,000+
   a. How has caregiving affected your budget?

Caregiving and Other Relationships

1. How has caregiving affected your family life?
   a. Do family members resent the time that you spend taking care of your grandparent?

2. Has caregiving affected your social life? Please explain.

3. Is there anything else that you feel you are spending less time on than you’d like because of caregiving, or you are spending less time caregiving than you would like because of your commitment to this?

Financial and Legal Issues

1. Who, if anyone, has power of attorney for your grandparent?
   a. How do you feel about this?
   b. How was this decision made?
2. Who is the legally designated health care proxy for your grandparent?
   a. Is this according to your grandparent’s wishes?
   b. How do you feel about this?
   c. How was this decision made?

3. In reference to questions #1 or #2, are you in agreement with this appointment?
   a. If the legally designated power of attorney or health proxy (other than you) makes a decision for your grandparent that you are in disagreement with, will you dispute it? Why or why not?

4. Are there any other legal aspects of your grandparent’s care (ex: insurance, estate handling) that you take care of?
   a. How has this experience been?

5. Have you ever tried to get any work benefits for caregiving for your grandparent? (Ex: having them listed as a dependent on your health insurance; using family sick leave to care for them; using your flex-benefits to have tax deductions based on care for them)
   a. if yes, has it been successful?
   b. if no, have you tried?
   c. How has this affected your job?

Stress and Burden Associated with Caregiving

1. How has caregiving affected your relationship with your grandparent? Any other relatives or friends we haven’t mentioned?

2. What types of feelings do you have because of being a caregiver (anger, sadness, happiness, guilt, etc.)?

3. How do you feel you’re prepared as a caregiver?
   a. What personal life experiences have prepared you for this role?
   b. Do you feel competent in the role of caregiver?

4. Do you interact with other caregivers?
   a. If yes: Can you describe this?
   b. If no: what has prevented you from doing so?

5. What is most stressful about caregiving?
6. Do people in your personal life (outside of family members) realize that you are a caregiver?
   a. Why or why not?
   b. If yes: who?
Positive Aspects of Caregiving

1. What do you feel you’ve gained by caring for your grandparent?

2. How has caring for your grandparent affected your self-esteem?

3. Has taken care of your grandparent caused any improvements with relationships with other family members?

4. What meaning have you derived from your caregiving experience?

5. Have any of the positive aspects of caregiving helped to ease the burdens and stresses of caregiving? Please explain.

6. What is your favorite aspect of being a caregiver?

V. Sources of Support

Social Network and Social Support

1. Can you rely on any family members or friends to help you care for your grandparent?
   a. if yes, do you ask for their help? How often?
   b. if no, why not?

2. If someone is providing you with support, who?

Formal Supports

1. Do you depend on any paid help to aid in your caregiving?
   a. why/why not?
   b. can you list the services you use?

2. If yes, how did you begin relying on this support?
   a. How did you initially feel about receiving the help? Has this changed?
   b. How do you pay for this support?

Other Sources of Support or Assistance

1. Have you ever attended a support group for caregivers?
   a. If yes: Can you tell me a little about it? Do you still attend?
   b. If no: What has prevented you from doing so?
2. Have you ever used the internet as a source of finding out more about your grandparent’s illness? Chatting with other caregivers?
   a. If yes: Can you tell me a little about it? Do you still use the internet as support?
   b. If no: What has prevented you from doing so?

3. Are there any other sources of support that you rely on which were not mentioned so far?

4. Have social support and formal support helped to ease the burdens and stresses of caregiving? Please explain.

VI. Questions about Family Structure

I’d like to get some background information about your family, in order to better understand how you came to be a caregiver for your grandparent.

1. Do you have a spouse/children?
   a. If yes: details- first spouse? How many children/ages?

2. Do you have any siblings?
   a. If yes, how old are they? Are they brothers/sisters? Full or step/half? Where do they live?

3. Parents’ Generation
   a. Can you tell me about your mother and father?
   b. Are they married, divorced, widowed, never married, etc?
   a. Does your mother have any siblings?
      i. if yes, how old are they? Are they brothers/sisters? Full or step/half? Where do they live?
   b. Does your father have any siblings?
      i. if yes, how old are they? Are they brothers/sisters? Full or step/half? Where do they live?
   c. Do either of your parents have any dependent children?
      i. if yes, how old are they? If they are over 18, why are they considered dependent?

5. Grandparents’ Generation
   a. Is your grandparent living alone or with someone?
      i. if living with someone, who?
   b. Where does your grandparent live?

6. Growing up Household
   a. Can you describe the family setting that you grew up in?
   b. On a day-to-day basis, how involved were your parents in raising you?
c. On a day-to-day basis, how involved were your grandparents in raising you?
Appendix B: Demographic Questionnaire

“Adult Grandchildren as Caregivers to Their Elderly Grandparents” Demographic Questionnaire

Patient Study ID #: _______________________

**Caregiver Information**

1. What is your year of birth? ______

2. Gender (check one): ☐ MALE ☐ FEMALE

12. Are you currently living alone?
☐ YES
13. NO

If NO, with whom are you living?
________________________________________________________

14. What is your current marital status? (Check one)
☐ Married
15. Single- never married
16. Divorced
17. Separated
18. Widowed
☐ Other

If MARRIED, how long have you been married to your spouse/partner? (years or months) __________

19. What is your Race/Ethnicity? (Check one)
☐ White (non-Hispanic)
20. Black
☐ Hispanic
□ Other—Specify:

______________________________________________________________

_____

21. What is your employment status?
   □ Employed (Full-time)
   □ Employed (Part-time)
   □ Unemployed
   □ Retired
   □ Disabled

7. What is (was) your primary occupation? (Please be specific)

____________________________________

8. What is the highest level of education that you have completed?

____________________________________

9. If married, what is your spouse’s/partner’s primary occupation?

____________________________________

10. What is your average monthly household income?

____________________________________

22. When did you start giving your care recipient special help because of his/her illness?  
   (please indicate the number of years and/or months ago)

____________________________________

23. How many hours per week on average do you spend on caregiving activities?

________________________
Appendix C: Letter to Agencies

<recipient’s name>
<recipient's address>

Dear <to be entered>,

My name is Tamara Smith, and I am a Sociology Ph.D. Candidate at the University at Albany, State University of New York. I am writing to request your assistance in recruiting a sample for my Doctoral Dissertation Project. I am researching the roles adult grandchildren play providing care for their grandparents. Specifically, I will be conducting face-to-face qualitative interviews with adult grandchildren across New York State.

The grandchildren that I seek must be 18 years old, and must be providing a minimum 4 hours of care per week to their grandparent. The interview will last approximately 90 minutes and will include questions that measure aspects of quality of life, perceived burden, stress, knowledge of community resources and pressing problems. The questionnaire has been reviewed by members of my doctoral committee and the project has been approved by the University at Albany Institutional Review Board.

This research seeks to determine (1) why adult grandchildren care for their grandparents, (2) what their competing stressors may be, (3) whether grandchildren use formal care, (4) what their levels of burden are, (5) sources of support available for these adult grandchildren, and (6) the positive and negative effects resulting from caregiving. The goal of this research is to be able to create support groups, services and support aimed toward this group of caregivers, as well as encouraging changes to family policies to recognize and include grandparental care.

I am able to pay my research subjects a modest sum of $10 for their time. If you know of anyone who fits the criteria for this project, I’d be extremely appreciative if you would have them contact me directly at 518-442-5344 or tsmith@albany.edu. I am enclosing a flyer for the study as well. If you would consider posting it at your organization, I’d be very grateful. Thank you for your time. I look forward to hearing from you.
Thank you,
Tamara L. Smith

Appendix D: Recruitment Flyer

Seeking
Adult Grandchildren
for an
Interview Study!!!

Are you or someone you know...

• providing at least four hours of assistance per week to a grandparent because of their illness (examples: driving to appointments, cooking, cleaning, providing personal care)?
• at least 18 years old?

I am seeking adult grandchildren caring for their grandparents to participate in a 90 minute interview and questionnaire. If eligible, you will be paid $10 for your time. For more information, please call 518-442-5344, or email tsmith@albany.edu. Thank you!

*This research has been approved by the University at Albany Institutional Review Board*
Appendix E: Newspaper Advertisement

Newspaper Advertisement:

Researcher seeking adult grandchildren for interview study. Must be over 18 and providing at least 2 days of care to ill grandparents. If eligible, participants will be paid $10 for their time (approximately 90 minute interview). For more information, please call 442-5344 or email tsmith@albany.edu. This research is being conducted through SUNY Albany, and has been approved by its Institutional Review Board.
Appendix F: Consent Form

Adult Grandchildren as Caregivers for Their Elderly Grandparents

Consent Form

I understand that by signing this consent form, I am agreeing to participate in a research study entitled, “Adult Grandchildren as Caregivers for Frail Elderly Grandparents.” This study will be conducted by Tamara Smith, a doctoral student at the University at Albany, State University of New York. I understand that this is a research study to investigate the experiences, histories, stressors, burdens, and services used by adult grandchildren who are caring for their frail elderly grandparents.

As a participant in the study, I agree to participate in a qualitative interview that will last approximately ninety minutes, conducted by Tamara Smith. During this interview, questions will be asked regarding my family background, the reasons why I am caring for my grandparent, the types of tasks that I perform, and the stresses and competing demands of caregiving that I experience. I will be asked permission to allow this interview to be audio-taped. I understand that during the interview, I should avoid mentioning the names of or identifying information about third parties. If this kind of information is mentioned inadvertently, the taping will be stopped, the identifying information erased, and the caution repeated before the taping resumes.

I will be paid $10 for my participation. There is a small risk of becoming upset by the nature of the questions asked. I understand that I can contact Michele Zinoman, CSW-R (certified social worker) at 591-8725 if I need additional assistance. I may also contact the Samaritans Assistance Hotline at 518-689-4673.

I understand that:

• All personal information obtained for the purpose of this study will be kept confidential.
• I will be given a list of community resources at the end of the interview.
• My name will not be included in any reports or publications resulting from this study.
• There are no costs to me for participation in this study.
• My participation or refusal to participate in the study will in no way adversely affect me.
• My participation is voluntary and I may refuse to answer questions or may withdraw from this study at any time.
• There are no physical risks involved in participating in this study.
• I will be given a copy of this consent form.

It is my right as a participant in this study to contact the Investigator. I may contact Tamara Smith at (518) 442-5344. If I have any questions concerning my rights as a research participant that have not been answered by the investigator or if I wish to
report any concerns about the study, I may contact the Office of Research Compliance at 518-437-4569 (or toll free 800-365-9139) or orc@uamail.albany.edu.

_____ I agree to participate in this study. I have read and understand the information provided regarding this study.

_______ I give permission for the qualitative interview to be audio-taped for the purpose of transcribing.

_______ I do not give permission for the qualitative interview to be audio-taped for the purpose of transcribing.

_____ I do not wish to participate in this study.

Name_____________________________ Signature______________________________

Address___________________________ Date _________________________________
Appendix G. Available Services for Grandchildren

These resources were provided for the study by the Albany Senior Services Center and can be found online at: http://www.seniorservicesofalbany.com/links.htm

**American Association of Retired Persons (AARP)** (www.aarp.org)
601 E Street, NW
Washington DC 20049
1-888-OUR-AARP (687-2277) (toll-free)

**Administration on Aging (AoA)** (www.aoa.gov)
Department of Health and Human Services (DHHS)
Washington DC 20201
Public Inquiries: 202-619-0724
Eldercare Locator: 1-800-677-1116 (toll-free)

**Alzheimer’s Association** (www.alz.org)
225 N. Michigan Avenue, Floor 17
Chicago IL 60601
1-800-272-3900 (toll-free)
Fax: 1-866-699-1246

**Alzheimer’s Disease Education and Referral Center (ADEAR)**
(www.nia.nih.gov/Alzheimers)
PO Box 8250
Silver Spring MD 20907-8250
1-800-438-4380 (toll-free)
301-495-3311 (English, Spanish)
Fax: 301-495-3334

**Benefits Check Up** (www.benefitscheckup.org)
_A free online service provided by the National Council on Aging, this program allows people to find programs that can help them meet health care and other costs._

**Children of Aging Parents (CAPS)** (www.caps4caregivers.org)
P.O. Box 167
Richboro PA 18954
1-800-227-7294 (toll-free)

**Department of Veterans Affairs (VA)** (www.va.gov)
Office of Public Affairs
Eldercare Locator  (www.eldercare.gov)
National Association of Area Agencies on Aging
1730 Rhode Island Avenue, NW, Suite 1200
Washington DC 20036
1-800-677-1116 (toll-free) Fax: 202-872-0057
(Nationwide directory assistance service helping older people and caregivers locate local support and resources for older Americans; funded by the Administration on Aging.)

Family Caregiver Alliance  (www.caregiver.org)
180 Montgomery Street, Suite 1100
San Francisco CA 94104
1-800-445-8106 (toll-free), or 415-434-3388
(Community-based nonprofit organization offering support services for those caring for adults with AD, stroke, traumatic brain injuries, and other cognitive disorders. Programs and services include an information clearinghouse for publications, as well as a variety of online services.)

Food and Nutrition Information Center  (www.nalusda.gov/fnic)
Agricultural Research Service/National Agriculture Library
Beltsville MD 20705-2351
301-504-5719 Fax: 301-504-6409

Lighthouse National Center for Vision and Aging  (www.lighthouse.org)
The Sol & Lillian Goldman Building
111 East 59th Street
New York NY 10022
1-800-829-0500 (toll-free) 212-821-9200
Fax: 212-821-9707
(Provides advocacy, support, information, and resources on vision impairment and blindness.)

Medicare Rights Center  (www.medicarerights.org)
1460 Broadway, 17th Floor
New York NY 10036
212-869-3850 Fax: 212-869-3532
(National, nonprofit service helping older adults and people with disabilities get good, affordable health care.)

National Alliance for Caregiving  (www.caregiving.org)
4720 Montgomery Lane, 5th Floor
Bethesda MD 20814
(Nonprofit coalition focusing on issues of family caregiving. The Alliance offers information for caregivers as well as supporting the Family Care Resource Connection.)

National Caucus and Center on Black Aged (www.ncba-aged.org)
1220 L Street, NW, Suite 800
Washington DC 20005
202-637-8400 Fax: 202-347-0895
(A national, nonprofit organization providing health and social service information, advocacy, and assistance to African Americans and low-income older people.)

National Center on Elder Abuse (www.elderabusecenter.org)
1201 15th St. NW, Suite 350
Washington DC 20005-2842
202-898-2586 Available between 9:00 AM - 5:30 PM EST
Fax: 202-898-2583
(Operated jointly by the National Association of State Units on Aging, the National Committee for the Prevention of Elder Abuse, and the University of Delaware to disseminate information about abuse and neglect of older people.)

National Council on Aging (NCOA) (www.ncoa.org)
1901 L Street, NW, 4th floor
Washington DC 20036
202-479-1200 Fax: 202-479-0735
(A private, nonprofit organization providing information, training, technical assistance, advocacy, and leadership in all aspects of aging services and issues. Contact NCOA for information on training programs and in-home services for older people.)

National Domestic Violence Hotline (www.ndvh.org)
P.O. Box 161810
Austin TX 78716
1-800-799-7233 (toll-free)
(Open 24 hours a day, 365 days a year, provides crisis intervention, information about domestic violence, and referrals to local service providers to victims of domestic violence and those calling on their behalf.)

National Family Caregivers Association (www.nfca.cares.org)
10400 Connecticut Avenue, #500
Kensington MD 20895-3944
1-800-896-3650 (toll-free) 301-942-6430
Fax: 301-942-2302
(A grass roots organization providing advocacy, support, and information for family members who care for chronically ill, older, or disabled relatives.)
National Health Information Center (www.health.gov/NHIC)
Office of Disease Prevention and Health Promotion (ODPHP)
Washington DC 20013-1133
1-800-336-4797 (toll-free) 301-565-4167
Fax: 301-984-4256 Faxback: 301-468-1204
(Provides health information, contacts for Federally-supported health information centers, lists of national health observances, and toll-free numbers sponsored by the Federal Government.)

National Hispanic Council on Aging (www.nhcoa.org)
1341 Connecticut Avenue 4th Floor, Suite 4.2
Washington DC 20036
202-429-0787 Fax: 202-429-0789
(A national organization providing advocacy, education, and information for older Hispanic people.)

National Hospice and Palliative Care Organization (www.nhpco.org)
National Hospice Foundation (NHF);
1700 Diagonal Road, Suite 625
Alexandria VA 22314
1-800-658-8898 (toll-free Helpline) 703-837-1500
Fax: 703-837-1233
(A nonprofit, membership organization working to enhance the quality of life for individuals who are terminally ill and advocating for people in the final stage of life. Also offers Caring Connections http://www.caringinfo.org), providing resources and information to help people make decisions about end-of-life care and services.)

National Women's Health Information Center
8550 Arlington Blvd., Suite 300
Fairfax VA 22031
1-800-994-WOMAN (96626) (toll-free)
(Health and referral center for women. Spanish language resources are available.)

Parkinson's Disease Foundation (www.pdf.org)
1359 Broadway, Suite 1509
New York NY 10018
1-800-457-6676 (toll-free) 212-923-4700
Fax: 212-923-4778

Social Security Administration (www.socialsecurity.gov)
Office of Public Inquiries
Baltimore MD 21235
1-800-772-1213 (toll-free)
Well Spouse Foundation (www.wellspouse.org)
63 West Main Street, Suite H
Freehold NJ 07728
1-800-838-0879 (toll-free) 732-577-8899
Fax: 732-577-8644
(A not-for-profit association of spousal caregivers. It offers support to the wives, husbands, and partners of chronically ill or disabled people. The Foundation has lists of support groups nationwide and sponsors recreational respite opportunities.)