

To the Graduate Council

I am submitting herewith a thesis written by Brooke Judkins Matchen entitled "Grandchildren and Dependent Grandparents A Qualitative Study of Family Caregiving for the Elderly " I have examined the final copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Science, with a major in Counseling

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GRANDCHILDREN AND DEPENDENT GRANDPARENTS:

A Qualitative Study of Family Caregiving for the Elderly

A Thesis

Presented for the

Master of Science Degree

The University of Tennessee, Knoxville

Brooke Judkins Matchen

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DEDICATION

This thesis is dedicated to my grandmother,
Phyllis Lipe Souther “Gammy” (1910-1994),
from whom I learned much about the art of writing

And to my mother, Carolyn Souther Judkins,
who has taught me what it means to be a caregiver

May the legacy continue

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I would like to express my gratitude to my advisor and committee chair, Dr. Bill Poppen, who has supported me through my masters program. At a critical point during the writing of my thesis, he said to me, "We'll get through this," and I think his statement captures the essence of his personal approach to teaching. I would also like to thank Dr. Will Conwill, for his willingness to serve on my committee and for his assistance in writing my thesis. None of this would have been possible without committee member Dr. Priscilla White Blanton, who along with Dr. Annabel Lee Agee, graciously invited me to work with them on the Family Caregiving Research Project. I appreciate Dr. Blanton's extensive help with the design and development of this study, and I look forward to doing more research with her in the future. Lastly, I wish to thank Dr. Agee for sharing with me her knowledge about elder care and qualitative research.

ABSTRACT

Due to the population growth of persons aged 65 and older, there will be increasing numbers of frail, elderly requiring assistance with daily living. Often, it is families that provide care for the dependent elderly, and the typical caregiver is an adult daughter who is middle-aged. While there has been substantial research on adult children caring for parents, there have been few studies that have considered the third generation, or grandchildren, in caregiving families. Therefore, the purpose of this study was to explore the meanings that grandchildren of physically or cognitively impaired elders give to the experience of family caregiving. A qualitative approach in the phenomenological tradition was chosen in order to capture the essence of grandchildren's caregiving experiences. Ten grandchildren between the ages of 15 and 30 participated in in-depth interviews.

Family legacies, or the intergenerational transmission of ways of relating to members of the family system, seemed to have significant impact on grandchildren's perceptions of and involvement in caregiving for their grandparent. Caregiving behaviors and attitudes appeared to be passed down through the generations. This primary finding supported previous research. It was speculated that discrepancies in the findings from this study and past research were due to differences in the age of the grandchildren, the place in which the care recipient resides, and the nature of the care recipient's impairment. Benefits and gratifications received from caregiving were reported primarily by older grandchildren, whereas younger grandchildren talked more about the demands and burdens associated with eldercare.

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CHAPTER 1

INTRODUCTION

Caring for an elderly parent who is physically or cognitively impaired has become a normative stressor for contemporary adult children and their families (Brody, 1985). With increased life expectancy, longer durations of chronic illnesses and disabilities among the elderly, and falling birthrates that limit the number of potential filial caregivers, more adult children can be expected to provide extended care for one or more aged parents (Brody, 1986). In the arena of parent care, earlier research was centered around the primary caregiver. More recent research, however, suggests that it is not only the primary caregiver who is influenced by the dependency of a frail, elderly parent, but that the effects of caregiving radiate to others in the family as well (Mellins et al, 1993, Pyke & Bengston, 1996, Pruchno et al, 1984)). Some research has been done on the siblings (Brody et al, 1989, Stoller, Forster & Duniho, 1992) and spouse (Franks & Stephens, 1996, Kleban, et al, 1989)) of the adult child who provides the bulk of the care for an elderly parent, but few studies have been done on the children of caregivers, or grandchildren of elders receiving care. These grandchildren are in a unique position to describe many aspects of what it means to them to have a dependent elderly grandparent receiving care from the members of the family system.

Importance of the Topic

It is estimated that by the year 2030, the 65+ age group will constitute 20% of America's population. That is a 106.8% increase from 1995 (Siegel, 1996), which means that there will be many more elderly people needing assistance with functions of daily

living than there are currently. In addition to the growing numbers of elderly persons, the average lifespan is increasing. As the elderly get older, however, their chances rise for developing chronic health conditions that impair their ability to function independently. Studies have shown that as an older person's condition deteriorates, families provide 80-90% of assistance with medical and personal care, household upkeep, transportation and shopping, as well as emotional and spiritual support (Brody, 1986, Kane and Penrod, 1995). If the spouse of an elderly person is deceased or unable to provide care, responsibility is typically taken by an adult child or children. Although there are adult sons who become primary caregivers (Harris, 1998), the majority of adults providing filial care are daughters (U S Department of Labor, May 1998). The phrase "women in the middle" has been coined to describe the increasing numbers of women who are caring for both children and parent(s), and who are also employed either part- or full-time (Brody, 1990). Since providing care for an elderly parent is a phenomenon currently affecting and predicted to affect in the future many families in America, it is important to study the ways in which families experience caregiving.

Statement of the Problem

Though much research has been done on adult children who provide care to a dependent elderly parent, and some studies have been conducted with siblings and spouses of these primary caregivers, only two quantitative studies have been found that focused solely on grandchildren in caregiving families. Two qualitative studies were found that *included* perspectives of grandchildren, but the primary focus of the studies were on the family system so that grandchildren shared the limelight with other family

members. Other studies included reports from adult caregivers about their children's current or anticipated involvement in the caregiving process (see Chapter 2).

Consequently, there is a need for more quantitative research but there is also an equal, if not greater, need for qualitative studies that focus on grandchildren and that investigate the profundity of the impact that eldercare has on their lives and their relationships.

Theoretical Perspectives

Eldercare is considered a family stressor because it constitutes provision of assistance as well as acceptance of the physical and/or mental decline of a loved one. How families deal with this stressor depends on a complex interaction of internal and external contexts. Carter and McGoldrick (1999) talk about family stress in terms of *vertical* and *horizontal* axes. The *vertical* axis includes ways of relating and functioning that are passed down through generations, as well as the family history, family attitudes and expectations. The *horizontal* axis contains developmental stressors, both predictable (e.g., marriage, birth, death) and unpredictable (e.g., acute or chronic disabilities, job loss, natural disasters). Consideration of the intersection between vertical and horizontal axes is necessary when looking at the ways in which families deal with eldercare.

Another paradigm for understanding family stress is McCubbin's Double ABCX model of family behavior (see Figure 1) (McCubbin & Figley, 1983). The aA Factor is constructed around the notion that stressful events do not occur in isolation. Rather, there are typically simultaneous stressors and strains occurring in families that result in a "pile-up" which may make the crisis even more daunting and difficult for the family. The bB Factor takes into consideration the resources that families have to help them deal

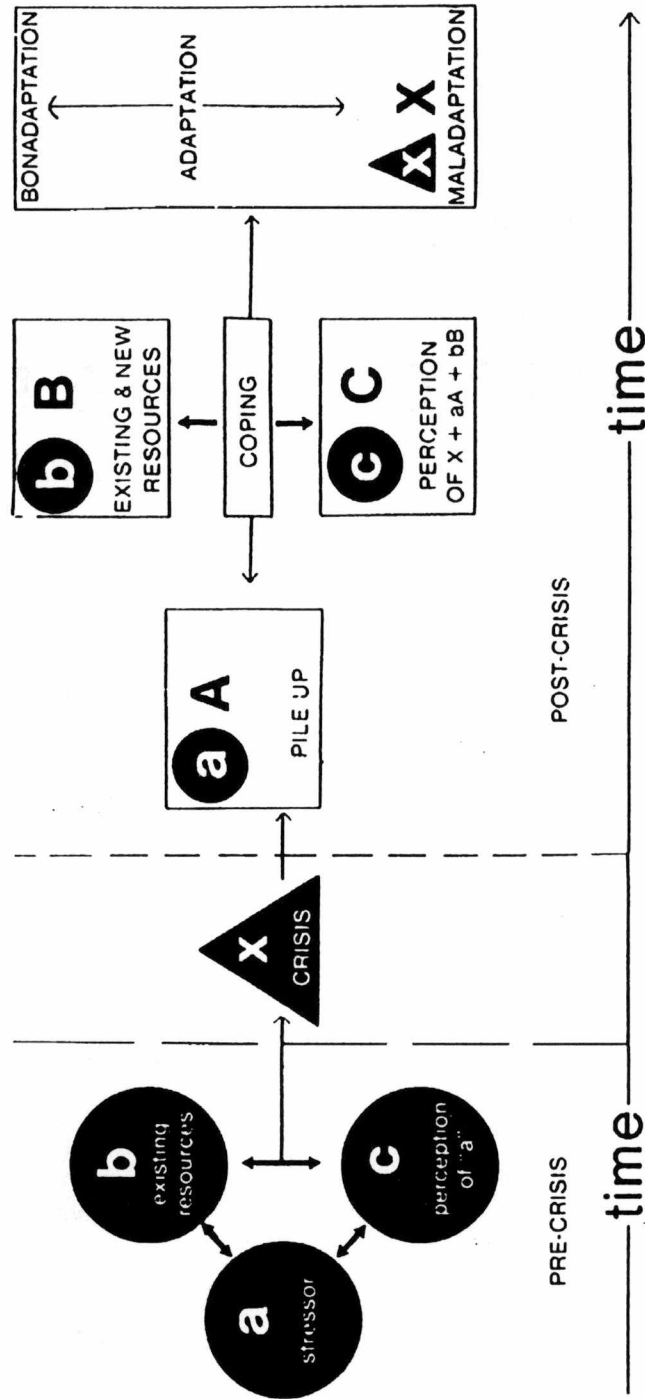


Figure 1. Double ABCX Model of Family Crisis
 Source: McCubbin, H. I., & Figley, C.R. (1983). *Stress and the family, Volume 1: Coping with normative transitions*. New York: Brunner/Mazel, Inc.

with crises. This includes both existing resources, which families have prior to a crisis, as well as expanded family resources that are developed as a means of coping with a crisis. The cC Factor is concerned with the definition and meaning that a family gives to a stressful event or situation. For example, one family may view a crisis as an “opportunity for growth” whereas another might look upon a similar event with a “why us?” attitude, with members engaging in self-pity and negative thinking.

The way in which a family perceives a crisis greatly influences the effectiveness of how they cope or manage the situation. Lastly, the xX Factor in McCubbin’s model represents the extent to which the family system adapts to a major disruption, taking into account the combined effect of the aA, bB, and cC Factors. Outcomes are placed along a continuum between balanced adaptation, characterized by the maintenance or strengthening of family cohesion, and unbalanced adaptation, which results in a deterioration of family integrity (p. 20)

Particularly relevant to the present study is Boss’s notion of “boundary ambiguity” as a factor in family stress (1988). Simply defined, boundary ambiguity is “not knowing who is in and who is out of the family” (p. 73). High boundary ambiguity in a family system acts as a barrier to stress management. According to Boss, high boundary ambiguity can occur when a family member is physically present but psychologically and emotionally absent, as with Alzheimer’s disease or dementia in the elderly. However, the degree of ambiguity experienced is determined by the family’s perception of the situation (cC Factor). Therefore, families that are able to accept a loss in terms of something gained will have a clearer understanding of the role that their

loved one has in the family system

Purpose of the Study

From a family systems perspective, a change in one member elicits a change in the entire family system. As an elderly person becomes mentally or physically unable to function without help, it effects the entire family system. Therefore, in this study I will be looking at one part of the family caregiving puzzle: children of adults who provide care for an elderly parent. The purpose of the study is to gain insight into the meaning that grandchildren give to the experience of having a frail, elderly grandparent who is becoming increasingly dependent on their mother or father for assistance with daily living and more extensive emotional support.

Research Question

In this study, I sought to answer the question, "What meanings do children of adults providing care for an elderly parent give to the process of caregiving by their families and their relationships with their parent, grandparent, and other family members?"

Definitions of Terms

Child/grandchild The adolescent or young adult child of a person providing care for a frail, elderly grandparent. Includes such relationships as those formed through biology, marriage or adoption. The sample in this study consists of grandchildren from middle and upper class households.

Adult child The man or woman providing care for a frail, elderly parent. Includes a daughter-in-law or son-in-law who is providing care to his or her spouse's

parent(s)

Frail, elderly parent/grandparent An adult who is physically or cognitively impaired to the extent that he or she is dependent upon an adult child (and his or her spouse) for assistance with instrumental tasks, personal care activities, and possibly emotional and spiritual needs This person may reside in the adult child's household, or in an assisted living or nursing home residence

Caregiving/eldercare Providing assistance to an elderly parent (includes mother-in-law or father-in-law) with activities of daily living (ADLs) which can include instrumental household tasks, transportation, medical care and financial tasks Also, eldercare may include provision of social, emotional or spiritual support (Agee, 2000)

The application of these terms to participants in the study were determined by the demographics information form as noted in Appendix A-4

Limitations of the Study

This study is an in-depth look at the experience of ten children whose parent is caregiving to a frail, elderly grandparent Therefore, the data and analysis contained in this study are not generalizable to the population of grandchildren in general As noted earlier, the sample consists of adolescent and young adult grandchildren from middle and upper class households, most of whom are Caucasian Therefore, younger grandchildren, grandchildren from lower income level homes, and grandchildren from various ethnic cultures are not represented in this study

CHAPTER 2

LITERATURE REVIEW

In looking at the literature on family caregiving for the elderly, it is evident that members of the third generation, the grandchildren, have been mostly overlooked. Whereas siblings and spouses of primary caregivers have been given the most attention in the literature as the "secondary caregivers" to an elderly parent or parent-in-law, children of primary caregivers are much less likely to be seen as part of the caregiving support system. Also, there are very few sources that have considered the thoughts and feelings of grandchildren in families involved in elder care. Although studies of grandchildren in aging families are limited, there are sources that suggest that these children are frequently and intimately involved in the caregiving process.

Reports show that in some families grandchildren provide emotional and instrumental support for their caregiving parent. Suitor and Pillemer (1993) found that 13.5% of adult daughters caring for a parent reported that their children gave them emotional and instrumental support. Children may help even more than spouses, who were claimed to be emotionally and instrumentally supportive by only 11.2% of caregivers. Furthermore, almost 20% of the daughters said that their children "should have helped more" with caregiving responsibilities, suggesting that in some families grandchildren are expected to be part of the caregiving team.

Grandchildren can also serve as providers of emotional and instrumental support for their care-receiving grandparent. In a study of adults with a parent aged 65 or older (Cicirelli, 1981), about 7% of the informants reported that their children offered

assistance to their elderly parent in the areas of homemaking, maintenance, transportation, and spiritual needs. When asked to predict the type and amount of help that other family members would provide in the future when their parent's need for assistance would likely increase, 10%-12% of adults expected that their own children would help out with the grandparent's needs for transportation, psychological support, homemaking, and maintenance. It is important to note that because this was not a study of caregiving adults, specifically, the estimates may be low. Although the sample consisted of adult children with an elderly parent, the amounts of care that the elderly parents required at the time of the study ranged from none to total dependence. Therefore, the percentages cited above might actually have been higher if the sample were comprised solely of adult children who were acting as primary caregivers for a frail, elderly parent in need of assistance.

The literature on filial care of the elderly suggests that grandchildren are significantly affected by the changes that caregiving brings about in their relationship with their parent. In Sutor and Pillemer's (1993) study, 18.6% of adult daughters reported that their children had complained that they had spent less time with them. Merrill (1997) provided a personal example of this from a caregiving parent who explained that her son "wants to go to a mother-son sleepover with Boy Scouts, but I can't leave my father alone that long, so he is disappointed" (p. 99). Other children in her study were reported as resenting the "on-call" nature of their parent's life, with plans having to be dropped or changed due to the immediate needs of the elderly grandparent. Looking at caregiving for elders with Alzheimer's disease, Creasey and Jarvis (1989)

found that children who had a burdened mother had a poorer relationship with their ill grandparent and their father

It is not only younger children that are affected by their parent's caregiving. There is evidence that older grandchildren are impacted by the demands that caregiving places on their parents as well. Merrill's research revealed that caregivers with grown children regretted not being able to spend more time with them and their families. Parents described not only missing out on such things as helping with new babies and taking their children to lunch now and then, but also having their children and their families visit less often due to the disagreeable nature of the elderly grandparent. One caregiver described

It is hard for the kids to come over. It is just not a happy house anymore.

My older daughter-in-law lets what my mother-in-law says roll off her back. But it is hard on my younger daughter-in-law. So I don't get to see my kids as much. (p. 99)

From their own perspective, older grandchildren are often concerned about the physical and emotional toll that caregiving for their grandparent takes on their parent, who are often no longer young and healthy themselves (Mellins et al, 1993). Although their worry may cause grandchildren to urge their parent to place the grandparent in a nursing facility, Pyke and Bengtson (1996) note the dilemma they face due to their competing concerns between the well-being of their parent versus their grandparent (p. 386).

The literature suggests that younger grandchildren may view the health decline of their grandparent in a more negative way compared to older grandchildren. Creasey et

al. (1989) found that younger grandchildren (Mean age=12.9) who had a grandparent with Alzheimer's disease reported lower levels of satisfaction with their grandparent on the scales of companionship, instrumental aid, intimacy, affection, and admiration compared to younger grandchildren with a healthy grandparent. Although there have been no similar empirical studies of older grandchildren's perception of their relationship with their elderly grandparent, Mellins et al. (1993) found that some older grandchildren (Mean age=32) described a changed life perspective as a result of the caregiving experience. The altered life perceptions reported included a changed view of the nature of the family or of one's place in the life cycle, and a new appreciation of one's caregiving parent (p. 23). The researchers speculate that family members who are somewhat removed from direct care for an elder, like older grandchildren, have the physical and emotional distance to ruminate about the meaning of the caregiving experience.

Whether grandchildren are young or grown up, though, their perception of eldercare is significantly influenced by the way in which familial relationships are viewed within the family system. In their study of families involved in eldercare, Pyke and Bengtson (1996) identified significant differences in the ways in which families with an individualistic orientation and those with a collectivist orientation approached caregiving. For individualistic families, or those who had tendencies towards independence and emotional distance, eldercare was viewed as a burden and the responsibility was taken on grudgingly. In collectivist families, in which interdependence and emotional closeness were more present, caring for an elderly parent

was seen as an opportunity to give something back to one's parent(s) and to get to know them better

Contrary to what was expected, grandchildren in the study tended to respond in contrast to their families' orientation. Those from individualistic families sometimes complained that they did not think that their parents provided enough direct care, although they themselves rarely adopted any caregiving responsibilities. Grandchildren from collectivist families expressed concern that their parents were doing too much, and worry about their parent's health caused some of these grandchildren to advocate placing their grandparent in a nursing facility. Unlike individualistic grandchildren, though, collectivist grandchildren typically assisted their parent(s) in caring for their grandparent. Pyke and Bengtson concluded that grandchildren can serve as "monitors" for their parents by "pressing them not to adopt overly collectivist or overly individualistic caregiving strategies" (p. 387). Intergenerational relationships including members of the fourth generation in families, or great-grandchildren, are being studied by Bengtson (1999), who has conducted longitudinal research on families for over 26 years.

As indicated in the literature, grandchildren in families caring for an elder contribute to the caregiver's *and* the care receiver's support system. Therefore, they can play either a direct or an indirect role in the quality of care that their grandparent receives. Research also shows that grandchildren are affected by the health decline and subsequent dependence of their grandparent. Some have more positive experiences with eldercare and others more negative, but nevertheless, it affects their lives and their relationships with other family members. There is still much more to learn, though,

about the ways in which grandchildren give to, and get back from, their families during the eldercare process

CHAPTER 3

METHODOLOGY

Introduction

There are few quantitative studies and no qualitative studies that have looked specifically at the perceptions of grandchildren in caregiving families, as was noted in Chapter 1 and reported in Chapter 2. Research that explores the meaning that grandchildren give to caregiving and to their grandparent's deterioration in health, as would be found in qualitative studies, is much needed. Consequently, I have chosen to take a qualitative methodological approach to the current study.

Qualitative research is characteristically interpretive and emergent (Rossman & Rallis, 1998). Researchers become part of the process and the information that is gathered is filtered through their own experience with the phenomenon being studied (Marshall & Rossman, 1999). Janesick (1994) uses dance as a metaphor for qualitative research, and implies that researchers are intimately connected to the process of designing and executing their studies like dancers are to the movements of their bodies as they perform. Qualitative research is emergent, in that informants are more likely to structure the data they report rather than report only that information which is asked of them on a questionnaire or survey, as in quantitative research. The result is a highly descriptive and personal account of informants' experiences with a specified phenomenon.

There are various traditions that fall under the heading of qualitative research, and the one I have chosen to follow is phenomenology. Phenomenology is the

investigation of lived experiences and the ways in which perceptions of experiences shape one's worldview (Marshall & Rossman, 1999) In contrast to the other qualitative methods of inquiry, the purpose of phenomenology, according to Marshall and Rossman (1999), is to "describe the meaning of a concept or phenomenon that several individuals share" (p 112) Therefore, it is the best approach to use for the current study since the intent is to provide a rich and descriptive picture of the meaning that grandchildren give to the phenomenon of family elder care

Research Design

The sample to be used in this study is taken from a larger data set that comes from the Family Caregiving Research Project that is being conducted by Dr Priscilla Blanton in the Department of Child and Family Studies (see Appendix A) This study is an on-going, qualitative inquiry into the phenomena of family caregiving The study focuses on situations in which a frail, elderly person is dependent on members of his/her family for assistance with daily living At least two, and sometimes three or four, members of caregiving families are interviewed

I became involved in the Family Caregiving Research Project at the beginning of the "data collection" stage Since I have been conducting interviews with participants and meeting regularly with other researchers working on the study, I am familiar with the methodology being used Although the study is broadly termed a "qualitative" study, the research methods are focused primarily on the use of in-depth interviews I have chosen to use Creswell's (1998) model of the activities involved in data collection in a phenomenological study (see Figure 2), to explain how the data were gathered

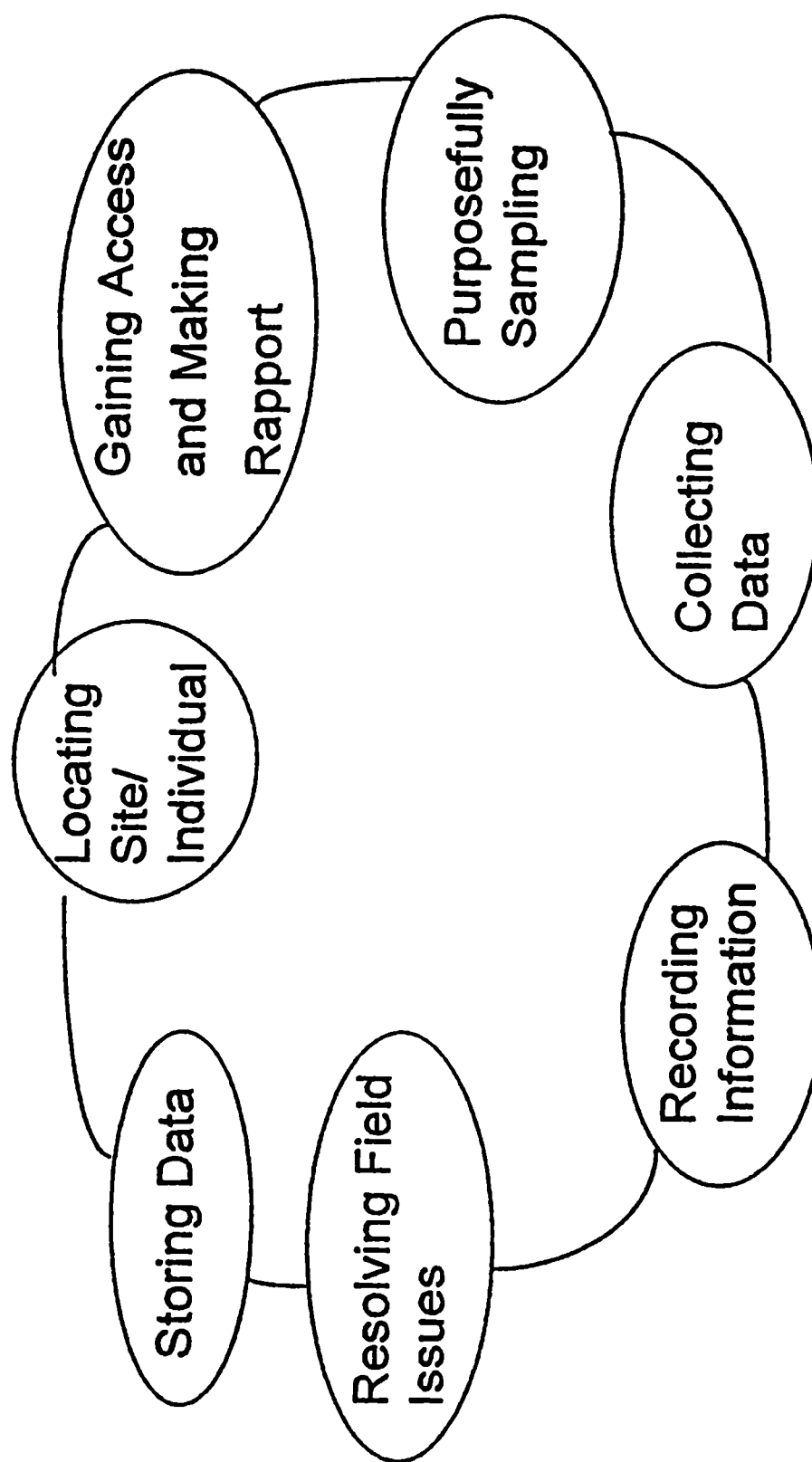


Figure 2. Data Collection Activities
Source: Creswell, J. W. (1998). Qualitative inquiry and research design: Choosing among five traditions. Thousand Oaks: Sage Publications

Locating Individuals

According to Creswell, the participants in a phenomenological study “must be individuals who have experienced the phenomenon being explored and can articulate their conscious experiences” (p 111) The subjects for the Family Caregiving Research Project were recruited by word of mouth, contacts with local assisted living facilities, and the snowball technique Criteria for participants was involvement in caregiving for a frail, elderly family member Once interviewed, subjects were asked to provide the names and telephone numbers of 1-2 family members that they felt were most involved in caregiving with them Research assistants contacted additional family members to request their participation in the study

Access and Rapport

Before subjects were recruited, approval for the Family Caregiving Research Project was given by the Human Subjects Research Board at The University of Tennessee, Knoxville Then, potential participants were given information about the study, and any questions they had were answered If they were willing to be involved, a time was set for them to be interviewed at the location of their choice Subjects signed consent forms and were informed that their participation was strictly voluntary and that they could withdraw from the study at any time They were also informed that if they experienced undue negative emotional responses to the interview process the interviewer would provide them with the name and telephone number of a mental health center in their area upon their request. The confidentiality of information shared in the interviews was assured, specifically in relation to other participating family members

Purposeful Sampling Strategy

The sample I have chosen to study consists of 10 grandchildren from the families participating in the Family Caregiving Research Project. In choosing the subjects for this study, I relied upon the criterion that subjects must have a parent who is providing primary care for a frail, elderly grandparent. Also, participants must have rather regular face-to-face interaction with their parent and dependent grandparent.

Collecting Data and Recording Procedures

As Creswell recommends, in-depth interviews were used to collect data from participants. Interviews were one and a half to two hours in length, and open-ended probes were used (see Appendix A-5). The semistructured nature of the interview allowed interviewer and interviewee some flexibility in the direction that the interview took, which was conducive to the emergent design of this study. Before each interview participants were given an explanation of the Family Caregiving Research Project, which included Dr. Blanton's office phone number, and then they were asked to read and sign an informed consent form (see Appendices A-1 & A-2). Next, interviewees were informed of the necessity of audio-taping, and interviewers asked their verbal permission to proceed with recording. Then participants were asked to complete a cognitive mapping activity (see Appendix A-3). This activity involved the use of concentric circles to indicate the connections of family members in relation to the participant, who placed him/herself in the center circle and then placed other family members in other circles depending on the perceived level of closeness felt by the participant. As the activity was carried out, interviewees were invited to elaborate on why they placed family members

where they did. A demographics information form was also completed by interviewees at the beginning of each interview (see Appendix A-4).

Field Issues

Before engaging in interviews with subjects, I conducted a "pilot interview" with Dr. Blanton in which I interviewed her about her experiences caregiving for her father. I also participated in a "bracketing interview" with Dr. Blanton in which I talked about my experiences in a caregiving family (Creswell, 1998), which occurred for three years when my mother provided primary care for my grandmother in our home. It was ascertained that I did not have any biases that would compromise the quality of my research. As a counselor-in-training, I have developed skills that are helpful with qualitative interviewing. For instance, I am experienced at listening to others so it is not difficult for me to say "little" during interviews. Also, I have learned effective ways to establish rapport with a person, and to reflect the content and feeling of what he/she is telling me which facilitates further information and expression from the client or subject. In talking with persons about the physical and/or mental decline of a loved one it was not uncommon for interviewees to have emotional outbursts in which they wept. Again, this is a typical experience for a counselor, so I was able to handle such situations with interviewees in a nonjudgmental manner, with minimal negative reinforcement for weeping.

Interviews were recorded on a small microcassette recorder. Participants who had agreed to be interviewed were willing to have an interviewer come to their home or to meet at a convenient location. Concerning the latter, the most difficult issue was

finding a location that was quiet enough and generally suitable for conducting a personal interview. In the few instances in which taping conditions were less than desirable, highly accurate transcriptions were obtained

Storing Data

After transcription and analysis, audio tapes and field notes will be destroyed. The data collected in this study will be stored in a locked file cabinet in Dr. Blanton's locked office (on UT campus) and will be destroyed after five years. Informed Consent forms will be stored in a separate locked file cabinet in Dr. Blanton's office, and will be destroyed after three years. The anonymity of participants will be protected by the use of pseudonyms in the data.

Data Analysis

Creswell's "Data Analysis Spiral" (see Figure 3) represents the on-going nature of data analysis in qualitative research. By using a spiral rather than a line to represent the analysis process, Creswell demonstrates the on-going nature of qualitative data analysis as well as the interdependency of the steps, with each building on the former. Using Creswell's Data Analysis Spiral adapted for phenomenology, I will explain how I studied and represented the data that I collected.

Data Managing

For each participant, a file (using a pseudonym) was created that included the transcribed interview, the Demographics Questionnaire, and the Cognitive Mapping Activity. Participants' files were alphabetized according to the letter of the family in which she/he is a member (i.e., Family A, Family B, Family C, etc.).

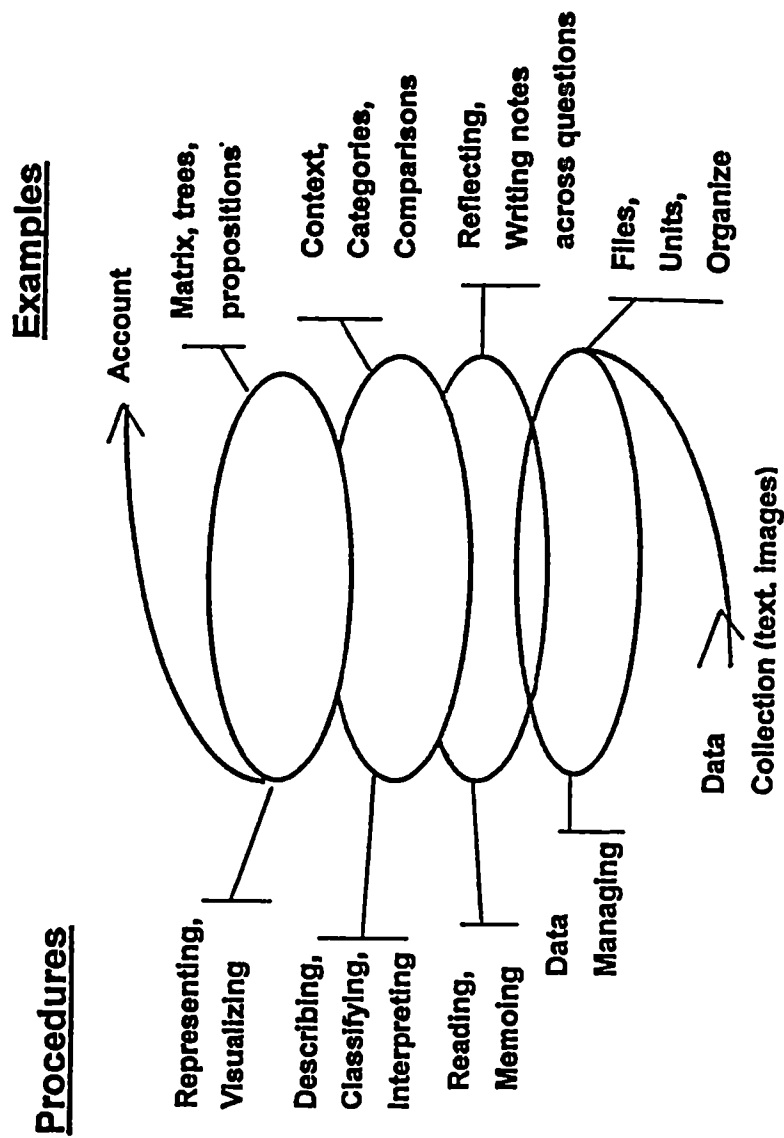


Figure 3. The Data Analysis Spiral
 Source: Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks: Sage Publications.

Reading, Memoing

During this stage of the process, transcripts were read and re-read in order to provide a sense of the overall nature of each interview, as well as to yield information about how the interviews fit together to make a “big picture” As the transcripts were read through, themes were highlighted and memos were written in the margins in the forms of “short phrases, ideas, or key concepts.”

Describing, Classifying, Interpreting

This stage of the data analysis was begun with a description of my experience as a granddaughter in a caregiving family (see Appendix B). Next, meaning statements from individual transcripts were identified and then classified into groups or meaning units The data was then interpreted in the form a “textural description” in which it was discussed *what had happened* in each of the informant’s caregiving experiences A “structural description” was also created that explained *how* the caregiving was experienced by informants The two kinds of descriptions were interwoven and presented as summaries of informants and their caregiving contexts The final step was the development and description of five themes which captured the essence of the participant’s experiences with caregiving (Moustakas, 1994)

Since the focus of the present study is on the *meaning* that informants have given to elder care, the report was organized around *themes* rather than around a timeline of events This type of report, which is synchronic in nature (Weiss, 1994), offers a snapshot view of the informant’s experience with this phenomenon

Representing, Visualizing

A table was created that uses illustrative quotes from participants to illustrate the thematic elements that were identified from the data (see end of Chapter 4)

CHAPTER 4

RESULTS

Descriptions of Informants and Their Caregiving Contexts

Maria Maria is a 17 year-old female who attends high school and works at a local restaurant for spending money. She is the adopted daughter of a middle-class couple in their late thirties who have three biological children, two girls and a boy, all of whom are younger than Maria. At the time of the interview Maria's grandmother, her mother's mother, had been living with the family for seven months. After a fall that broke her pelvic bone the grandmother was supposed to stay temporarily with the family for a few weeks, but due to her increasing memory impairment and her reluctance to leave, her stay with the family was extended indefinitely. Maria's parents, especially her mother, are not happy with having the grandmother in their home and see the only potential benefit as making a little money from the deal by renting out her house. Maria, however, having been raised in a South American country where "the little kids take care of the grownups," does not see what is so difficult about caregiving and even enjoys having her grandmother living there.

Lizbeth Lizbeth is a 23 year-old female who, at the time of her interview, had just moved back to Knoxville from the western U.S. and was living with her parents and trying to figure out what she wanted to do with her life. She comes from an upper middle class family that provided her with private school education and trips abroad. She has a close relationship with her mother, her grandmother (on mother's side), and her sister who is one year older than she (whom Lizbeth describes as being more like

their father) Lizbeth feels a strong intergenerational connection with her grandmother and her mother, with whom she shares the birth-given name "Elizabeth." Her grandmother resides in a local nursing facility, having been diagnosed with Alzheimer's disease 15 years ago. Lizbeth's mother is her primary caregiver. Although communication with her grandmother is limited, Lizbeth still feels like she gives something and gets something back when she visits with her

Lindsey Lindsey is a 20 year-old female who attends a university in western North Carolina and who works part-time there as a waitress. Our interview was conducted while she was home for Christmas break in Knoxville. Her mother is the primary caregiver for Lindsey's grandfather (mother's father), who lives in a local assisted living facility for Alzheimer's patients. She says that she was closer to her grandfather when she was younger, but that she thinks her two older brothers were closer to him than she was. None of the three children are very involved in the caregiving to their grandfather, and Lindsey reported several times that her parents rarely talk to her or her brothers about it. Lindsey visits her grandfather about once every 2 or 3 months, and it was obvious during our interview that she was very upset about his current condition.

Rachel Rachel is an 18 year-old female who is a senior at a local high school and who lives with her mother. She is the only child from her parent's marriage, which ended when Rachel was in her early teens. Her father lives in North Carolina with his wife and Rachel's two half sisters and two step sisters. Rachel's mother is also an only child and is the sole caregiver for her mother, whom she moved to Knoxville from Florida three years ago when her memory impairment made her no longer independent.

Rachel's grandmother resides in a local nursing facility. Throughout Rachel's life, there has been much intergenerational conflict between her grandmother, her mother, and herself. She claims that her relationship with her mother has gotten worse since her grandmother moved to Knoxville. Rachel is resentful of the time that her mother spends away from their home working at her part-time job, visiting with Rachel's grandmother, or being with her new boyfriend. The only positive aspect of her grandmother that Rachel sees is that she is wealthy, and Rachel knows that she will inherit a nice sum of money when she dies. Rachel visits her grandmother usually once a month, sometimes once every two months, upon invitation by her mother.

Jane Jane is a 25 year-old female who is pursuing a graduate degree. She is married and has a 10 year-old son. She and her mother have always been close to her 70 year-old grandfather, who was diagnosed with Alzheimer's last year. Jane describes him as being like a father to her since her biological father left her and her mother when Jane was a baby. Although Jane's grandmother is the primary caregiver for her grandfather, she says that in the "chain of command," her mother, the second oldest of four daughters, comes second. Jane placed herself as third in line. In addition to helping her grandfather, she sees herself as a source of support for her mother as her only child. Jane is saddened by the ways in which her grandfather is changing, but she tries to make the most of the time they do spend together.

DeeDee DeeDee is a 17 year-old African American female who, at the time of the interview, was finishing her senior year of high school. She was living with her mother, but hoped to move out on her own after she graduated. Her mother and her

mother's sister are the primary caregiver's for DeeDee's 90 year-old grandmother, who has had several falls, and is now bedridden. For a long time her grandmother was being cared for in her home, but she has recently gone to a nursing facility. DeeDee has a good relationship with her grandmother, but she was closer to her grandfather, who died when she was 10. She said it was very hard on her when he died because she was his favorite and he treated her "real well." There is much conflict in DeeDee's family due to the irresponsible actions of her uncle, her mother's brother, who has been living in her grandmother's house, but not paying rent or taking care of the place. DeeDee is resentful of her uncle for taking advantage of her grandmother and she wishes her mother and aunt would step in and kick him out of the house. Her mother and aunt also feel like their brother has been neglectful of their mother, but they are concerned about what he might do if they were to confront him.

Andrew Andrew is a 30 year-old male who is pursuing a college degree and working part-time. He moved to Tennessee 3 years ago to attend UT and he resided with his now 95 year-old grandfather who owned a large piece of land near Knoxville. Shortly after Andrew moved in, his grandfather fell and broke his hip and subsequently needed around-the-clock care. As Andrew explains it, "I took the nightshift and my aunt and uncle, who are retired, would take care of him so I could come to school." Andrew shared the caregiving responsibilities with his aunt and uncle for a year until his parents retired and moved to Tennessee. At that point, Andrew's father became the primary caregiver for his own father. Even though Andrew has lived in Knoxville for the last two years, he continues to make the hour drive to his grandfather's place at least once a week.

He generally goes to stay with his grandfather for one or two nights on the weekends so that his parents can take a break. At the time of the interview, Andrew's aunt was planning to move with her husband, from Arizona, to take over as primary caregiver because her brother was experiencing burn out. Andrew anticipates that as long as he is living in East Tennessee he will play a role in caring for his grandfather. He has three older sisters, two who live in a neighboring state and one that resides in western U S

Nicole Nicole is a 23 year-old female who is a married graduate student working full-time. She is an only child, and her parents divorced when she was 16. Her mother is also an only child, and she was the primary caregiver for her mother, Nicole's grandmother, who died in 1994. Now, Nicole's mother is secondary caregiver for her increasingly frail father, who has a girlfriend (of twenty years) that cooks for him and cleans but is in poor health herself and so cannot, as Nicole puts it, "tug on him and pull on him." She explained that caregiving for her grandfather is more difficult than caregiving for her grandmother because his personality is much less agreeable. Nicole sees herself as her mother's primary source of support. She and her mother visit her grandfather, who lives 30 minutes outside of town, about twice a week. She predicted that as her grandfather's health declines she and her mom will become more involved in his care, especially if his girlfriend's health deteriorates as well.

Laura Laura is a 15 year-old female who attends high school and lives at home with her parents and younger brother. Her mother's father was diagnosed with vascular dementia last year, and Laura's grandmother is his primary caregiver. Laura's mother's parents have lived in Knoxville since she was 9, but she feels like she is closer to her

father's parents who have always lived across the street from her nuclear family. She remembers her mother's father as always being real quiet, with a "dry sense of humor." Laura's contact with her ill grandfather is limited, and she sees her caregiving grandmother mainly at church. Laura has a 20 year-old female cousin who is extensively involved in caregiving for their grandfather and Laura said that his condition "really scares her a lot, really bad," and added that he had been like a father to her cousin after her biological father left the family when she was young.

Ann. Ann is a 26 year-old female who is married and pursuing a graduate degree. Her mother is the primary caregiver for Ann's paternal grandfather, who is 88 and was diagnosed with lung cancer in the fall of 1999. Shortly after his diagnosis, Ann's parents moved him to Tennessee from Florida and placed him in a skilled care facility. Ann described her grandfather as difficult to get along with, and she understood more about why he was that way when he was diagnosed with Narcissistic Personality Disorder at the nursing facility. Ann stated that she thinks her mother puts up with too much criticism from her grandfather, and she talked about how she tries to get her mom to stand up for herself. Ann views her father as being caught in the middle between his wife and his father. Ann appeared to be somewhat ambivalent about her grandfather, claiming that she *should* try to establish more of a relationship with him but that she does not "know how to communicate with him." She does not go to visit her grandfather at the nursing facility, but sees him at family functions and when he is over at her parent's house on the weekends. Ann has an older brother who lives in Atlanta and who sees their grandfather less frequently.

Themes

In looking at the data provided by the 10 informants it was clear that there were similarities and differences in how these grandchildren have experienced the care of an ill grandparent, but each of their stories was unique. Five themes were identified from the data set, and examples supporting the themes were chosen to illustrate different aspects of the themes rather than to exhaust all occurrences of the theme in the data. Using illustrative rather than exhaustive examples from participant's stories creates a complex and descriptive picture of the meaning that these grandchildren ascribe to their caregiving experiences. A thorough examination of each of the five themes is provided

(1) Grandchildren's experience with caregiving dependent on the nature of the relationship with the grandparent.

"He is a lot more hateful than my grandmother was."

The nature of the grandparent-grandchild relationship, as well as the parent-grandparent relationship, appeared to have an impact on how these grandchildren experienced caregiving. The better the relationship, i.e. more respect and warm feelings, the more involved grandchildren were in the process and the more positive they reported their experience as being. Nicole, for example, was the only informant that had helped care for two grandparents, her mother's mother and then later, her mother's father. She and her mother were both close to her grandmother and she explained, ". we had a really great relationship, all three of us did. I'm very close to my own mother." Nicole reminisced about when she was younger and her grandmother would greet her after school with a "hand-tossed salad" to eat as a snack, and she remembered her

grandmother sitting and helping her glue together Mardi-Gras masks as decorations for her senior prom in high school. Her respect for her grandmother was evident when she said that she had learned a lot from her, “ listening to her experiences .listening to where she wanted me to go with my life and what goals she would like for me to achieve ”

Nicole notices the difference though between caring for her grandmother and the current care she and her mom are providing for her grandfather. She reported, “ .my grandfather is very much a self-centered man. He is not considerate of anyone. he is a lot more hateful than my grandmother was ” Nicole talked about it being more difficult to care for her grandfather because of the way he is. She also notices this in her mother “I think my mom has a really hard time caregiving for my grandfather, I really do, because of how (he) treated my grandmother ” Nicole commented that she and her mother will continue to give her grandfather the care he needs, but she implied that the experience will be much less gratifying for both of them than had been caregiving for her grandmother.

Another example of this theme comes from Rachel, who claimed that her relationship with her mother’s mother “hasn’t been very good ever since I was born ” Rachel’s mother does not have a good relationship with her grandmother either, as is clear in Rachel’s observation that “Grandma’s always been down her back about everything. She’s the only daughter and Grandma likes to control ” Consequently, Rachel visits her grandmother at the assisted living facility as little as possible, and wishes that she was back in Florida so that “I wouldn’t have to get up and go see her

because I never had a relationship with my Grandma ” It is evident that a negative attitude toward caregiving, and anger, are being passed down in these three generations of women From Rachel’s comment concerning herself as a future caregiver.

Well, Mom, when you get old and decrepit like Grandma, I think I’ll put you in a nursing home and I’ll come see you once or twice a week

Rachel blames her grandmother for her mother’s depression and irritability, and commented several times that her mother “lets off all her pressure” on Rachel

Ann is also in a situation where her grandparent’s personality affects the kind of relationship they have She describes her grandfather as being a negative person who can be mean and verbally abusive She gave the following examples to support her feelings about him

Like when I told him I got into graduate school he just told me I was gonna get pregnant and end up dropping out anyway .I had a sinus infection at Christmas and I kept coughing and he accused me of just doing it to get on his nerves .(also at Christmas) He got kinda choked up and was crying just a little bit I could tell So I came over and just kinda lightly touched him, and he told me to leave him alone and go away

She also does not like the way that her grandfather treats her mother, who is his daughter-in-law and primary caregiver Ann expressed great frustration resulting from trying to get her mother to stand up for herself when he criticizes her, but she admitted that it is difficult for her to stand up to him, as well As a result of her grandfather’s abusive nature, Ann has little contact with him She explained

I don't know how my mom does it. I just don't even call him or anything 'cause he's so negative I don't know how to deal with it . I don't know how to communicate with him, and it's hard because I don't feel comfortable going over there (nursing home) by myself.

Unlike with Rachel, though, it appeared as if Ann *wanted* to have a better relationship with her grandfather, but she did not know how to relate to him

Jane paints a different picture than Rachel or Ann of her relationship with her grandfather As mentioned earlier, her grandfather was like a father to her after her biological father left the family Looking back, she said, "he was a very stable part of my life when I didn't have a part that was stable." She talked about spending lots of time at her grandparent's house when she was growing up, and she has always lived very close to them Her commitment to her grandfather stems from the strong relationship they have had, as is apparent in the following statement

I was just really close with Pappaw I was his favorite and I guess that's why I feel like I should be there for him now that he needs somebody else

Perhaps the most telling example of the kind of relationship Jane has with her grandfather comes from what she said about him letting her shave him, because his hands were too shaky, for the first time

it still makes me cry when I think about it, 'cause he trusted me that much You

know he loved me that much to let me put a razor to his face . that's a lot of trust.

Jane explained that her grandfather had given so much to her, instrumentally and emotionally, that she could not imagine not playing a significant role in his caregiving.

Another grandchild that described a close relationship with their grandparent was Lizbeth. Lizbeth, who shares the given name Elizabeth with her mother and her grandmother, feels a strong connection to her grandmother about whom she said, "I feel like we look alike. I look in her eyes and they look just like my eyes." Lizbeth's respect for her grandmother was evident when she was talking about her younger days when she took trains by herself, got her driver's license early, and traveled outside of the U S. Lizbeth's comment was, "I think she's a really strong woman, especially for the South." The transition from living out west and working to living at home and being unemployed has been difficult for Lizbeth, but she has found solace in her grandmother, stating that "she's really soothing for me to be around."

Maria, who met her adopted grandmother when she was 12, talked about the first time that they met.

She was like, "Oh my goodness!! Oh wow!! This is my other granddaughter- I'm so glad!" And she gave me a kiss and a hug, and I thought that was real special, and that was nice.

Maria seems to care about her grandmother a lot, and she said numerous times that she "likes taking care of her." Although the only statement Maria made about her relationship with her adopted mom was, "sometimes we get along, sometimes we don't," she did say, "I feel a lot closer to my dad." It may be the case that Maria's grandmother offers her the attention and companionship that she does not get from her mom.

(2) Nature of grandchildren's contribution to the caregiving process.

“On me it's been kinda light-touched.”

As would be expected, the quantity and quality of grandchildren's involvement in caring for their grandparent varied widely among the informants. One factor that appeared to affect the degree to which they were involved was how much their caregiving parent disclosed to them about their grandparent's condition and about their own feelings regarding caregiving for their elderly parent. The results suggest that the less disclosing their parent was, the less the grandchild was involved either in giving support to the grandparent or to their own caregiving parent.

For example, when Lindsey was asked what she remembered about when her grandfather's health first began to deteriorate she replied, “I'm not really sure when all that started 'cause I think they (parents) kinda like tried to keep all that away from me.” Lindsey appeared as equally in the dark about how her mother was feeling about being a primary caregiver, as was clear in her comment:

I've never really seen her get upset about it. She gets frustrated a lot and like real stressed out about it and I mean I know that it upsets her, but I don't think that she'd ever let me see how much it upsets her.

Lindsey is kept at an emotional distance from her ill grandfather and from her mother, and this may be one reason why she said, “I don't think I've ever really had a part in helping to care for him.” Due to Lindsey's feelings of disconnection from the care of her grandfather, as well as physical distance that is created by her attending a college three hours away, she does not spend much time with him. Lindsey reported:

I saw him Christmas and I saw him Thanksgiving and before that it was probably, I went to go see him one time when I was here and it was probably in August I see him about once, every like, 2 or 3 months.

An exception to the “less disclosing parent, less involved grandchild” finding occurred with Maria Maria’s mother disliked having her mother in their home and dealt with the situation by making efforts to avoid seeing her elderly mother Maria described, “I don’t see my mom that much ‘cause she’s always in the bedroom.” Consequently, Maria seemed to pick up the slack from her mother’s unwillingness to fully accept her new responsibilities

when she first moved in, right after she got home from the hospital, I was right next to her every single time, because she couldn’t walk, she had to use the “walk thingy” I like every 5 minutes say, “Are you okay?”, and sometimes (I’ll) be on the phone or on the computer and I come down and ask her if she needs anything, and sometimes she’ll be like, “I need some water” and I’ll be like, “Okay, comin’ right up ”

Maria also talked about fixing her grandmother “peanut butter and jelly sandwiches” and soup, as well as occasionally bringing her food from the restaurant where she works It appeared that Maria felt like she needed to take care of her grandmother because her mother was not doing it in a way that she perceived as being right, based on her upbringing Her sense of responsibility was evident when she said

sometimes I may not really even take good care of my grandmother That is, times I’m busy and don’t want to do anything But then I realize that I’m doing

something wrong, and I just blame myself, you know, sometimes I feel guilty for not doin' something for her

Maria commented several times that she did not think it was hard to take care of a grandmother, because caring for parents and elders is something she grew up doing and it is a common occurrence in her native country

In looking at the quality of grandchildren's involvement in caregiving, what came across strongly from the data was that they were more likely to provide emotional support than instrumental support (i.e. bathing, feeding, changing, etc.) for their grandparent. One example came from Andrew, who explained that his involvement in caregiving had enriched his relationship with his grandfather.

We've certainly gotten much closer. He's one of my best friends now. We tease each other a lot, but it's good, it keeps him, keeps his spirits up. I tell him that if he doesn't shape up we're going to tie him to a tree in the woods and leave him. I just kid him, he knows I'm joking.

Jane said that she was not going to stop doing the things with her grandfather that she used to do with him before he got sick. She also reported that, unlike other family members, she was not going to patronize her grandfather.

I'm gonna try to make things as best as I can right now. I'll pick him up for a baseball or basketball game. Everybody tries to make such an issue out of it, but he's not a vegetable. He's still a person. He's not a child. He still has a lot of abilities that people don't even know he has. So I try not to baby him, and I think he appreciates that.

Maria talked about the value of the companionship that she shared with her grandmother:

I like to be around her and talk to her a lot.. I'm glad that she's not goin' back (home) because then I'd be missing having somebody to talk to or somebody to watch T V with and have a little conversation about. a baseball game or whatever she watches

The approach that Lizbeth took to her relationship with her grandmother was to focus on the ways that she could still connect with her grandmother, rather than focus on what had been lost as a result of her illness

I love for her to laugh and so that's basically what I try to do, and we go walk and I usually sing with her I just go out there and if I can make her happy or make her smile it makes me feel good when I leave

Although there were some grandchildren, mainly Andrew and Jane, who provided both emotional and instrumental support to their grandparent, the most likely role for the grandchildren to play was that of emotional supporter. This may be the case because these grandchildren are not primary instrumental caregivers, and it is not their parent who is dying, so they have more emotional energy to give to their grandparent. Some of the grandchildren commented on this "distance" that they have from the caregiving situation. For example, DeeDee agreed with the interviewer that caregiving has been hard on her mom and said, though, that "on me it's been kinda light-touched." Lizbeth admitted, "I take it more lightly than my mom does" and she explained that they have different purposes in taking care of her grandmother.

My mom, you know, makes her brush her teeth and change her Depends and do

all these things that I don't do mom just has the need to clean her up and tuck in her shirt but I don't think about it and I don't care doing it so much

Andrew acknowledged the emotional differences between what he and his father were experiencing when he was asked what dynamic he brings to the caregiving context that his father does not, and he replied, "Levity, (I) lighten things up a little bit cause my father, his father is dying I think it's more dramatic for him "

Grandchildren also served as providers of emotional support for their caregiving parents Several granddaughters talked about being there for their mothers when they needed someone to confide in Jane appeared to be a source of strength and encouragement for her mother

My mother and I, we talk about things often I realize how important she is to him, and to my grandmother she helps them both so much that I can't let her get weak so I'm the one that has to stand back and say, "It's okay It's gonna work out. You just keep doing what you're doin'".. if she is really upset about something I'll have to be there for her, because she's next in line, you know?

Nicole played the role of her mother's confidante, listening to her mother while she externalized her thoughts and feelings At times, though, she found that being her mother's confidante was burdensome

We did a lot of sitting up 'til one or two in the morning sittin' around talkin' about how my mother felt. And I became a counselor (chuckles) So, just listening My mother really sees me as the, as her other arm. so I'm the only person that she's got, and um, sometimes I resent it I'm not gonna say I don't

Ann recognized her mother's need for support and wanted to provide this for her, yet, like Nicole, she found it difficult sometimes.

for awhile she was callin' me *every day*, like telling me everything he did because she needed someone to bounce it off of I know she needs somebody and I'm the one. I mean, it's hard for her to keep tellin' my dad 'cause it just gets him upset sometimes, you know, I'm just like, "God, I don't want to hear another story," but I just try to suck it up and listen to it

What comes through in these statements is that the granddaughters feel a sense of responsibility for their mother's well-being, which at times, they experience as demanding Andrew, also, seems to serve as part of his father's emotional support system, although evidence of this is much more covert

I think just being close to one another, you know, has helped us to further heal our relationship we see each other a lot now And there's a common, you know, there's something, we have a job in common to talk about

Andrew's example illustrates the different way in which fathers and sons relate to each other compared to the way mothers and daughters interact, as noted in the examples from Nicole, Ann, and Jane The impression is given that the three daughters serve as confidantes, whereas Andrew is helping his father to carry out a task Both kinds of roles, though, appear to offer support to the caregiving parent

(3) Grandchildren's perceptions of the demands and gratifications associated with caregiving.

“I cried the day he let me shave him for the first time.”

All of the grandchildren in the study talked about some kind of demand or burden that was put on them or their family in relation to caring for their ill grandparent. The burdens ranged from assisting grandparents with personal hygiene to resenting the time that their parent spent as a caregiver. Several of the grandchildren whose grandparents had been diagnosed with Alzheimer's disease commented on getting tired of repeating things over and over and dealing with repetitive behaviors from the care recipient. A few mentioned burdens such as their family having less “freedom” than they used to (Maria), or having to stay home and take care of their grandparent during school vacations “while everybody else was having fun” (DeeDee).

There were also demands that grandchildren talked about that were more than isolated “annoyances.” For example, Rachel saw so much negativity resulting from having her grandmother there that she said, “sometimes I wish she'd just die a big burden would be off of me.” Laura thought that “the hardest part of having her grandfather sick” was the strain that it put on her grandmother. She commented that caregiving “puts a real hindrance on her, not being able to go and do” and “How it's affected her life, it's so awful.”

Two of the grandchildren talked about “pile-up” that occurred in relation to caregiving. Nicole explained that she and her mom had an especially difficult time because of other major life changes that they were dealing with at the same time.

I think it was that we had everything all at once. My dad left home in '92. My grandmother got sick in '93. just bam, bam, bam, so close together we never had time to grieve.

Andrew talked about how his sister's husband had battled a brain tumor and eventually died last year, leaving behind Andrew's sister and his young niece and nephew, who live about 7 hours from Knoxville. This occurred while his father was taking care of Andrew's grandfather full-time, with his mother giving him a 2 or 3 hour break once a day. Andrew shared that it had been a very difficult period, especially for his parents who wanted to be with their daughter and grandchildren, but who also had responsibility for Andrew's grandfather. He described

for a while like when he was getting pretty bad, my parents were going over a lot, taking turns. One of them would stay here with (grandfather) and the other would go, and then I would go to (my sister's). we were doing a lot of juggling. These examples show that caregiving does not occur in isolation. Rather, caregiving families and their members continue to experience predictable and unpredictable life events that make handling elder care responsibilities more challenging.

It was more unusual, though, for a grandchild to mention something good that had come out of their caregiving experience. In contrast to some of the grandchildren who seemed to focus on what had been lost, for instance, grandparent's quality of life and how this affected themselves and their family, others were able to see what was still left of their grandparent and some way that they had benefitted from the experience.

For Jane and Lizbeth, gratification came from being able to contribute to their

grandparent's well-being Jane expressed a feeling of privilege for being able to participate in her grandfather's care.

I cried the day he let me shave him for the first time.. it made me feel really, I don't know, wanted? Welcomed? You know, for him to be that comfortable with me it really felt good It really did

Lizbeth talked about the warm feelings that she gets from her visits with her grandmother, which result from her ability to focus on the "here and now"

it makes me feel good to be there and it doesn't matter if I was there yesterday or you know, six months ago But she's glad I'm there for that time those moments that you make her happy, and it can be for five minutes, it's so worth it for me

She also noted a benefit that she and her mother have gotten from caregiving She said, " it gives me meaning to my life, it gives my mom a lot of meaning for (her) life."

Another kind of gratification that Ann and Andrew experienced came from their relationships with other members of their family Ann, who through her schooling and internships, has worked with the elderly and has seen several different nursing facilities When her grandfather first became sick, Ann's father asked her to help him find a place for his father to go She explained that her mother, too, often comes to her for advice about how to deal with her grandfather Ann recognized that this had changed her relationship with her parents in some ways, and she commented.

(It's) made me more, maybe, an equal with them from that standpoint I kind of helped them Kind of guided them a little bit because I had experience with that

in school

For Andrew, he said caregiving was rewarding for him because he was able to give back to his grandfather who “gave his life to his family ” He also mentioned that his contributions to the care of his grandfather had not gone unnoticed by his family.

I’ve been made to feel special by other family members . you know, (it) makes me feel good there’s rewards for doing it, you know, to have people affirm you and stuff like that

(4) Grandchildren being caught in the middle.

“My own personal life has to be put on hold.”

This theme emerged from the data from a sense that some of the grandchildren were being pulled in different directions in relation to some aspect of the caregiving situation Some of the grandchildren were aware that there were opposing forces acting upon them, and this was a source of frustration for them Ann, for example, shared that her husband thinks her grandfather is “a horrible person ” She said that she would go visit her grandfather more if she had someone to go with her, because she does not feel comfortable going to see him by herself Ann expressed a desire for her husband to go with her, but she explained that, “He just doesn’t want to go over there He just doesn’t think he’s a very nice person so that makes it hard on me ” Ann also talked about differing perceptions of her grandfather’s behavior, which causes confusion for her

then sometimes if my dad talks to him (grandfather), then he’ll just get upset.

Like he’ll cry or something, “Well I didn’t even know I was doing that”...And my husband’s just like, “Oh bullshit. He knows what he’s doing He’s just

manipulating him” But sometimes I just feel kinda caught in the middle, ‘cause I can see where my parents are going wrong, and I can see where my husband’s wrong, and then I can see where I don’t know what to do

As well, Andrew recognized that he gets “triangled” in his family He talked about times when his parents and his aunt and uncle would have disagreements about the caregiving, and he said, “ sometimes I get in the middle, which is not where I want to be because I get along pretty well with everybody ” It appeared that Andrew’s awareness of being “in the middle” helped him to avoid that position

Other grandchildren were unaware of feeling pulled in different directions, but from the circumstances that they presented it appeared that they had experienced being caught in the middle DeeDee talked at great length about how much she disliked her uncle When she was 14 years-old he had hit her Now he was living in her grandparent’s house, not paying any bills or rent, and letting the house get run down She does not like the way he treats her grandmother, either, because he is disrespectful towards her DeeDee feels caught because she wants her mother and her aunt to kick her uncle out of her grandparent’s home, yet she has little control in the situation She explained

He’s crazy He has problems but no one would believe me, I think They don’t listen I told them a long time ago this was going to happen but nobody would listen to me ‘Cause I’m, you know, they say “you’re a child, you’re a child ”

And again

you know he keeps putting on his little front. He’s going to get what he wants

But I see past all that I'm the only one that can see past all that. And I just leave her alone because I get tired of arguing about it.

DeeDee had decided that she would deal with the situation by not bringing up the issue with her mom, although it appeared that was still feeling conflicted

Rachel also seemed to be caught in the middle between contradictory realities about her grandmother. On one hand, Rachel knows that her grandmother is old, frail, and dying. She knows that she is dependent on others to feed and bathe her. This is not the image of a strong and powerful woman. Yet, Rachel also knows that her grandmother still has control over her life in some ways. As noted earlier, Rachel believes that much of the conflict between she and her mother occurs because of her grandmother's condition. She also disclosed that her grandmother's trust fund will be paying for her college, on certain conditions.

I think, basically, she said if I made a 2.5 or higher in college I'd get the money.

If I made lower it all goes to the Boy's and Girl's Club.

So, even though her grandmother is on her deathbed, Rachel continues to feel like she holds power over her life.

Maria appeared to be caught in the middle between her feelings about elder care and her adopted families' feelings about having her grandmother in their home. Maria liked having her there, and she made sure to point out that she did not mind "doin' things" for her grandmother because she was used to from her upbringing. She said, "I don't think it's really that hard to be takin' care of a grandmother. I think it's pretty easy." Maria is aware, though, that her feelings about caregiving are different from the

rest of her family

But, well everybody else will be like, "Once she'll be needing something, and then the next minute she'll be asking for something else"...it goes on and on, and probably everybody will get like, "I'm so tired" and "I wish I wasn't here I wish I was somewhere else where I don't even have to hear my grandmother say, 'Go get me this. Go get me that' ." But I don't see anything hard about it.

Her frustration with how her family approaches caregiving was evident in her statement Maria is in a difficult position within her family since she wants to feel like she is part of her adopted family, yet the way in which she was raised is at odds with the attitude toward caregiving in her family

Lack of time was an issue for Nicole She talked about how caregiving for her grandfather puts added demands on her already full schedule.

Being married I do have my own family Being in school I have things that I need to be taking care of And it's like my own personal life has to be put on hold anything that I have to do, either I take with me or it doesn't get done.

She explained that her grandfather lives about 45 minutes outside of town, which contributes to the amount of time that caregiving takes. From a developmental perspective, Nicole seemed to be "stuck" between maintaining, if not nurturing, the family and the life that she has created for herself and the needs of her family of origin In contrast, though, is Lizbeth, who made the decision to move home for an indefinite amount of time and "take a break" for awhile She commented.

a lot of the reason I came home was because I wanted to spend time with my

mother and my father, but especially my mom and then also knowing that my grandmother won't be around forever and being able to help my mom out was a, I mean, a consideration in coming home.

Lizbeth avoids becoming "developmentally stuck" by choosing to set some time aside to spend with her grandmother and to help her mother with caregiving.

(5) Grandchildren's perspectives on caregiving.

"You just see people open up in ways you never saw before."

Some of the grandchildren talked about something personal they had learned from their experience with caregiving which gave them a new perspective on life, their grandparents or other family members. When asked if there was something good that had come out of her grandmother being sick, DeeDee replied, "It gave me a lot more wisdom and a greater outlook on life- period . and that life is what you make it " Jane spoke about what she had learned about her family

I mean you just see people open up in ways you never saw before. You see 'em love in a way you never thought they were capable of loving, when somebody gets sick

She also talked about the process of accepting that her grandfather has Alzheimer's disease

I dreamt of him often. Just of him passing away, of him going. It took a long time for me to realize, look he's not dead. And he's not dying. You know, this is not some terminal illness that's gonna kill him in three weeks, three months, three years .

Lizbeth made similar comments about acceptance of her grandmother's illness

.if you don't make it a sad thing because it can be a sad thing, it would be the worst possible thing that can happen that your grandmother wouldn't know who you are (but) if you can accept it for what it is and gain from it what you can it's like it's not the worst thing

She admitted that she used to think that her grandmother would just be "better off dead," but that over time she's learned to appreciate what her grandmother has to offer Lizbeth described a new appreciation for her mother, as well, saying that the most significant thing she has learned from her caregiving experience is "for me to see how incredible my mother is she is just an amazing person "

Grandchildren also talked about what they had learned in terms of "advice" they would give to other grandchildren in caregiving families Lindsey recommended, "Get to know them, and learn about them " Maria had the following suggestions

if somebody had a chance to take care of their grandmother, they should take and chance and do it .because their grandmother's not gonna live forever I think people should tell their grandmother(s) how much they love 'em.. take a chance and take care of 'em.

Lizbeth shared, " it's just the moment that matters, and they can be happy in that moment and you can make them happy in that moment." In watching her family struggle with the increasing dependence of her grandfather, Jane has learned from seeing "the agony people go through" when they try to do all the caregiving themselves. Seeing herself as a future caregiver for her mother, if necessary, Jane commented that she has

“seen first-hand that you cannot take care of an older parent- no matter what the illness is- without help from the outside.”

Like Jane, several of the grandchildren anticipated being primary caregivers for their parent(s) in the future. Lindsey said, “ .it will probably be me” as opposed to one of her two older brothers. She shared.

I’ve always kinda wanted to be a caregiver .I don’t think that would be a bad thing ..I mean if somebody had to do it I think I’d like to know what was going on and make sure that, you know, that the decision was right

Ann was clear about the caregiving role that she was willing to play in her parent’s future, exclaiming, “Oh, I mean definitely, I would do it for my parents.” She explained why she believed that she would be a more effective caregiver than her older brother

it’s not because my brother wouldn’t do it. He’s real shy and quiet. he just wouldn’t know how to take charge or what to do. .he’s not as open and warm. He’s more to himself. Or he doesn’t need people as much. He doesn’t like to be asked his feelings a lot. So, therefore, I think it would be harder for him to caregive

Andrew also noted a difference between his and his older sister’s suitability for caregiving, describing that she “isn’t that type to help out. she doesn’t, she’s just not as connected. . she just doesn’t relate to people the same way.” Lizbeth anticipated that she and her sister will share caregiving responsibilities, each providing for different needs.

I think it’s more in my nature to be that person (sole caregiver) than my sister. she will do all the finances and make sure she’s (mom) in the best place and

make sure she has everything, but it's more in my nature to be the people person

Although Maria did not talk about herself as a future caregiver, she did imply that she thinks that she is a better caregiver than her younger sisters, who are 12 and 13 years old. She explained

sometimes my sisters will try to do something and I'll be like, "I'll do it Why don't you just go play or something" They help some, but it's not like I . the way I do it

In contrast to the grandchildren who perceived themselves as "natural caregivers," Rachel appeared to want to avoid that role as much as possible. She is relying on money from her grandmother's trust fund to pay for all of her mother's future caregiving needs, since she is an only child and does not want that responsibility herself. As mentioned earlier, Rachel said that she would stick her mom in a nursing home and come see her "once or twice a week " When the possibility of the money not being there in the future was brought up, Rachel replied, "that'd be like the worst situation I would do, take care of her "

Summary

Contrary to what is typically thought, family stressors do not create *new* issues and conflicts for the family system. Rather, they highlight issues that already exist within families but that may be less obvious in times of lower stress. For example, it appeared to Rachel that her grandmother's poor health and close proximity were causing conflict between herself and her mother. However, it was apparent that Rachel and her

mother had never really had a close and gratifying relationship, so it is likely that the stressor of caregiving brought out sensitive issues between them that had been lying dormant. It is not only conflict, though, that is highlighted by family stressors. For Lizbeth, Jane, and Andrew, their experiences with their grandparent's deterioration of health brought out issues such as new respect for one's parent and grandparent, exploring one's identity and roots, and wanting to give something back.

For a visual representation of the five themes that were identified and discussed, see Table 1

	Theme One Nature of Relationship with Grandparent	Theme Two Contributions to Caregiving Process (disclosing parent, emotional support)	Theme Three Perceptions of Demands & Gratifications	Theme Four Being Caught in the Middle (relationally, developmentally)	Theme Five Perspectives on Caregiving (learning about self & others, advice, caregiving nature)
Maria	She gave me a kiss and a hug and I thought that was real special	I like to be around her and talk to her a lot	We don't have as much freedom like we used to	I don't think it's really that hard to be taken care of a grandmother	They [sisters] help some, but it's not the way I do it
Lizbeth	I look in her eyes and they look just like my eyes	I love for her to laugh and so that's basically what I try to do	Those moments that you make her happy it's so worth it for me	Knowing that my grandmother won't be around forever was a consideration in coming home	I think it's more in my nature to be that person [sole caregiver] than my sister
Lindsey		I don't think I've ever really had a part in helping to care for him			I've always kinda wanted to be a caregiver
Rachel	I wouldn't have to get up and go see her because I never had a relationship with my Grandma		Sometimes I wish she'd just die a big burden would be off of me	she said if I made a 2.5 or higher in college I'd get the money	that'd be like the worst situation I would do, take care of her
Jane	I was just really close with Pappaw I feel like I should be there for him now that he needs somebody else	I try not to baby him and I think he appreciates that	I cried the day he let me shave him for the first time		I've seen first-hand that you cannot take care of an older parent without help from the outside

Table 1. Illustrative quotes from the Five Themes

	Theme One Nature of Relationship with Grandparent	Theme Two Contributions to Caregiving Process (disclosing parent, emotional support)	Theme Three Perceptions of Demands & Gratifications	Theme Four Being Caught in the Middle (relationally, , developmentally)	Theme Five Perspectives on Caregiving (learning about self & others, advice, caregiving nature)
DeeDee			I would take my whole Christmas vacation and stay with my grandmother while everybody else was having fun	I told them a long time ago this was going to happen, but nobody would listen to me	It gave me a lot more wisdom and a greater outlook on life- period
Andrew		We tease each other a lot, but it's good keeps his spirits up	I've been made to feel special by other family members	sometimes I get in the middle, which is not where I want to be	she's [sister] just not as connected doesn't relate to people the same way
Nicole	My grandfather is very much a self-centered man he is a lot more hateful than my grandmother was	My mother really sees me as her other arm	My dad left home in '92 My grandmother got sick in '93 we never had time to grieve	anything that I have to do either I take with me or it doesn't get done	
Laura			How it's affected her [grandmother's] life, it's so awful		
Ann	I just don't even call him or anything 'cause he's so negative	For awhile she was callin' me every day, telling me everything he did	[It's] made me more an equal with them because I had experience with that in school	He [husband] just doesn't think he's a very nice person so that makes it hard on me	it's not because my brother wouldn't do it he just wouldn't know how to take charge

Table 1. Illustrative quotes from the Five Themes (cont.)

CHAPTER 5

DISCUSSION

The question that the present study sought to answer was, "What meanings do children of adults providing care for an elderly parent give to the process of caregiving by their families and their relationships with their parent, grandparent, and other family members?" In the discussion that follows, the interpretations of the findings are not intended to be conclusive or generalized to the larger population (Lester, 1999). Rather, the interpretations of the findings are meant to expand on the currently limited amount of literature on this subject, and to inform future research in this area. According to Lester (1999), though, in multi-participant qualitative studies "the strength of inference which can be made increases rapidly once factors start to recur with more than one participant" (p. 1). It is important to note, therefore, that there were *at least* six examples from informant's stories to illustrate each of the five themes identified from the data.

Comparisons Across Interviews

The findings indicated both similarities and differences in how grandchildren experience family caregiving for an elderly grandparent. The most salient similarity found was that grandchildren provided more emotional support than instrumental support. Eight out of ten grandchildren reported giving emotional support to their grandparent or their caregiving parent, and a few offered emotional support to both. Another similarity was that many grandchildren mentioned that they had learned something from their experience with caregiving. They spoke of having a deepened perception of themselves, new appreciation for their parent or grandparent, and of being

more knowledgeable about the caregiving process. Not all of the learning that grandchildren talked about was positive, though, because in some cases caregiving had brought out unlikable characteristics in a family member. Nonetheless, the information that grandchildren learned heightened their awareness of themselves, others, and what it is like to care for an elderly family member. Understanding the caregiving process is important to several of the grandchildren, who shared the belief that they will be future caregivers for their parent(s) and parents-in-law. The reasons that they gave for this prediction was either that they were only children and there was no one else to take care of their parent, or that their personality was better suited to being a caregiver than that of their sibling(s).

What made some of the findings unlike others, though, was not dissimilar issues but rather contrasting experiences with the same issue. For example, all of the grandchildren were involved in caregiving for their grandparent, although, the quantity of their involvement ranged from virtually nonexistent (Rachel, Lindsey) to significantly involved (Andrew, Jane, Lizbeth). This variance occurred in part due to the extent that caregiving parents communicated to their children what they could contribute to the caregiving process. The less that grandchildren were invited or encouraged by their parent to participate in their grandparent's care, through support for the care recipient or the caregiver, the less involved they became. In contrast, the more that grandchildren were invited or encouraged by their parent to participate the more involved they became. However, if parents asked for too much, for example when Ann and Nicole got tired of being their mothers' confidantes, they felt resentful.

Another instance of contrasting experiences came from the nature of the boundaries around dyadic relationships within grandchildren's families. In line with Bowenian theory, which states that persons in dyadic relationships characterized by tension and anxiety will pull a third person in to stabilize the relationship, several grandchildren appeared to be caught in the middle between two opposing forces. Examples came from Andrew, who at times found himself "triangled" between his parents and his aunt and uncle, and DeeDee, who was stuck between wanting something to be done about her uncle, but not having the power to do it. Ann, also, experienced feeling caught between how her parents perceived her grandfather's behaviors and how her husband viewed them. In Maria's situation, she was pulled between her adopted family's attitude toward caregiving for her grandmother and her own beliefs which were different from theirs. Certainly, Rachel felt stuck between her mother and her grandmother. For these grandchildren, boundaries around relationships in their families appear to be too flexible. Consistent and clear boundaries might have helped the grandchildren more aptly deal with the caregiving situation.

In opposition to being caught in the middle, though, is being left out of a dyadic relationship. This occurs when the boundary around a relationship is so rigid that very little is let in or let out. The most salient example of this came from Lindsey, who portrayed the image of a young woman looking in on the relationship between her mother and her grandfather from the outside. Rather than being pulled in to play a "stabilizing" role in family relationships like the grandchildren mentioned above, Lindsey was left out and consequently, was not given a role to play in caregiving for her

grandfather

A third contrast that was found dealt with the age of the informant. It appeared that the younger grandchildren have a less positive experience with caregiving than did older grandchildren. Their experiences differed in terms of level of involvement, perceptions of demands and gratifications, and what they had learned from the caregiving situation. Perhaps, caregiving parents were more willing to involve older grandchildren in the process of eldercare because they viewed it as more developmentally appropriate than for younger grandchildren. In addition, the older grandchildren in the present study were in a different stage of life than the younger grandchildren, who were either in high school or just beginning college. In their mid to late twenties, several of the older grandchildren had begun families of their own or had been living away from their parents for some time. Perhaps these experiences led older grandchildren to a greater understanding of and appreciation for the meaning of family.

Comparisons to Existing Research

Much of the literature that was found and reviewed for the current study revealed findings based on caregivers' reports of how grandchildren reacted to and participated in caregiving. It is difficult to make direct comparisons between those studies and the findings of the present study due to the difference in *who* is doing the reporting. However, when considering the similarities and differences between the findings, it is important to be aware that the information in the present study comes directly from grandchildren themselves rather than a secondary source, such as their caregiving parent.

The findings of the present research support the studies of Sutor and Pillemer

(1993) and Cicirelli (1981), which suggested that grandchildren are important sources of emotional support for both their care receiving grandparent and their caregiving parent. Unlike the findings from these studies, though, grandchildren in the present study were not as involved with provision of instrumental support. The ages of the grandchildren being reported about were not included in the studies of Suito and Pillemer or Cicirelli, so it is impossible to make a comparison based on age difference. There was also no indication about the residency status of care receiving grandparents in those studies, whether they still lived alone, in the primary caregiver's home, or in a skilled care facility. Therefore, it is only possible to speculate that the grandchildren who would be most likely to provide various kinds of instrumental support would be those who were living at home, and whose grandparent either lived in the home with them or alone nearby.

Consistent with the findings of Mellins et al (1993), several grandchildren in the present study talked about having a changed life perspective or new appreciation for their parent or grandparent as a result of their experience with caregiving. Other changed perceptions that were reported in the current study included increased awareness of family members' strengths and flaws, and a better understanding of the dynamics operating in one's own family system. There is no evidence from the data that contradicted the speculation of Mellins et al that older grandchildren, being somewhat removed from direct care for an elder, have the physical and emotional distance to ponder the personal meaning that caregiving has for them.

The findings of Pyke and Bengtson (1996) about grandchildren from

individualistic and collectivist families were partially reinforced by the reports from grandchildren in the present study. Certainly, from what grandchildren described, families appeared to have either a more collectivist or a more individualistic orientation, which influenced the way in which grandchildren responded to the needs of their grandparent and caregiving parent. The most salient examples of collectivist families were those in which grandchildren reported their grandparent as being unlikeable or difficult to get along with, yet the message that came through from them was that "if it's your family you just do it, whether you like that family member or not." The most individualistic families were characterized by approaching caregiving as an impersonal obligation or burden.

What was not found in the present study was support for Pyke and Bengtson's notion of grandchildren as "monitors" for their parents, preventing them from either being overly or inadequately involved in caregiving. As Pyke and Bengtson explained, the collectivist grandchildren that they interviewed were likely to be concerned about their parent's health and subsequently assisted them with caregiving responsibilities. Individualistic grandchildren, though they tended to feel like their parents should be doing more for their grandparent, often did not take on any caregiving responsibilities themselves. The difference between Pyke and Bengtson's findings and those of the present study may be due in part to the age of the grandchildren, or other unknown factors. The mean age of grandchildren in the present study was 21 years, whereas in Pyke and Bengtson's study it was 33 years. It follows, therefore, that older grandchildren are likely to have older parents for whom health may be more of a concern than for

younger grandchildren whose parents are still young and healthy Likewise, it can be speculated that older grandchildren may be more mature and have more life experience which enables them to have greater concern about the care that their grandparent is receiving than younger grandchildren, though they may not take on any caregiving responsibilities themselves

Although caregiving parents in Merrill's (1997) research reported distress over not spending as much time as they would like with their adult children and their families, only one grandchild in the present study felt like her mother was not spending enough time with her Contrary to what grandchildren in the Mellins et al. (1993) study described, concern about the physical and emotional toll that caregiving was taking on their parent was rarely mentioned by grandchildren in the present study This may largely be due to *where* the care recipient resides Although there is no conclusive evidence of this, it is logical to postulate that caregiving is most physically and emotionally demanding when the care recipient lives in the caregiver's home The next greatest amount of care being provided may occur when the care recipient lives near the caregiver, but in her own home Situations in which the care recipient lives in a skilled care facility likely require the least amount of instrumental assistance from caregivers, though the emotional demands may still be strong Since 17 of the 23 care recipients in the Mellins et al study either lived with the caregiving family (8) or in their own homes (9), there may have been a greater strain on the primary caregivers than on those in the present study, in which only 1 care recipient resided with the caregiving family and 4 lived in their own homes However, 3 of the 4 care recipients who resided in their own

homes were cared for predominantly by a spouse or significant other, with their adult child acting as a secondary caregiver. It was not specified who were the primary and secondary caregivers in the Mellins et al study.

Another factor that needs to be considered is that of the nature of the care recipient's illness. It can be speculated that caring for an elderly parent with Alzheimer's disease may be more physically, and certainly more emotionally, draining than caring for a parent who is primarily physically impaired. Both kinds of impairment require assistance with activities of daily living (ADLs), but Alzheimer's patients gradually lose the ability to carry on a conversation or to consistently connect with others on a personal level, and some may wander from home or act out aggressively. These characteristics of Alzheimer's disease place added strain on caregivers, particularly if the elder is living in the caregiver's home. This is not to say that caregiving for an elder who is primarily physically impaired is easy, but rather, that caring for an Alzheimer's patient places different kinds of demands on caregivers. Although there was a greater percentage of care recipients with predominantly cognitive impairment in the present study as compared to the Mellins et al study, only 1 of these elders lived with their adult child's family, and the remaining 5 patients lived in skilled care facilities. It was not reported in the Mellins et al study where the 9 elders with cognitive impairment resided.

Implications for Research

What emerged from the present study is that there needs to be more research which explores the experience of grandchildren in caregiving families. The findings suggest that grandchildren can play a unique role in both the care receiver's and the

caregiver's support systems, primarily in the form of emotional and spiritual support. What stood out clearly from the data was that grandchildren provided a kind of "caregiving for the caregiver," through assisting with their grandparent's care and offering their parent a "listening ear" or a shoulder to cry on when that was needed. It was also found that older grandchildren are intimately affected by the deterioration of their grandparent's health and the dependency on the family that follows. Family caregiving for an elderly grandparent appeared to either draw grandchildren closer to other family members, namely their parent and grandparent, or create more of a distance in their relationships. Nonetheless, grandchildren did not go unaffected by the situation.

As well, several grandchildren talked about *benefitting* from their experience with elder care. Whether it was something they had learned, a new dynamic in their familial relationships, or a changed life perspective, it was clear that there were gratifications for grandchildren from being part of a caregiving family. Future research needs to consider what grandchildren can gain from having a relationship with their grandparent. The focus in much of the past research has been on the negative aspects of caregiving, or the demands and burdens. In order to have a more complete and accurate understanding of this phenomenon, though, the benefits of elder care need to be studied as well.

The fact that there was only one grandson, out of ten grandchildren interviewed, in the present study points to yet another implication for future research. There need to be more grandsons interviewed about their involvement in and perspectives on family caregiving for an elderly grandparent. Although males involved in elder care are much more difficult to find because there are fewer of them, they are out there and their stories

need to be told. Hopefully, future generations will have less gendered attitudes about caregiving, for the young and the old, and more males will become involved in this potentially enriching process

Implications for Theory

In considering the theoretical perspectives that undergirded the present study, the findings can be applied to the concepts of vertical and horizontal axes. Illustrations of the vertical axis were seen most clearly in the cases of Lizbeth, Rachel, and Lindsey. Two contrasting ways of relating and functioning by the members in a family system were passed down through three generations of women in both Lizbeth's and Rachel's families. Lizbeth talked about a positive and reinforcing legacy that included admiration, warmth and a feeling of connection in relation to her grandmother and mother. Whereas, Rachel revealed a negative and debilitating legacy with patterns of criticism and control, and a feeling of disconnection between herself, her mother and her grandmother. In Lindsey's family, the unspoken attitude was "Don't talk about it", which created an atmosphere of uncertainty and emotional distance.

Along the horizontal axis, *unpredictable* developmental stressors were reported by Andrew and Nicole. Dealing with his brother-in-law's struggle with cancer and untimely death, as well as taking care of his grandfather, Andrew's family experienced a sad and difficult period. For Nicole, having her father leave home and then her grandmother becoming ill was almost too much for her and her mother to handle. The *predictable* developmental stressor that all grandchildren and their families face is the pending death of their grandparent. Consideration of factors on the vertical axis will be

important in an assessment of how families cope with this horizontal stressor

Another way to view the data is by applying it to McCubbin's Double ABCX model of family behavior. The horizontal stressors from Andrew's and Nicole's stories, described above, are good examples of the aA Factor, or "pile-up." Another example of pile-up comes from DeeDee's case, in which her strong dislike of her uncle and her desire to get him out of her grandparent's house is coupled with the health decline of her grandmother. There were also illustrations of the bB Factor in the data, which is concerned with the resources that a family has to help cope with stressors. A primary resource that was revealed was support from other family members, which was most notably reported by Andrew, DeeDee, Lizbeth, Jane, Nicole, and Ann. A lack of resources was apparent in Rachel's family and Maria's family, although Maria and her grandmother seemed to have a small support system operating between the two of them. The family's perception of caregiving for an elderly grandparent, or the cC Factor, was clearly evident in the data. Jane, for example, perceived caregiving for her grandfather as an opportunity rather than a loss, therefore she seemed to have a more "balanced adaptation" (xX Factor) than did Lindsey, who lamented the disappearance of the grandfather that she knew growing up, and could not accept the different person he had become. As noted in Theme One in Chapter 4, the nature of the grandchildren's relationships with their grandparents impacted their experience with caregiving.

Boundary ambiguity, or "not knowing who is in and who is out of the family system" (Boss, 1988), was particularly relevant in the cases of DeeDee, Lindsey, and Rachel. DeeDee did not feel like her uncle was part of their family, based on his

behaviors, but technically he was a member of the family system. For Rachel, her grandmother was no longer physically present as an active part of the family, but she still had a lot of emotional and financial power over Rachel and her mom. In Lindsey's case, she knew that her grandfather was still alive, yet she did not know much about the details of his condition or about her mother's feelings about caregiving for him. Her distance from the situation created ambiguity about who her grandfather was, "If he's not who he used to be than who is he now?" and about what role, if any, he played in the family system.

Implications for Practice

The findings of the present study demonstrate the important role that grandchildren can play in the caregiving process. It is important, therefore, for professionals who work with the elderly and their families to include grandchildren, as much as possible, in the types of services that they offer. One situation in which grandchildren are typically not included is in the process of moving an elder from home care to institutional care. Grandchildren should be encouraged, by their own families and service providers, to take part in the selection process and to help their grandparent get moved in and situated in their new home. Often, after their grandparents are placed in an institutional facility grandchildren lose contact with them. This may be unhealthy for grandchildren because they learn that there is no longer any value in a relationship with their grandparent and they may have difficulty achieving closure to the relationship after their grandparent dies. As well, grandparents suffer because they are not visited by their grandchildren and this may contribute to feelings of abandonment and depression.

Considering the positive experiences of several of the grandchildren in the present study, it appears that continuing a relationship with a frail, elderly grandparent, and participating in their care, may benefit grandchildren in some unique ways

In light of evidence from the data that reinforces the concept of intergenerational transmission of ways of relating to family members, caregiving parents should be aware that “what goes around comes around ” This information can aid caregiving parents in understanding more about their relationship with their elderly parent, as well as shed light on parenting techniques and behaviors that they engage in with their own child Parents must ask themselves, “Am I setting a good example of how we treat older members of our family system for my child?” Grandchildren learn about what to do when their own parent becomes elderly and needs assistance from seeing how their parent cares for their dependent grandparent

Lastly, the information that emerged from the present study has therapeutic implications Therapy can aide the transitions that occur within families when an elderly grandparent needs care Counselors can encourage caregivers to include grandchildren, grandparents, or those members who, for whatever reason, are on the periphery of the family system in the decision-making processes regarding the elder’s care. Therapeutic intervention may also help families work through difficult issues that were brought to the surface when caregiving became a reality Lastly, counselors have the opportunity to assist members of caregiving families in identifying benefits or gratifications that may come from involvement in the care of an elderly relative

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APPENDICES

APPENDIX A
FAMILY CAREGIVING RESEARCH PROJECT

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A-1. Summary of Family Caregiving Research Project

RESEARCH ON CAREGIVING

Dr Priscilla Blanton, a professor of Child and Family Studies at The University of Tennessee, is conducting a study of caregiving to an elderly family member Her study is being done to provide a description of the challenges and rewards experienced by family members in the process of caregiving The findings of the study will identify ways in which caregiving families can be helped and supported Participants will be interviewed for 1-2 hours at a time and private location of their choosing Dr Blanton and her research assistants hope to interview 2-3 members from each caregiving family However, each person will be contacted individually and will agree to their own participation If you are interested in participating in the study, please contact Dr Blanton at her UT office at 974-6270 She will give you further information about the study

A-2. Informed Consent Form

INFORMED CONSENT

1. The purpose of this study is to explore the process of family caregiving through interviewing family members who are providing care to an elderly family member.
2. As a participant, you will be interviewed at a time and private location of your choosing. Each interview will last approximately an 1½ - 2 hours and will be held in a private area. The interviews will be audio-taped. The audiotapes will be transcribed.
3. After transcription and analysis, the tapes and field notes will be destroyed. The data will be stored in a locked file in a locked office. The data will be kept for five years and then destroyed.
4. Your identity will be kept totally confidential through the use of pseudonyms. The consent form will be stored in a separate locked file from the interview transcription in a locked office for three years and then destroyed.
5. There are few anticipated risks involved in your participation in this study. However, if the interview elicits any negative emotions that are troubling to you, Dr. Blanton will provide information as to how you can talk to a trained mental health professional if you wish to do so. You will receive a Direct benefit of a Directory of services for the elderly in your community. The results of the study will be used to help develop a better understanding of the impact of caregiving on families.
6. Your participation in this study is voluntary. If you decide to participate, you may withdraw from the study at anytime without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed, your data will be returned to you or destroyed, per your request. The tape of your interview will be erased in your presence if you so desire.
7. All data are confidential. Data will be used for research purposes. Data will be prepared in manuscript format and may be published in professional journals and books. The data may also be presented at professional meetings.
8. You may contact the following persons if you have any further questions or concerns about the project or your participation in it.

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Knoxville, TN 37996-1900
(423) 974-6270
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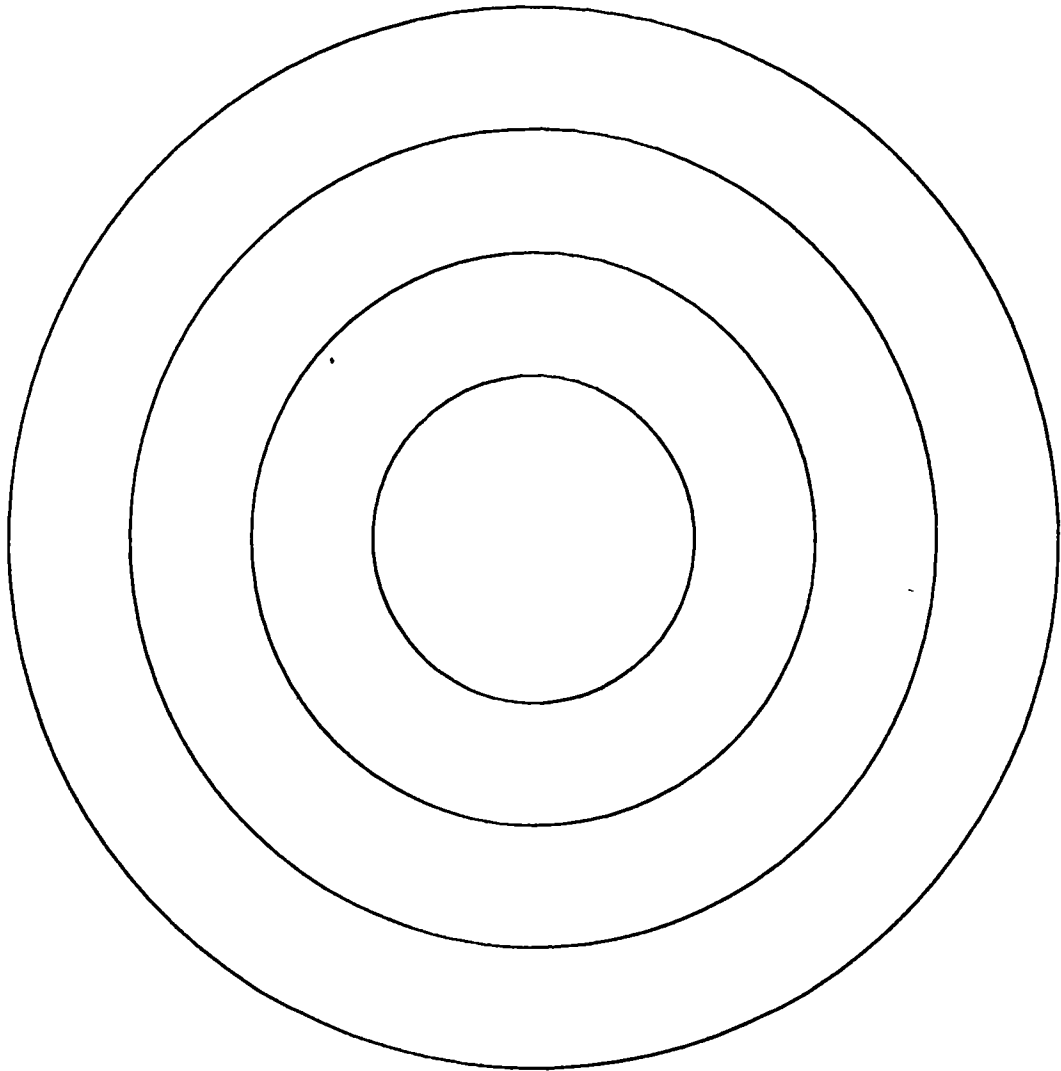
Your signature below indicates that you have read the above information, agree to participate in this study, and have received a copy of this form.

Participant Name (print) _____

Participant Signature _____

Date _____

A-3. Cognitive Mapping Activity



A-4. Demographic Information Sheet

Please check or fill in the following information.

Gender M _____ F _____

Marital Status Married __, Divorced __, Separated __, Widowed __, Never Married __

Age _____

Educational Level (check one):

- _____ some high school
- _____ high school degree
- _____ some college work
- _____ college degree
- _____ some graduate work
- _____ master's degree
- _____ doctoral degree

Occupation _____

Number of hours you work on your job each week _____

Number of Children _____

For each child, please provide their age, gender, and residence

Grandchildren : _____

Gender		Age	Lives with you	
M	F		Yes	No
_____	_____	_____	Yes _____	No _____
_____	_____	_____	Yes _____	No _____
_____	_____	_____	Yes _____	No _____
_____	_____	_____	Yes _____	No _____
_____	_____	_____	Yes _____	No _____
_____	_____	_____	Yes _____	No _____

(optional) Your personal annual income _____
 Your family annual income _____
 Annual income of elderly care recipient _____

Have you ever paid others to help with care? Yes _____ No _____
 If yes, how often? _____

Have you ever used home health services? Yes _____ No _____
 If yes, how often? _____

Relationship to elderly care recipient _____

Is your mother living? Yes _____ No _____
 If yes, age: _____

Is your father living? Yes _____ No _____
 If yes, age: _____

Is your mother-in-law living? Yes _____ No _____
 If yes, age: _____

Is your father-in-law living? Yes _____ No _____
 If yes, age: _____

Please list the gender and age of each of your siblings

Gender		Age
M	F	
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

A-5. Interview Guide

- ___ Informed Consent
(Turn on recorder)
- ___ Demographics (Discuss resources, community services, other formal assistance)
- ___ Family circles activity

WARM UP

- Explain your thinking in how you constructed your family in the circles
 - How did you decide who to include/exclude?
 - How would you describe your role in the caregiving process?
 - What roles do each of these family members play in the caregiving process?

- Describe a typical day/evening/visit for you when you are providing care or assistance
 - What do you talk about? What do you do?

THE STORY

- How did all of this come about? When did you become aware that care or assistance was needed, that your family member was having trouble?
- How did you get involved? Who would you say is the primary caregiver?
- To what extent are responsibilities shared with other family members/friends/ others?
 - How are decisions made about caregiving?

- In what ways has caregiving affected your life? Your job? Your family relationships?
 - Your marriage? Your leisure/recreational time activities?
- What do you do to relieve stress?
- What is the most difficult/challenging aspect of caregiving for you?
- What is the easiest part for you? Most rewarding/fulfilling part?

- What has been your experience in working with the service provider network?
 - Who has been the most helpful? The least helpful?
- What resources or services do you need to help you care for your family member?

WRAP UP

- What do you predict for the future with your caregiving experience?
 - What do you think will happen during the next few months? Years?
- What advice would you give to other family caregivers?
- In what ways is your experience as a caregiver unique/different from others? Similar?
 - How is your family different from other families that you know of? Similar?
- What else would you like to add to your story that I haven't asked you about or you haven't had the chance to mention?
- Who else do you think I should talk with to understand your family's experience?

APPENDIX B
MY FAMILY CAREGIVING EXPERIENCE

9

APPENDIX B

My Family Caregiving Experience

When my maternal grandmother, Gammy, was 82 years old the decision was made that she could no longer live alone. After two falls, the last one in which she broke her hip, and emphysema that was increasingly debilitating, Gammy's home in North Carolina was packed up and she moved in with my family in Alabama. My mom, the oldest daughter, became her primary caregiver. With my two older sisters living out on their own and myself in college, but home during the summers, there was an extra bedroom that was made into Gammy's room.

Prior to Gammy's move into our home, I think that she and I had had a typical granddaughter-grandmother relationship- loving but not particularly close. Growing up I came to know her as a strong, witty, and somewhat sad person who always had to be doing something. Visits to Gammy's house were not spent relaxing, but helping her clean, fold clothes, run errands, pick dandelions, or any other miscellaneous task that she needed us to do. By the time Gammy came to live with us, though, her age and poor health had forced her to slow down. Her mobility confined by her shortness of breath and subsequent use of an oxygen supplying machine, Gammy spent most of her time in her room reading, writing letters, sleeping, and watching news shows on TV. When I was home from college on weekends and during the summer I would hang out with Gammy in her room. She would ask me about what was going on in my life and I would ask her to tell me about her past and about other family members that I never knew. Sometimes we would sit and read together, or I would help her with something that she

did not want to burden my mother with. When I was away at college we wrote each other letters, though she wrote many more than I was able to.

My mother wholeheartedly accepted her role as Gammy's primary caregiver, but naturally at times she felt overwhelmed and her interactions with her mother were tense. I remember trying to comfort both of them when this happened, by helping my mom gain some perspective on the situation and by letting Gammy know that mom had reacted in a similar way to me at times and that it would pass. Together, Gammy and I were able to find humor in some of mom's overreactions and occasionally we would laugh ourselves to tears. There were also times that her nerves were so bad that I could not reach her and I felt helpless to ease her anxiety.

I cherish the relationship that my grandmother and I were able to develop at the end of her life. I got to know her as a complete person, with strengths and flaws like everybody else. The experience also helped me to see my mother in a similar way. By observing her interactions with her mother, I understood more about why she thought, felt, and behaved in the ways that she did. Ultimately, my family experience with caregiving helped me to know myself better, by giving me the opportunity to become more connected with my past.

VITA

Brooke Judkins Matchen was born in Knoxville, Tennessee on March 7, 1973. She attended a public elementary school in Brevard, North Carolina and a public middle school in Huntsville, Alabama. Her high school education was also completed in Huntsville, Alabama at the private Randolph School. She began her freshman year of college in 1991 at Auburn University in Alabama, transferred to Meredith College in Raleigh, NC for her sophomore year, and then returned to Auburn where she completed her Bachelor of Arts in English in August of 1995. After a three month stay in Japan and employment within the natural health products industry, she returned to school at The University of Tennessee, Knoxville to pursue a masters of science degree in Mental Health Counseling. Her masters of science degree will be conferred in December, 2000. Brooke will begin the doctoral program in Child and Family Studies at The University of Tennessee, Knoxville in August of 2000. After completion of her Ph.D. she plans to teach at a university and have a part-time marriage and family therapy practice.