

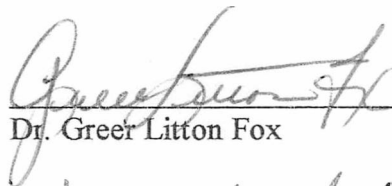
To the Graduate Council:

I am submitting herewith a dissertation written by Annabel Agee entitled, "Family Caregiving Experiences with Alzheimer's Disease: A Collective Case Study." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Human Ecology.

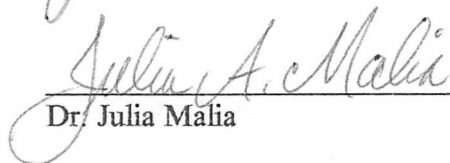


Dr. Priscilla W. Blanton, Major Professor

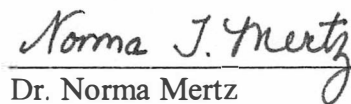
We have read this dissertation
and recommend its acceptance:



Dr. Greer Litton Fox



Dr. Julia Malia



Dr. Norma Mertz

Accepted for the Council:



Associate Vice Chancellor and
Dean of The Graduate School

Family Caregiving Experiences with Alzheimer's Disease:

A Collective Case Study

A Dissertation
Presented for the
Doctor of Philosophy
Degree

The University of Tennessee, Knoxville

Annabel Lee Agee
May 2000

Copyright © 2000
by
Annabel Agee

All rights reserved

DEDICATION

I dedicate this manuscript to the love of my life, my husband,
David Ted Zwolinski,
whose enduring support and patience
made it possible for me to devote this time in my life
to learning more than I ever expected.

ACKNOWLEDGMENTS

In addition to the love and support of my husband, David Ted Zwolinski, I have had the privilege to be surrounded by family, friends, and faculty who have influenced me in positive ways and encouraged me in all my academic pursuits and life endeavors.

My parents have loved and nurtured me all of my life, and I am truly grateful. In fact, if I were given the opportunity to choose from all the parents in the world, I would, without a moment's hesitation, choose the two sweetest, kindest human beings on earth: my father, Oliver King Agee, and my mother, Dorothy Francis Martin Agee.

Also, I acknowledge the wonderful ways I continue to be influenced by the memories of my grandparents, especially my two dear grandmothers: Annabel King Agee (Mom Mom), who gave me my love of horses and patent leather shoes and Chassie Lee Eckhart (Mimi), who taught me to use a sewing machine and to be open minded.

I appreciate the unconditional love and acceptance of my husband's family, especially his parents and his maternal grandmother: Ted and Mary Ann Zwolinski and Charlotte Hill (Grandma).

Certainly, I am grateful for the many ways my life has been enriched and the many ways I have grown and developed as a person through the many teachings and the many joys offered to me by my children (and their significant others): Mark David Hughes (and his girlfriend, Sara Call), Kimberly Marie Agee, Kelly Ann Zwolinski-Hogan (and her husband, Matthew Hogan), and Dena Renee Zwolinski. Though all grown up and making their ways into adulthood, each of these dear ones will always remain close in my heart.

For their pure affection, precocious insights, and the many ways they have enriched my life, I acknowledge my grandchildren: Keeana Ikeria Agee, Sean Tyler Zwolinski, and Brittany Nicole Gibbs.

To Dr. Asafa Jalata, a sociology professor who gave me the opportunity to begin my study of aging from a global perspective, I am grateful for the encouragement and patience I needed at a time when I needed it the most.

For being the kind of leader that I have aspired to be and for demonstrating the meaning of having vision, I sincerely thank J. L. Goins, my friend, colleague, and mentor.

To my dear friend, colleague, and confidante, Dr. Doris Jean Ivie, I gratefully acknowledge the enduring beauty of our friendship and the many ways my spirit has been nourished by her unconditional love. I cherish the genuine mutuality of our relationship.

Last but certainly not least, I acknowledge the amazing and thorough support I have enjoyed in working with the brilliant and wise women on my committee, who have each given me the kind of encouragement and direction that made my experience as a doctoral student the intellectual high point of my life. The quality of my experience has been dramatically influenced by each of these faculty, and I feel fortunate to have had the opportunity to learn in the kind of intellectually stimulating environment that they have created for me. Humbly, I express my gratitude to my faculty committee: Dr. Priscilla White Blanton, Dr. Greer Litton Fox, Dr. Julia Malia, and Dr. Norma Mertz.

ABSTRACT

This collective case study was designed to explore the perspectives of families who are involved in caring for someone with Alzheimer's disease and the cognitive impairment it entails. The collective design (i.e., extension of the study to multiple cases) facilitated understanding and interpretation of these phenomena associated with family caregiving experiences with Alzheimer's disease through not only within-case but also cross-case analyses. Advances in health care and medical technology have resulted in increased life expectancy, which means more people are expected to live longer. Parallel to these predictions for increases in the aging population over the next 50 years, the demand for community and family resources for elder caregiving is expected to increase, creating a need to explore the array of caregiving resources available to support the needs of frail elders. Especially important to explore are the contributions of families to the caregiving process. The inductive research process used for this study involved listening to the stories of four Alzheimer's families by means of personal, in-depth interviews with multiple family members. To make sense of the rich narrative data that were gathered, the family was used as the unit of analysis. Systematic qualitative analyses were conducted for each family, using a constant comparative process beginning with local integration of the data and continuing through the production of case reports. Finally, the analyses were extended to interpretation of cross-case observations. The data revealed family processes and patterns related to the caregiving situations in these families, and thematic elements were identified within families as well as across families.

Families shared their experiences related to the critical issues identified in the caregiving literature--decision making, relationship changes, and stress--and the themes that emerged provided valuable insights regarding the overall challenges and rewards of family caregiving experiences with Alzheimer's disease. These families were using creativity and humor to find ways to cope with the impact of the elder caregiving process on roles and relationships, and they were influenced by intergenerational legacies with an emphasis primarily on either connection or conflict. Themes that emerged across families included protectiveness as integral to the decision-making processes and intergenerational legacies primarily of either connection or conflict in family relationships in general. The families' perceptions of relational issues and experiences of loss associated with the Alzheimer's disease process were influenced by their perceptions of ambiguity. Stressful caregiving events were perceived as either overwhelming burden or opportunity for relational growth and development. The most stressful times in the caregiving process were the transitions required in the nature of caregiving as the needs of the care recipient changed and, thus, the demands on caregivers changed.

Because formal resources simply may not be available or affordable to meet the elder caregiving demand during the next 50 years, family science professionals need to consider strategies to help preserve and nurture the informal resources of family and friends. The present study offered the opportunities to gain perspective about some of the resources on which these families had drawn as they faced the perceived challenges and rewards of being involved with a complex and potentially very demanding caregiving process.

TABLE OF CONTENTS

CHAPTER	PAGE
1. INTRODUCTION	1
Purpose of the Study	1
Definition of Terms	2
Dementia, Alzheimer's Disease, and Vascular Dementia	3
Family Caregiving Concepts	4
Research Questions	7
Importance of the Topic	7
Demographics of Aging	8
Changes in Families	9
Economic Shifts	10
Rationale for the Study	11
2. LITERATURE REVIEW	14
Theoretical Considerations	15
Relationship Changes in Alzheimer's Families	16
Concept of <u>Ambiguous Loss</u>	17
Caregiver Dyad Relationships	18
Marital Relationships in Alzheimer's Families	20
Decisions About Caregiving Resources in Alzheimer's Families	22
Concept of <u>Role Taking</u>	22
Decisions About Financial Resources	23
Decisions About Caregiving Roles	24
Effects of Stress and Perceptions of Burden in Alzheimer's Families	26
Concept of <u>Stressor Pile Up</u>	26
Concept of <u>Definition of the Situation</u>	28
Concept of <u>Vertical and Horizontal Stress</u>	29
Predictors of Nursing Home Placement	31
Myth of Abandonment	32
Research Imperatives	33
3. METHODOLOGY	35
Research Design	37
Definition of Case Study	39
Rationale for Design Choices	41
Using the Family as the Unit of Analysis	41
Using a Collective Case Study Approach	43
Procedures	44
Description of Dr. Blanton's Family Caregiving Project	45
Sampling Procedures	49

CHAPTER	PAGE
Qualitative Analysis Strategies	56
Coding Processes	57
Diachronic Framework: Turning the Story	59
Standards of Verification	60
Qualitative Research Considerations	62
Assumption that Research Power is Shared	64
Assumption that Context and Experience are Inseparable	65
Assumption that Language and Experience are Integral	65
4. RESULTS	67
Contextual Description of Cases	67
Case One: Alma's Family	67
Case Two: Cora's Family	68
Case Three: Belle's Family	69
Case Four: Elizabeth's Family	69
Case One: "My Very Best Friend"	70
Three Years Ago	73
Trip to Florida	73
She Needs to Come In Over Here	75
Trying to Get Some Help	77
Family Caregiving Decisions	79
Remembering Jay	81
Analysis of Case One	82
Theme of Friendship	83
Theme of Protectiveness	85
Theme of Recognition of Impact of Losses	88
Case Two: "An Easier Pill to Swallow"	91
First Few Weeks	94
Adjusting to Extended Time	98
Analysis of Case Two	100
Theme of Perceived Injustice	101
Theme of Legacy of Mother-Daughter Distance	106
Theme of the Process of Denial	108
Case Three: "Cousins Are All She Has"	112
Before Her Broken Hip	114
When She Broke Her Hip	114
Belle's Symptoms in Retrospect	115
Caregiving Turnover	116
All Her Houses	118
Analysis of Case Three	119
Theme of Caregiving Traditions	120

CHAPTER	PAGE
Theme of Protectiveness	122
Theme of Uncertainty	123
Theme of Creativity	125
Theme of Importance of Appreciation	126
Theme of Female Comraderie	128
Case Four: "I Don't Want to Give Up Yet"	130
Transition to Widowhood	132
Most Frustrating Period	135
Analysis of Case Four	140
Theme of Emphasis on Structure	141
Theme of Importance of Autonomy	145
Theme of Intergenerational Continuity/Exchange	149
5. DISCUSSION	153
Conclusions from Cross-Case Analyses	153
Decision-Making Processes	155
Relationship Patterns	156
Perceptions of Challenges and Rewards	158
Comparison of Findings to Alzheimer's Family Literature	161
Daughter-in-law and Son-in-law Motivations	162
Progressive Importance of Family in Decision-Making	162
Importance of Appreciation and Emotional Support	163
Influence of Uncertainties of Alzheimer's Disease on Relational Processes	164
Theoretical Implications	164
Process of Denial/Family Immobilization	165
Influence of Perception on Experience of Stress	166
Patterns of Intergenerational Influences: Family Legacies	166
Methodological Implications	168
Suggestions for Future Research	169
Suggestions for Interventions with Caregiving Families	170
Implications for Caregiving Families Themselves	171
Limitations of the Study	173
Strengths of the Study	174
REFERENCES	176
APPENDICES	188
Appendix A. Dr. Blanton's Family Caregiving Project	189
Appendix B. Bracketing Activities	207
VITA	220

LIST OF FIGURES

Figure 1. Double ABC-X Model of Family Crisis	27
Figure 2. Horizontal and Vertical Flow of Anxiety	30
Figure 3. Long Qualitative Interview: Four-Part Inquiry Process	38
Figure 4. Caregiving Time Line for Case One	74
Figure 5. Caregiving Time Line for Case Two	92
Figure 6. Caregiving Time Line for Case Three	113
Figure 7. Caregiving Time Line for Case Four	133

CHAPTER 1

INTRODUCTION

I am remembering a morning when I was five or six years old and had stayed overnight with my grandmother. I was sitting cross-legged on her antique, red velvet love seat, smoothing the velvet one way and then the other, fascinated by the changes in color as I directed the fibers with my small hands. My grandmother stood in the foyer observing my quiet appreciation of her most cherished piece of furniture, and she said, “Ansy, you really love old things. Will you take care of me and love me when I get old?” My natural and easy affirmative response to her question was followed by a genuine puzzlement that such a question could be asked. My fascination with the beauty of the old and my puzzlement over the questions about family connections with the old have continued to be expressed in my life as I have reached middle age. In fact, both my fascination and my puzzlement are explored in this study of family experiences with elder caregiving. Perhaps, I finally understand the real question as I observe my own granddaughter and wonder if she will take care of me and love me when I get old.

Purpose of the Study

The goal of this research effort was to explore how a family system is affected by the presence of a condition of degenerative cognitive impairment in an elder family member and the process of the family’s involvement in caregiving. To address this goal, the present study was designed to explore the lived experiences of Alzheimer’s families,

that is, to try to understand these phenomena from the perspectives of families who are involved in caring for someone with Alzheimer's disease or a similar condition of memory loss. Regardless of whether the caregiving situation involves responding to a frail elder's physical needs, cognitive needs, or both, review of the literature, as discussed in the next chapter of this document, revealed certain critical issues that caregiving families must address, including (a) changes in family relationships, (b) decisions about caregiving resources, and (c) stress generated by the caregiving process.

By listening to what Alzheimer's families have to say about their experiences related to these critical issues--by hearing their stories through the multiple perspectives of more than one family member--I believe I have been able to get of sense of what the family experience was, not just what the individual experience was within the family. Using the family as the unit of analysis in a collective case study approach (Moon & Trepper, 1996; Stake, 1994) permitted qualitative analyses of both within-case and cross-case processes and patterns (Creswell, 1998; Miles & Huberman, 1994; Weiss, 1994). By considering these thematic overlays within families and across families, the goal of understanding the overall challenges and rewards of the caregiving experiences of Alzheimer's families was achieved.

Definition of Terms

This study of families in relationship to the caregiving process for a family member with Alzheimer's or other condition of dementia requires a discussion of what is meant by the technical terms dementia, Alzheimer's disease, and vascular dementia (Amaducci,

Falcini, & Lippi, 1993; Cutler & Sramek, 1996; Henderson, 1990). In addition, the family caregiving concepts of elder, frail elder, elder care, elder caregiving process, informal elder care, formal elder care, frail elder with Alzheimer's disease, family, and Alzheimer's caregiving family are specific concepts used in this study that need clarification in relation to the participants and the research process.

Dementia, Alzheimer's Disease, and Vascular Dementia

Medical assessment and diagnosis are important for a person who is expressing symptoms of dementia, as well as for his or her family, because many of the causes of dementia are reversible, including vitamin or nutritional deficiencies, pharmaceutical drug interactions, depression, or structural damage to the brain (Cutler & Sramek, 1996; Rubin, 1990). In other words, determining the cause of impairment of mental functioning is essential in making decisions about treatment.

Dementia is a general term used by the medical community to describe a set of illnesses that express symptoms of cognitive impairment, including mental confusion, memory loss, and intellectual impairment. The symptoms of dementia may or may not be *reversible* and may or may not be *degenerative*, depending on the underlying cause(s) (Cutler & Sramek, 1996; Rubin, 1990).

Alzheimer's disease (AD) is considered the most frequent cause of irreversible dementia (Amaducci, Falini, & Lippi, 1993; Henderson, 1990). It is a degenerative process that begins with mild impairment in the early stages, moves to moderate loss of intellectual function in the middle stages, and continues to extreme functional disability in

the late stages (Cutler & Sramek, 1996; McKeith et al., 1999; Rubin, 1990). This cognitive decline is most likely the result of degeneration of nerve cells in the areas of the brain that involve thinking and remembering. Examination of brain tissue in autopsies reveals two features characteristic of Alzheimer's disease: neurofibrillary tangles, which are groupings of proteins that ordinarily make up the outer layer of nerve cells in the brain, and neuritic plaques, which are groupings of several types of protein, including amyloid (Cutler & Sramek, 1996).

The second most common condition of irreversible dementia is vascular dementia, sometimes called multi-infarct dementia or hardening of the arteries (Amaducci, Falini, & Lippi, 1993; Henderson, 1990). This condition of impaired cognition is caused by multiple strokes in the brain that destroy enough brain tissue to impair intellectual functioning (Cutler & Sramek, 1996; Rubin, 1990). A primary distinction between Alzheimer's disease and vascular dementia is that vascular dementia is not considered a degenerative disease like Alzheimer's, even though it is considered irreversible like Alzheimer's (Cutler & Sramek, 1996; Rubin, 1990).

Family Caregiving Concepts

In addition to defining the technical terms associated with Alzheimer's disease, it is important to clarify how certain concepts associated with family caregiving have been used in designing the parameters of this study.

Elder means any adult member of the family over age 55. Even though the symptoms of Alzheimer's disease may onset when a person is in his or her 40s or 50s, this

study includes no families with frail elders younger than the age 55 parameter. A frail elder is an adult who is physically and/or cognitively impaired to the extent that he or she is unable to provide self-care in essential areas of daily living, including instrumental tasks and personal care activities, sometimes called activities of daily living (ADLs). Also, an elder may be considered frail if he or she needs assistance in seeking resources related to social, emotional, or spiritual needs.

Elder care includes assistance with instrumental household tasks, transportation, medical care, financial tasks, or ADLs provided to a frail elder who is unable to perform the tasks independently. Elder care also includes provision of or assistance in seeking social, emotional, and spiritual support. The elder caregiving process includes all the steps and components involved in providing direct care or assistance or in making decisions or arrangements for the provision of formal or informal care of a frail elder. The process also includes changes and adjustments precipitated or influenced by the family caregiving situation.

Informal elder care includes resources available within the family and friends support network, usually (but not always) provided without financial obligation. Informal care or assistance usually is provided in a home environment but also may be provided by family and friends through their involvement with the frail elder in an institutional setting. In contrast, formal elder care includes resources available outside the family and friends support network, usually provided as a paid service but sometimes provided free through community volunteer organizations. Formal care or assistance usually is provided in a public or private institutional setting such as a hospital, assisted living facility, day

treatment center, or nursing home but may be provided in a home environment by professional staff.

In this study, a person with a dementia condition that appears to be irreversible and degenerative is referred to as a person with Alzheimer's, frail elder with Alzheimer's, cognitively frail elder, or person with disabling memory loss. Thus, a frail elder with Alzheimer's disease or similar condition of memory loss refers to any person expressing symptoms of Alzheimer's disease or other condition of degenerative cognitive impairment, whether formally diagnosed as probable Alzheimer's disease or not. Because medical diagnosis of Alzheimer's disease is a matter of eliminating other causes of the symptoms of dementia, a common way to indicate a diagnosis is to use the term senile dementia of the probable Alzheimer's type (SDAT), with an official diagnosis made only after an autopsy (Rubin, 1990; Terry, 1992).

The term family refers to the social unit composed of members related by law (i.e., marriage or adoption) or biology. Family was defined broadly for this study to include the frail elder and his or her informal network of immediate and extended family members. Depending on the progression of the disease, the perspective of the cognitively frail elder may or may not have been available for inclusion in the study. A family involved in the caregiving process for a frail elder with Alzheimer's disease or similar condition of memory loss is sometimes referred to as an Alzheimer's caregiving family, a family with a cognitively frail elder, or simply an Alzheimer's family.

Research Questions

Through a process of constant comparative analysis, considering thematic elements both within families and across families, I expected to gain insight regarding answers to the following research questions related to the experiences of caregiving families who are faced with the challenges of coping with a condition like Alzheimer's disease:

1. How do families make caregiving decisions regarding frail elders?
2. How does the caregiving situation affect family relationships, roles, and responsibilities?
3. How are family conflicts and connections expressed in the caregiving situation?
4. How do families perceive the physical and emotional stress of caregiving?
5. What are the challenges and rewards of the caregiving process?

Beyond these questions, which were, of course, no more than my best guesses about what areas would emerge in the rich narratives of the participants, I hoped to discover ways to help answer some questions about issues that may be anticipated by other families as they approach similar caregiving responsibilities. And, of course, as in any qualitative study, the answers to these questions may have been described more appropriately as the discovery of the questions yet to be explored.

Importance of the Topic

During the decade of the '90s, family science and gerontology literature reflected an increased interest in the topic of families and elder caregiving (Bengsten, Rosenthal, & Burton, 1996; Dillehay & Sandys, 1990; Holstein, 1997). Researchers, service providers,

and policy makers, as well as the general public, have begun to recognize the potential impact of cultural/demographic shifts on access to informal and formal caregiving resources (Aneshensel et al., 1995; Greenberg, 1996; Harlton, Keating, & Fast, 1998; Keith, 1995), caregiver stress/burden (Brody, 1990; Dilworth-Anderson, Williams, & Cooper, 1999; Mui, 1995; Reinhard & Horowitz, 1995), caregiving roles and relationships (Allen & Walker, 1992; Allen, Goldscheider, & Ciambrone, 1999; Blieszner & Shiflett, 1990; Boss, 1999; Chelsa, Martinson, & Mulwaswes, 1994; Harris, 1998; Horowitz, 1985), balancing work/family responsibilities (Doty, Jackson, & Crown, 1998; Frederickson & Sharlach, 1997; Neal et al., 1993; Pohl, Collins, & Given 1998; Starrels et al., 1997), the impact of cognitive impairment on family relationships (Boss, 1993; Cicirelli, 1984; Fisher & Liebermann, 1994; Long, 1997; Mellins et al., 1993), and cultural expectations for filial responsibility (Choi, 1996; Coleman, Ganong, & Cable, 1997; DeGenova, 1997; Dupuis & Norris, 1997; Globerman, 1996; Ikkink, Tilburg, & Knipscheer, 1999; Kriseman & Claes, 1997; Schoenberg & Coward, 1997). Significant cultural and demographic shifts that have generated high interest in elder caregiving include the demographics of aging, changes in family form and function, and concerns about economic resources.

Demographics of Aging

The most obvious and significant development to consider in relation to the salience of the topic of families and elder caregiving is the changing demographics of aging. Advances in health care and medical technology have resulted in increased life

expectancy, which means more people are living longer. Estimates are that by the year 2050, approximately 20% of the U. S. population will be over age 65 and almost 10% will be over age 80. In fact, it is projected that more than one million of these individuals will be over the age of 100 (U.S. Bureau of the Census, 1989). Because Alzheimer's disease and similar degenerative conditions of cognitive impairment are not the natural result of aging but are increasingly higher risks for people as they age (Amaducci, Falcini, & Lippi, 1993; Henderson, 1990; West et al., 1997), this increase in overall life expectancy means an increase in our chances of experiencing the symptoms of Alzheimer's or similar conditions of memory loss (Cutler & Sramek, 1996). We may be startled by the findings of epidemiological studies that suggest that the prevalence of dementia increases with age exponentially, with the prevalence being 1-2% of the age 65 population and then doubling approximately every 5 years after age 65, up to age 95 (Henderson, 1990). Other studies suggest that a person's chances of experiencing Alzheimer's or similar disabling memory loss triple every 10 years beyond age 65 (Amaducci, Falcini, & Lippi, 1993). In either case, as more people live longer, there will be greater demand for both elder caregiving and caregiving resources, including the potential contributions of families.

Changes in Families

Compounding the effects of dramatic increases in the numbers of individuals reaching old age is the "baby bust" phenomenon created by decreased fertility rates of post-World War II Baby Boom women (Devarics, 1999). Because the Baby Boomers had few or no children, fewer adult children will be available to provide family resources for

elder care (Devarics, 1999), an issue recognized as a critical concern for families (Aneshensel et al., 1995; Brody, 1990; Erlanger, 1997; Gubrium, 1991; Hargrave & Hanna, 1997; Long, 1997; Pearlin et al., 1996). Furthermore, nontraditional families, including remarried families, single-parent families, never-married couples, and extended family or affiliated kin arrangements, have emerged in greater numbers, with diversity now the rule rather than the exception (Choi, 1996; Coleman, Ganong, & Cable, 1997; DeGenova, 1997; Dupuis & Norris, 1997; Gubrium & Holstein, 1990). One result of increased family diversity is increased numbers of individuals within the family who may need care. That is, because more adult children have been divorced and remarried, they may have responsibility for not only their parents but also step parents and parents-in-law, creating an immediate need to make sense of filial obligations for family caregiving when nontraditional relationships are involved.

Economic Shifts

With the elderly population growing both in size and in proportion to the whole population (Olson, 1994; Friedland & Summers, 1999; U. S. Bureau of the Census, 1989), we are afraid not only of having a shortage of potential family caregivers but also of running out of financial resources like social security benefits and physical resources like space in nursing homes (Binstock & Murray, 1998; Caron, 1997; Cowgill, 1974; Dobrof & Ericsson, 1993). In the past, there have been more working-age people to support the financial needs of the older, retired population (Olson, 1994, Friedland & Summers, 1999). As such, the economic system has been able to remain in balance because there

have been more working people than nonworking dependents, such as children and retired elderly (Devarics, 1999; Friedland & Summers, 1999). According to population experts for the United Nations, the economic impact of demographic shifts will be felt in the area of access to formal and informal health care resources, with an expected shortage of informal caregivers (Dervarics, 1999). In addition, trends in female labor force participation predict a significant decrease in the availability of informal caregivers, who have traditionally been female (Allen & Walker, 1992; Brody, 1990; Kriseman & Claes, 1997), thus increasing the demand for formal services (Doty, Jackson, & Crown, 1998; Olson, 1994).

Because demographers are wondering if we will have enough money to pay for both the basic needs and the health care needs of the growing numbers of elders, family science and gerontology researchers need to study how families experience the caregiving process and identify the types of resources families need to support their efforts. In fact, because formal resources simply may not be available to adequately meet the elder caregiving demand during the next 50 years, we need to do everything we can to preserve and nurture the informal resources of family and friends.

Rationale for the Study

Because the challenges and rewards of family caregiving experiences are complicated by the presence of Alzheimer's disease in addition to or instead of physical impairment issues (Agee & Blanton, in press; Ory et al., 1999; Vetter et al., 1999), I was especially interested in how caregiving families have responded to circumstances that

involve Alzheimer's disease or related dementias. Families caring for someone with Alzheimer's disease face especially complex challenges because a cognitive disease process tends to have dramatic effects on family roles and relationships (Long, 1997; Zarit, Orr, & Zarit, 1985). Another factor that increases the complexity of the caregiving situation is that the traditional medical model upon which we have learned to rely to cure disease, ease pain, and adjust to physical disabilities or frailties falls short of our hopes and expectations in response to degenerative dementia (Barusch, 1991; Binstock & Murray, 1998). Notwithstanding recent excitement over medical research in hormone therapy, genetic links, and neural cell growth (Burke & Morgenlander, 1999; Cutler & Sramek, 1996; McKeith et al., 1999; Post, Whitehouse, & Zin, 1998; Rubin, 1990; Waters, 1997; Whitehouse, 1998) that may be useful in slowing or reversing the expression of the symptoms of degenerative memory loss, no quick remedy is available, no prescription will cure the disease, and no change in lifestyle will reverse the damage to brain tissue (Amaducci, Falcini, & Lippi, 1993; Cutler & Sramek, 1996; Gauthier, 1999; Long, 1997; Mace & Rabins, 1999; McKeith et al., 1999).

Because families are struggling to find ways to cope with the impact that this kind of cognitive impairment has on roles and relationships (i.e., on the family system itself), it is important to ask families what processes they are discovering and what resources they need to help them during their relatively uncharted journey through caring for someone with Alzheimer's disease. In this sense, Alzheimer's families are like explorers in a new world, discovering their own depth of resources and creativity as they face the demanding

challenges and potential rewards of being involved with this complex and potentially overwhelming caregiving process.

CHAPTER 2

LITERATURE REVIEW

We depend on the informal resources of families to provide the majority of care for cognitively frail elders. In fact, more than 60% of all elder care, regardless of the severity of illness or disability, is provided directly by family members (Aneshensel et al., 1995; Bengsten, Rosenthal, & Burton, 1996; Brody, 1990). In both family science and gerontology literature, caring for an Alzheimer's patient is described as a challenging and sometimes overwhelming process (Dillehay & Sandys, 1990; Dupuis & Norris, 1997; Holstein, 1997; Long, 1997). Even popular television and print media reflect high interest in and concern for how families and individuals are affected by the Alzheimer's disease process (Carroll, 1989; Chamberlain, 1999; Mace & Rabins, 1999; McGowin, 1993; Reagan, 1999).

Examining the following review of the caregiving literature revealed that Alzheimer's families struggle with a variety of critical issues during the caregiving process. These critical issues included (a) adjusting to changes in family relationships (Blieszner & Shifflett, 1990; Boss, 1999; Chelsa, Martinson, & Muwaswes, 1994; McGowin, 1993), (b) making decisions about caregiving resources (Globerman, 1996; Greenberg, 1996; Suitor & Pillemer, 1994; Wright, 1993), and (c) coping with stress and perceptions of caregiver burden (Aneshensel et al., 1995; Cohen & Eisdorfer, 1988; Fisher & Lieberman, 1994, 1999; High & Rowles, 1995; Miller, Prohaska, & Furner, 1999; Pearlin et al., 1996; Riddick et al., 1992; Snyder, 1992; Wright, 1993; Zarit, Orr, & Zarit, 1985).

Theoretical Considerations

By reflecting on these areas of concern from a theoretical perspective, perhaps we can begin to understand more fully the experiences of Alzheimer's families and to help future Alzheimer's families approach the caregiving process with the benefit of those experiences. I have used a combination of symbolic interactional, family systems, and family stress theories to provide a comprehensive theoretical basis for understanding the phenomena associated with the family caregiving process. Family systems theory views the family as a whole, as a unified set of subsystems interacting with each other and with the broader cultural environment (Klein & White, 1996), and symbolic interactionism defines the family as an interactive context for making sense of the world (Klein & White, 1996). In addition, family stress models add the dimension of time and stress-related concepts to these theoretical frameworks.

The systems perspective reflected in the literature on family relations and elder caregiving has typically focused on (a) caregiving relationships from the perspectives of primary caregivers (Blieszner & Shiflett, 1990; Boss, 1999; Chelsa, Martinson, & Mulwaswes, 1994; Greenberg, 1996; Harris, 1998), (b) the logistical factors involved in making caregiving decisions with or for a frail elder (Caron, 1997; Cicirelli, 1991; Groger, 1994; High & Rowles, 1995; Jett et al., 1996; Keysor, Desai, & Mutran, 1999; Liberman & Fisher, 1999; McGrew, 1998; Miller, Prohaska, & Furner, 1999; Schoenberg & Coward, 1997; Zarit & Whitlach, 1992), or (c) the physical and/or emotional burdens experienced by caregivers (Aronson, 1992; Boss, 1993; Fisher & Lieberman, 1999; Mui,

1995; Reinhard & Horowitz, 1995; Starrels et al., 1997; Vetter et al., 1999; Zarit, Orr, & Zarit, 1985).

The caregiving literature devoted to family issues and Alzheimer's disease has focused on similar issues and has drawn on concepts from both family systems and symbolic interactional theoretical perspectives to show how the presence of Alzheimer's disease or similar conditions of dementia impacts the entire family system (Long, 1997). Specifically, the interactive, communicative elements of the theories that are discussed in this review of the literature include Boss' (1988, 1993, 1999) concept of ambiguous loss in relation to her concept of boundary ambiguity; Mead's (1934) concepts of definition of the situation, self, and role taking (Klein & White, 1996); McCubbin and Patterson's (1982) concept of stressor pile up in their revision of Hill's (1949) ABC-X model of family stress; and Carter and McGoldrick's (1989) concept of vertical and horizontal stress in their model of the flow of anxiety in families over time. Certainly, these theoretical concepts help inform our interpretations of data in the studies cited in this review and, likewise, should prove useful in making sense of the narrative data collected in this research project.

Relationship Changes in Alzheimer's Families

A review of the literature on relationships in Alzheimer's families suggests that changes in family relationships are an inevitable part of the disease process (Dillehay & Sandys, 1990; Long, 1997; Zarit, Orr, & Zarit, 1985). Overall, studies suggest that families who deal with Alzheimer's disease feel powerless over the disease process and its

effects on the family (Cohen & Eisdorfer, 1988; Dillehay & Sandys, 1990; Long, 1997; Zarit, Orr, & Zarit, 1985).

Concept of Ambiguous Loss

One theoretical concept that is useful in explaining how Alzheimer's disease impacts family relationships is Boss's (1993, 1999) concept of ambiguous loss, which she used to inform her studies of Alzheimer's families struggling with grieving for cognitively-impaired family members who were slipping away psychologically but not physically. Related to another concept described by Boss (1988) as boundary ambiguity, ambiguous loss results from not knowing who is in or out of the family. Another theoretical concept that helps explain ambiguous loss experiences in Alzheimer's families is Mead's (1934) concept of self as a mirrored identity defined by interactions with others (Klein & White, 1996). Associated with the cognitive decline of Alzheimer's disease is the gradual but often unclear loss of one's identity in relation to others, an ambiguous situation that may be interpreted by family members as partial or total loss of the patient's identity as a person and as a member of the family (Dillehay & Sandys, 1990; Mace & Rabins, 1999; McGowin, 1993). McGowin's (1993) personal narrative of her experiences with symptoms of cognitive decline illustrated the power of interactions with family members and other significant people in her struggle to retain her sense of self. She reached out to people who had known her in high school, sensing that only in these relationships could she remember herself as she used to be, and she measured her decline through the

reactions and interactions of her adult children and her husband. Her identity, almost literally, resided in the essence of her interactions with significant others.

Caregiver Dyad Relationships

Boss (1999) and others have described the complicated feelings of family members who are trying to make sense of the erratic behaviors and personality changes of the person with Alzheimer's disease in relation to (a) the afflicted person's presence and identity as part of the family (Chelsa, Martinson, & Muwaswes, 1994; McGowin, 1993), (b) caregivers' perceptions of losing emotional intimacy with care receivers (Blieszner & Shifflett, 1990), and (c) experiences of ambiguous loss (Boss, 1993, 1999).

Family Role Identity. As noted by Chelsa, Martinson, and Muwaswes (1994) in their 1½-year longitudinal study of 30 Alzheimer's families, caregivers' descriptions of their relationships with their care receivers fell into three categories in comparison to their relationships prior to the onset of disease symptoms: *continuous*, *continuous but transformed*, or *radically discontinuous*. From hermeneutic analyses of caregivers' daily care narratives, the researchers discovered that even ordinary communication with a person with Alzheimer's can be challenging and frustrating, precipitating subtle and/or dramatic changes in how family members interact and how they perceive each other as members of the family. In relationships labeled *continuous*, caregivers continued to clearly identify themselves and their care receivers in the context of their roles prior to the illness, not necessarily denying the dramatic losses but finding comfort and security in familiar gestures and preferences. In those relationships labeled *continuous but transformed*,

caregivers were able to function with a high level of ambiguity, considering the care receiver as lost but maintaining a strong commitment to preserving the dignity of the person they used to know as (most often) a partner or parent. In relationships labeled *radically discontinuous*, caregivers described the family member with Alzheimer's disease as unrecognizable. Boss (1999) referred to this phenomenon as a coping strategy used by the family to close ranks (i.e., clarify boundaries, in order to reduce the stress of the situation).

Loss of Mutuality. Alzheimer's caregivers experience loss of mutuality in their relationships with their care receivers, sometimes feeling like they are having to fill in for both sides of the relationship (Dillehay & Sandys, 1990; Mace & Rabin, 1999), and they may interpret this ambiguous position as a loss of closeness or intimacy in the relationship. In their study of 11 caregiving dyads during the 18 months before and after Alzheimer's diagnosis, Blieszner and Shiflett (1990) found a perceived decline in emotional closeness or intimacy for both spousal and parent-child dyads. They also found that during the early stages, especially prior to diagnosis, family members felt frustrated, confused, hurt, and angry in response to the afflicted person's physical presence but emotional absence, reporting difficulty in being patient or understanding. After diagnosis, these caregivers reported (a) less difficulty in being patient and understanding with but (b) increasing emotional distance from their care receivers, acknowledging the gradual but unpredictable loss of mutuality in the relationship.

Grief Process. Because family members with Alzheimer's typically live from 2 to 10 or more years after the onset of symptoms (Cutler & Sramek, 1996), caregivers

experience the gradual loss of family members in varied and often ambiguous ways, not knowing when or how to begin grieving the losses they have experienced (Blieszner & Shiflett, 1990; Boss, 1999). In Boss's (1999) study involving focus groups with Alzheimer's family members, many caregivers reported that they felt confused by the incongruence of physical presence and psychological absence as well as by the unpredictability of the caregiving situation. Because of the ambiguity associated with their losses, these caregivers had trouble beginning the grief process, feeling reluctant to focus on other primary relationships because of the continued physical presence in spite of the progressive psychological absence of the cognitively impaired elder. She used the term frozen grief to describe this phenomenon. Some participants reported that the stress generated by the uncertainties of the disease process was more devastating than the stress associated with the severity of the symptoms.

Marital Relationships in Alzheimer's Families

Some Alzheimer's caregiving studies have focused on marital relationship issues for adult-child and child-in-law caregivers (Globerman, 1996; Sutor & Pillemer, 1994) or for caregiving spousal dyads (Wright, 1993).

Marital Relationships of Caregiving Spousal Dyads. Wright's (1993) study comparing relationship dynamics of Alzheimer's couples and non-Alzheimer's couples revealed that when the symptoms of Alzheimer's disease began to be expressed, many of the Alzheimer's couples experienced shifts in traditional roles in marital relationships, including those related to basic household tasks, personal care, transportation, and

financial matters. Husbands caring for wives with Alzheimer's had to assume new responsibilities for cooking and grocery shopping, and wives caring for husbands with Alzheimer's started doing all the driving and check writing. As the disease progressed, other areas in the marital relationship were affected, including companionship, affection, commitment, and sexual activity as well as relational tension. The participants in this study reported that in spite of the frustrations and challenges in the shifting roles and expectations in marriage relationships in which one partner had Alzheimer's disease, many persons with early to middle stage Alzheimer's disease symptoms were aware of their partner's feelings and were able to sense and react to feelings of rejection, abandonment, love, understanding, and joy. These findings suggested that as long as caregiving spouses were able to sense the affective signals of their partners and to be flexible in their roles, they were able to some extent to continue communicating with their partners longer than they initially had assumed.

Marital Relationships of Adult Child/Child-in-law Caregivers. Suitor and Pillemer's (1994) 1-year panel study of the impact of Alzheimer's disease on marital satisfaction involved analyses of both quantitative and qualitative data from 94 daughters and daughters-in-law caring for parents or parents-in-law with irreversible dementia. Results suggested that changes in marital satisfaction over the course of the first year of caregiving were influenced mainly by husbands' attitudes about the caregiving process. Emotional support from husbands increased marital satisfaction, with husbands perceiving wives' caregiving roles as complementary to family role performance. Emotional negativity from husbands decreased marital satisfaction, with husbands perceiving wives'

caregiving roles as interfering with family role performance. In other words, to the extent that wives received emotional support and approval for taking on the role of caregiver, they felt good about their marital relationships. The primacy of this emotional support for role taking was reinforced by the additional finding in this study that instrumental support from husbands had little effect on the quality of marital relationships.

Decisions About Caregiving Resources in Alzheimer's Families

Making complicated and sometimes difficult decisions about caregiving resources in Alzheimer's families is considered as inevitable as having to adjust to changes in relationships (Dillehay & Sandys, 1990; Long, 1997; Zarit, Orr, & Zarit, 1985).

Concept of Role Taking

From a theoretical perspective, Mead's (1934) symbolic interactional concept of role taking, defined as putting self in the role of the "actor" who is bound by the rules or expectations of a person in that role (Klein & White, 1996), informs our understanding of the impact of Alzheimer's disease on family role performance. A person who assumes the role of caregiver for a frail elder relative takes on a set of rules and expectations associated with that role. Cultural expectations about filial responsibilities influence decisions about caregiving resources, including money and people. If families are unable to fulfill filial expectations that frail elders be cared for only through the informal resources of family, transitions to care provided by formal resources may be difficult. Likewise, if daughters-in-law resist taking on caregiving roles in spite of cultural expectations that

women automatically should act in caregiving roles, their husbands may be surprised by having to take on the responsibilities of taking care of their own parents.

Decisions About Financial Resources

Deciding how to negotiate financial decisions with/for a cognitively frail elder sometimes emerges early in the caregiving process because caring for a person with a condition of dementia related to Alzheimer's disease can deplete a family's financial resources quickly (Dillehay & Sandys, 1990; Long, 1997; Mace & Rabins, 1999). Many of the caregiving needs of a cognitively frail elder are not addressed by the medical model upon which health insurance is based, and so many of the resources designed to meet the needs of Alzheimer's families, including day treatment/care and assisted living arrangements, are available only through a private pay system, rather than being covered by insurance or Medicare (Long, 1997). Because only a minority of Alzheimer's families have the benefit of long-term care insurance designed to cover the array of services needed in the event of cognitive impairment (Long, 1997), the majority of Alzheimer's families have depleted savings account monies and other financial resources during the early and middle stages of the disease, sometimes before physical functioning is significantly impaired (Mace & Rabins, 1999). Another reason that financial issues have appeared early in the caregiving process is that a common, early symptom of Alzheimer's disease is having difficulty with managing numerical abstracts (Cutler & Sramek, 1996). A person in the early stages of Alzheimer's may have been able to function without noticeable difficulty in many ways, including talking on the telephone or driving a vehicle.

Concurrently, that person in early Alzheimer's disease may no longer be able to keep up with a checkbook balance, recognize correct change back at the grocery store, or successfully negotiate other daily tasks or problems that involve numerical abstracts (Cutler & Sramek, 1996).

Decisions About Caregiving Roles

The literature on decisions about caregiving resources in Alzheimer's families revolves primarily around who takes on caregiving roles and why, revealing a variety of motivations for decisions of spouses and adult children/children-in-law to become and stay involved in the caregiving process (Globerman, 1996; Greenberg, 1996; Wright, 1993), as well as influences from differences in gender role expectations and perceptions in families (Globerman, 1996). The role of caregiver is gendered; that is, culturally, we expect caregivers to be women rather than men. Therefore, men who become caregivers may encounter cultural resistance to their performance of direct, personal care activities. In fact, men as caregivers typically are described more accurately as care managers, coordinating the provision of formal services needed to meet the needs of the frail elder (Harris, 1998) rather than providing direct care. In contrast, women as caregivers are more likely to be providing direct care and feeling guilty if they *manage* care rather than *give* care (Doty, Jackson, & Crown, 1998; Horowitz, 1985; Kriseman & Claes, 1997).

Adult Child/Parent Role Reversals. While some of the communication and relationship challenges for caregiving spouse dyads may be applied to the challenges for adult children caring for cognitively frail parents, Greenberg (1996) noted that the

unexpected reversal in parent-child roles can precipitate either feelings of discomfort about reversing roles with their parents or expressions of renewed hope for resolving unfinished business. In her work with Alzheimer's family members, Greenberg (1996) found that unfinished business related to issues of dependency in parent-child relationships made it difficult for both the adult child and the cognitively frail parent to feel comfortable with the adult child as the authority in making decisions about finances, medical care, transportation, housing, and other daily living issues. Also, in the process of taking on roles that felt like being parents to their own parents, some adult children overstepped their new authority, taking over decisions that parents actually were still competent to make. Other adult child caregivers used the role shift as an opportunity to reframe and improve the relationship, to work on unresolved issues, and, in a sense, to finish growing up.

Adult Child-in-law Caregiving Motivations. Globerman (1996), in her study of 16 children-in-law involved in Alzheimer's caregiving, noted four motivational patterns for role taking by daughters-in-law and sons-in-law: obligation, reactive, proactive, and managerial, with notable gender differences in perceptions of caregiving roles. Daughters-in-law perceived their caregiving functions to include helping sons (their husbands) connect with their declining parents, consistent with expectations for women to act as kinkeepers as well as direct caregivers. Sons-in-law viewed their caregiving contributions as a matter of responding to the emotional or instrumental needs expressed by their wives, consistent with expectations for men to maintain a somewhat more peripheral role in caregiving.

Effects of Stress and Perceptions of Burden in Alzheimer's Families

As family members begin to notice changes in the abilities of an individual with Alzheimer's or other condition of memory loss, they tend to rationalize the unusual behaviors, accounting for the elder's confusion or agitation as stress-related or interpreting the memory difficulties as a function of normal aging (Cutler & Sramek, 1996). Family members sometimes ignore or deny the realities of Alzheimer's symptoms, hoping they will disappear (Cutler & Sramek, 1996; Mace & Rabins, 1999).

Dillehay and Sandy's (1990) review of Alzheimer's care literature suggested that families experience stressful events within the context of what has already happened because of progressive deterioration and extended time period of the illness. Cohen and Eisdorfer (1988) found that over half of caregivers in Alzheimer's families were depressed, perhaps as a function of their feelings of powerlessness as they tried to cope with the extended time involved in the disease process and the bleak prognosis.

Concept of Stressor Pile Up

A family systems concept that is useful in explaining the experiences of Alzheimer's families is stressor pile-up, described by McCubbin and Patterson (1982) in their Double ABC-X revision of Hill's (1949) ABC-X model of family crisis. The revised model added the dimension of time and accounted for the increased stress that comes from an accumulation of stress over time. As illustrated in Figure 1, Alzheimer's families may experience stressor pile up (a with A), requiring a doubling of efforts by family members

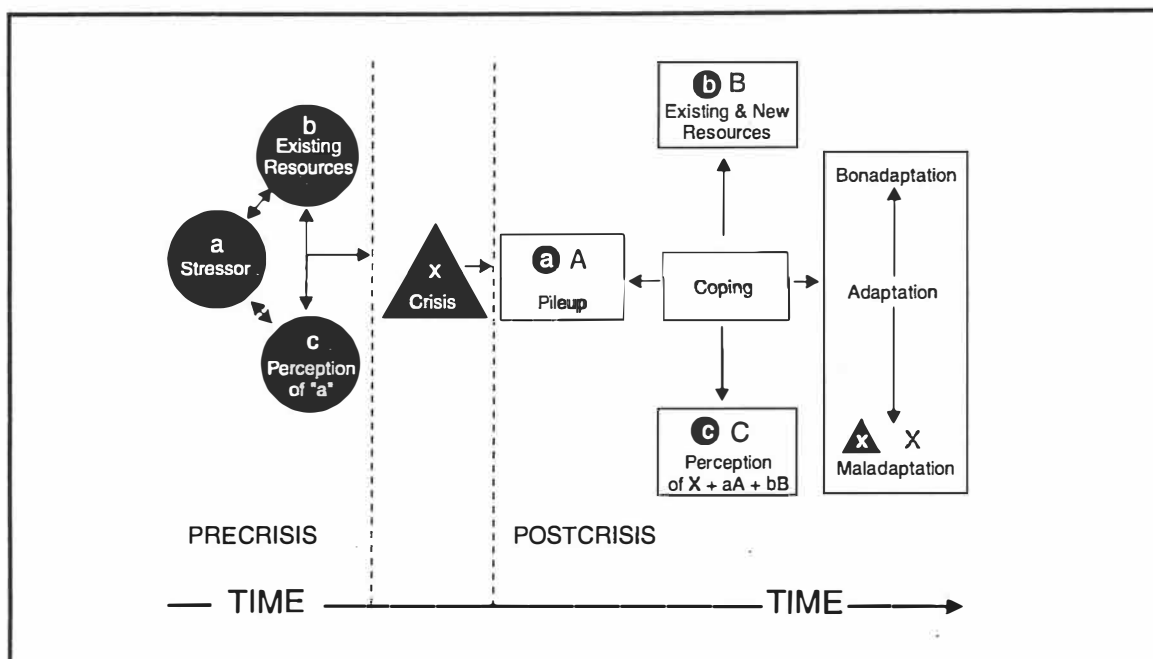


Figure 1. Double ABC-X Model of Family Crisis

Source: McCubbin, H. I., & Patterson, J. M. (1982). Family stress, coping, and social support. Springfield, IL: Charles C. Thomas.

to identify new resources and stretch existing ones (b with B) and creating a cumulative effect on perceptions of present events in the context of past events (c with C), influenced by boundary ambiguity. Thus, financial and personal resources may be exhausted and the situation may be perceived as rather hopeless, precipitating a double crisis (x with X), sometimes with an outcome of a mental or physical breakdown of the primary caregiver. Boss (1988) pointed out that she believed that the *perception* aspect of the model was the most influential, but least studied, aspect of the family stress process. The present study is an attempt to address this gap in the family stress literature for families dealing with Alzheimer's disease.

Aneshensel's et al. (1995) comprehensive, longitudinal study of experiences of caregivers of cognitively impaired elders revealed the influence of primary stressors,

including relationship changes and problematic behaviors of care receivers, and secondary role strains, including work and family conflicts. Their model incorporates the concept of stress proliferation as a function of the extended time involved in the caregiving process, another way to express the effects over time of stressor pile up in McCubbin and Patterson's (1982) Double ABC-X model.

Concept of Definition of the Situation

Mead's (1934) symbolic interactional concept of definition of the situation also helps explain how stressful events in Alzheimer's families become crises. In studies of Alzheimer's families during the pre-diagnosis period, family members may interpret sudden behavioral shifts of the affected family member from cooperativeness to hostility or agitation as a matter of interpersonal conflict, not understanding the changes as part of a disease process (Bleiszner & Shifflett, 1990; Long, 1997). In other words, family members may experience the situation as a relational problem, not recognizing changes as symptoms of a degenerative disease.

In studies describing the progression of Alzheimer's families into the middle and late stages, the symptoms of dementia became so noticeable and problematic that intervention was necessary for the safety of the person experiencing the symptoms of Alzheimer's disease as well as for the safety and well-being of others around them (Aronson, 1992; Cohen & Eisdorfer, 1988; Cutler & Sramek, 1996; Fisher & Lieberman, 1994, 1999; Pearlin et al., 1996). These shifts necessitated a transition from defining the situation as benign to defining the situation as dangerous. For example, Cutler and

Sramek (1996) noted that driving a car was too dangerous when cognitively frail elders could not remember the way home or did not recognize the meaning of a traffic signal so that family members were compelled to intervene by taking away the car keys or disabling the vehicle. In another example, they noted that unsupervised access to a kitchen was dangerous when cognitively frail elders not only forgot about turning on the stove but also failed to recognize what the whistle of the teapot meant.

The progression of Alzheimer's disease varies from person to person, with some people experiencing a very gradual decline and others experiencing a very rapid deterioration, so that family members literally do not know what to expect from one day to the next (Cutler & Sramek, 1996). This progressive deterioration poses serious problems for families because the cognitively frail elder's physical ability to walk suddenly becomes the ability to wander and get lost or injured, or his or her physical ability to turn on the stove in the kitchen unexpectedly becomes the ability to start a house fire (Mace & Rabin, 1999). These changes are sometimes sudden rather than gradual.

Concept of Vertical and Horizontal Stress

Another way to understand what happens over time in Alzheimer's families is explained by Carter and McGoldrick's (1989) model of vertical and horizontal stress, which describes the flow of anxiety in families over the life cycle. As depicted in Figure 2, the flow of anxiety or stress includes both predictable and unpredictable developmental events experienced by families over time. The vertical flow of anxiety or stress is composed of all the patterns of relating, cultural expectations, and family

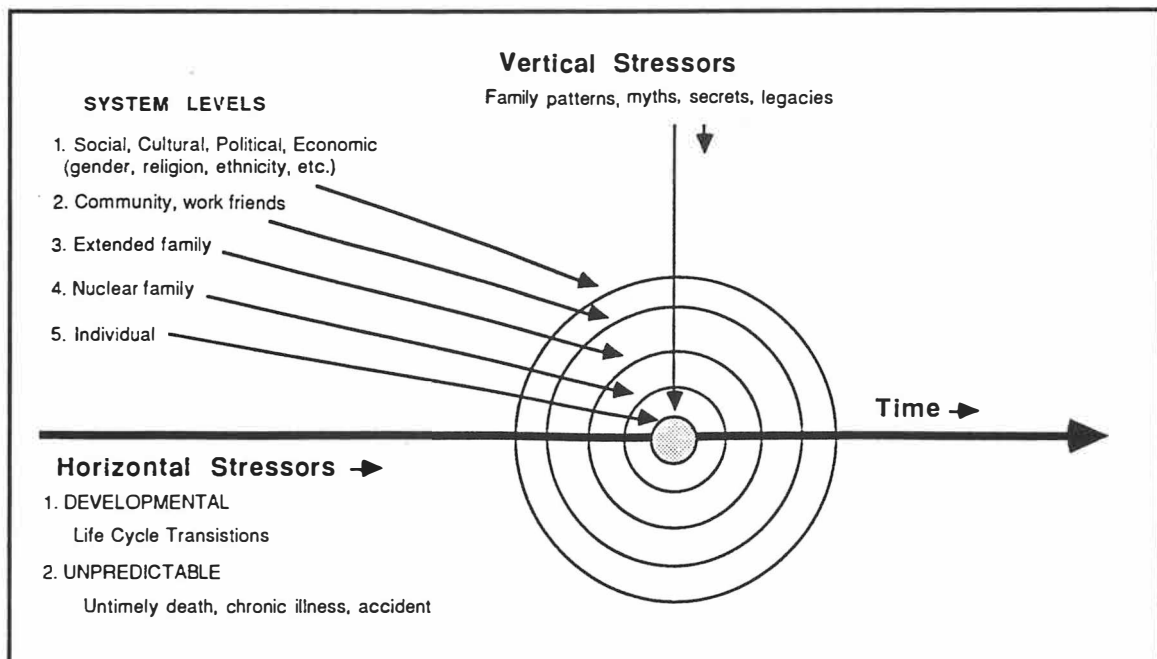


Figure 2. Horizontal and Vertical Flow of Anxiety

Source: Carter, B., & McGoldrick, M. (1989). The changing family life cycle: A framework for family therapy, 2nd ed. Boston: Allyn and Bacon.

myths/secrets that are passed on from one generation to the next, such as beliefs about filial responsibilities or secrets about abuse or neglect. The horizontal flow represents the developmental events of the family, including predictable ones like mid-life transitions or retirement as well as unpredictable or unexpected ones like the onset of Alzheimer's disease. The key to understanding this model is that the transition point where vertical stressors *intersect* with horizontal ones, such as a decision about nursing home placement, may result in an intense surge of stress in the family (McCubbin & Patterson, 1982). Further, developmental demands in other realms of family experience contribute to the drain on both psychic and fiscal resources of the family during the caregiving process. Placement in a nursing home or other institutional environment is an option that many families consider, especially as the disease progresses and the process of caregiving

becomes too demanding and complex (Cutler & Sramek, 1996; Long, 1997). Sometimes family members have promised their loved ones that they would never institutionalize them (vertical flow of anxiety), and, consequently, tend to delay such action until the strain becomes critical, affecting the physical and/or emotional well-being of the caregiver(s) (Snyder, 1992).

Predictors of Nursing Home Placement

Increased likelihood of nursing home placement has been related to such variables as living alone, being poor, being unable to perform activities of daily living, being female, number of medical problems, presence of incontinence, and amount of caregiver burden or strain (Long, 1997). While the presence of a primary caregiving family member (especially a spouse) has been correlated as a *preventive* factor for institutionalization (Miller, Prohaska, & Furner, 1999; Wright, 1993), illness or death of a primary caregiving family member (horizontal flow of stress) has been identified as a risk factor for institutionalization (Aneshensel et al., 1995).

Stress. According to several studies (Aneshensel et al., 1995; Mace & Rabins, 1999; Zarit, Orr, & Zarit, 1985), the question of institutionalization emerges as the degenerative nature of Alzheimer's disease wears thin the physical and emotional resources of the family. The family, especially the primary caregiver, needs emotional support during the decision-making phase and may need even more support during the transition phase immediately after placement of the cognitively frail elder (Riddick et al., 1992).

Family Dynamics. In contrast to the general preoccupation with the influence of demographic variables on the likelihood of nursing home placement, Fisher and Lieberman's (1999) 2-year study of 164 caregivers of dementia patients revealed an influence of family dynamics on nursing home placement decisions. Their results illustrate the intersection of vertical and horizontal anxiety, with high measurements on negative interaction patterns, lack of emotional closeness, and inefficiency in decision making (vertical flow of anxiety) increasing the likelihood of earlier nursing home placement.

Myth of Abandonment

At the intersection of vertical and horizontal stress, families may perceive nursing home placement as the worst thing that could happen and may need additional support in making the transition from the informal care environment to the formal care systems of nursing homes or other institutional care facilities. Contrary to the persistent myth of abandonment described by Brody (1990) and others as a belief that families tend to abandon relatives at the point of institutionalization, High and Rowles (1995) found that neither did families abandon filial contact nor did they turn over decision-making authority to personnel of nursing homes or other formal care resources. Instead, the families became more and more involved as the conditions of the cognitively frail elders worsened, progressively providing decision-making assistance or serving as decision-making substitutes for cognitively-impaired relatives.

Research Imperatives

More family science and gerontology research efforts need to consider the family caregiving experience from a multidimensional, process-oriented perspective (Brubaker, 1990; Dupuis & Norris, 1997), attempting to account for the phenomena associated with the interface between formal and informal elder care resources over time (Agee & Blanton, in press; Dempsey & Pruchno, 1993; Gallagher, 1994; Gubrium, 1991; High & Rowles, 1995; Naleppa, 1996; Zarit & Whitlach, 1992). In addition, intergenerational connections in relation to the progression of Alzheimer's disease need to be explored via longitudinal and multigenerational studies (Brubaker, 1990; Bengsten, 1996). Other areas that might be addressed through longitudinal study is what happens in families when Alzheimer's symptoms first begin to appear, as well as what happens in families after the death of the Alzheimer's patient.

Even though some of the caregiving literature does assume a family systems perspective, more research efforts are needed to highlight the experience of the family as a whole (Brubaker, 1990; Dupuis & Norris, 1997), using the family rather than the individual primary caregiver or the caregiving dyad as the unit of analysis . Using the family as the unit of analysis and capturing the essence of the experience of caregiving to frail elders is a goal that may be achieved most effectively through the inductive processes of qualitative methodologies (Rosenblatt & Fischer, 1993).

Other relatively unexplored areas of potential study include observation of the changing perceptions and narrative abilities of individuals as they experience the Alzheimer's disease process (McGowin, 1993) and the flexibilities and creative resources

within their families that help them all cope with the stressful realities of Alzheimer's disease. Perhaps we can begin to discover the salient issues and concerns, challenges and rewards, and internal and external resources as we continue to listen to families articulating their caregiving experiences with Alzheimer's disease.

CHAPTER 3

METHODOLOGY

Methodological considerations for the design of this study were driven by several assumptions of qualitative research, including respect for insiders' perspectives and recognition of context and language as interactive with the meanings of experiences (Denzin, 1978, 1989; Glaser & Strauss, 1968; Lincoln & Guba, 1985; Maxwell, 1994). According to Rosenblatt and Fischer (1993) in their discussion of the theoretical perspectives of symbolic interactionism and family systems in relation to qualitative research, inductive methods such as participant observation and in-depth interviewing are especially powerful in research that seeks to understand the complexities of family experiences.

The inductive processes involved in making sense of the large set of narrative data involved in the present study tended to place *the data* at the center of the stage. However, it was important to include in the analysis process consideration of the extent to which the data addressed the issues identified through review of the literature, development of research questions, and discussion of theoretical concepts. In the Handbook of Qualitative Research (Denzin & Lincoln, 1994) chapter on case study research, Stake (1994) referred to the statement of these preliminary issues as the posing of foreshadowed problems by the researcher, while Rosenblatt and Fisher (1993) called this process theoretical grounding open to revision as data are gathered.

According to Janesick (1994) in her discussion of the complexities of the qualitative research process, the best metaphor for this inductive, free-flowing process is that of dance. She asserted that the spirit of dance captures the essence of qualitative design. Like a serious dancer, a qualitative researcher begins with a warm-up period in which tentative questions are raised and stretched and, perhaps, initial rapport is established in the research setting. After the warm-up period, like a dancer who immerses himself or herself in the movement of the dance, the qualitative researcher devotes his or her total energies to the interactive research milieu. The next phase of the research process involves an intentional withdrawal from the center of the stage and a systematic process of regaining perspective, like the dancer who breathes and stretches to cool down after the dance. As I conducted this research and articulated the findings from it, I sought to be true to the message of the dance: “to make understandable the familiar in a contextual, personal, and passionate way” (Janesick, 1994, p. 217).

In concluding this research project report, I discussed findings from the present study in the context of my research questions, in comparison to earlier research findings about issues and concerns, and in relation to applicable theoretical concepts. However, consistent with Stake’s (1994) assertion that the issues used to organize a study may not end up being those most useful in reporting the case to others, some of the issues that seemed important at the beginning of the research process were deemed less important than some of the elements that emerged unexpectedly from the data. Also applicable to the process of data analysis was Stake’s (1994) contention that the act of observing is

different from the act of reporting. Thus, I found that the content of the case developed in part during the writing process itself.

Included in this chapter on methodology are descriptions of the (a) inductive processes of inquiry used in approaching the study, (b) rationale for research design choices, (c) purpose and methodologies involved in Priscilla Blanton's Family Caregiving Research Project (Appendix A) from which the data were extracted, and (d) procedures used in conducting this particular study on the experiences of Alzheimer's families. Also included are descriptions of the qualitative analyses that were considered appropriate for making sense of the data. Finally, the basic assumptions of the qualitative approach to research that guided the methodological decisions of the study are discussed. Of course, discussion of the findings in relation to the research questions, scholarly literature, and theoretical concepts, along with additional insights and interpretation of these foreshadowed areas (Stake, 1994), have been provided in a later chapter.

Research Design

The approach used in conducting this study followed McCracken's (1988) four-step inquiry process, which he applied to the method of using the long, in-depth interview in qualitative research, as illustrated in Figure 3. In this model, the analytic domains are represented by the first and fourth steps, and the cultural domains are represented by the second and third steps. The first step of my approach, identified in the model as a review of analytic categories and the beginning of the interview design, included extensive review of the literature and development of preliminary interview questions. My second step,

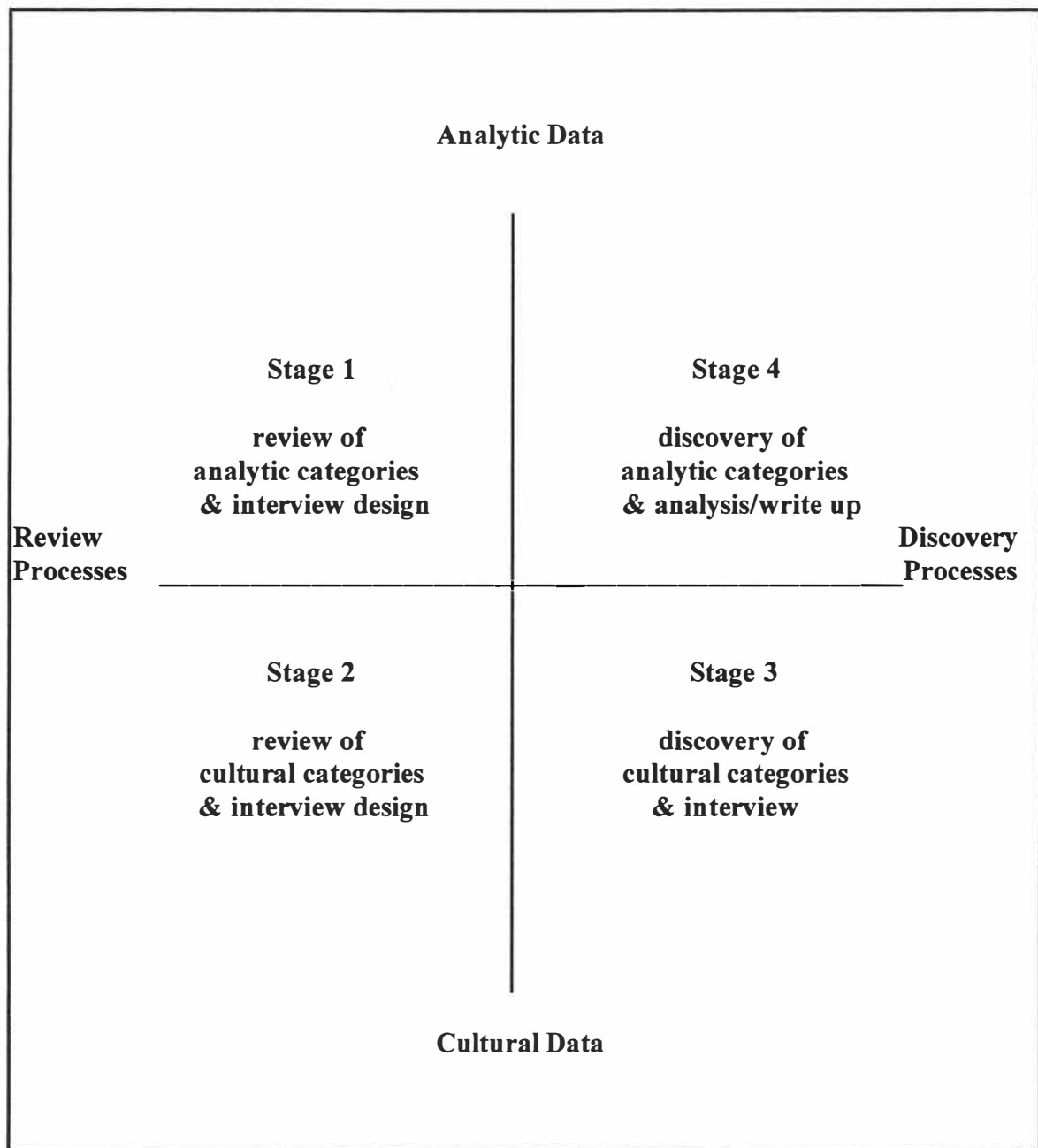


Figure 3. Long Qualitative Interview: Four-Part Inquiry Process

Source: Adapted from McCracken, G. (1988). The long interview. Newbury Park: Sage Publications.

labeled review of cultural categories, included systematic immersion in elder caregiving environments and the bracketing of those subjective experiences. The third step of my inquiry, identified in the model as exploration of cultural categories, involved collecting data in the form of audiotaped interviews and subjective field noted observations. The fourth step returned my attention to the analytic domain, identified in the model as data analyses and interpretation, and led to the creation of qualitative data displays--particularly caregiving time lines--and to the use of triangulation strategies, such as collaborative discussion of emerging themes to guide analyses and verify credibility of conclusions. My intuitive approach to this research project on family caregiving, like McCracken's (1988) model, was that of a natural flow from one step to the next, with the boundaries between steps overlapping and interactive. This flow has permitted a continuous movement through these four steps, refining my thinking and improving my ability to make more sense of my observations with each cycle of the inquiry process.

Definition of Case Study

A renewal of interest in case study research methodology has resulted from recent attention to rigorous standards for analyses of qualitative data (Creswell, 1998; Miles & Huberman, 1994; Stake, 1994, 1995; Weiss, 1994) and from reacknowledgment of the power of this model to address social science questions (Rosenblatt & Fischer, 1993; Stake, 1994). This interest in case study inquiry was reflected in the literature as discussions of both case study methodologies and case study analysis strategies (Creswell, 1998; Miles & Huberman, 1994; Moon & Trepper, 1996; Stake, 1994, 1995; Weiss, 1994;

Yin, 1989). Empirical studies in the gerontology literature that have reflected the usefulness of case study design include Harris' (1998) qualitative study of caregiving sons, High and Rowles' (1995) inquiry on decision-making processes for families who place a frail elder in a nursing home environment, and Kivnick and Jemstedt's (1996) study of resiliency in aging.

In a chapter in Denzin and Lincoln's (1994) Handbook of Qualitative Research, Stake (1994) identified three types of case studies, based on differences in the purposes of inquiry: (a) intrinsic case study, based on interest in understanding the phenomena associated with a particular case, for the sake of the case itself; (b) instrumental case study, primarily aimed at understanding an issue or advancing theoretical perspective, with secondary interest in the particular case; and (c) collective case study, with a focus consistent with the instrumental purpose of gaining knowledge/insight about phenomena associated with a larger system but extended to the study of more than one case. These three types of cases parallel Moon and Trepper's (1996) discussion of informal and formal case study categories, also based on research intention and design. According to their typology, informal (i.e., intrinsic) case studies are undertaken because of special interest in understanding a particular case, a method used typically in clinical action research. In contrast, they described formal (i.e., instrumental or collective) case studies as models designed to advance theory or knowledge about phenomena larger than the individual case. Moon and Trepper (1996) also discussed analytical and design differences associated with focusing on a single case versus selecting multiple cases for formal study. They noted that when a formal case study involves a single case, comparisons can be made only

within the case and against the literature. In contrast, when multiple cases are used, additional comparisons can be made across cases. Stake (1994) recommended that multiple or collective case studies usually involve no more than four cases. His assessment was that more than four cases, while perhaps increasing the breadth of comparisons, limits the depth needed to present fully each particular case.

Rationale for Design Choices

Critical decisions about the qualitative research design of the present study included determining the most appropriate unit of analysis to be the family, the most useful tradition of inquiry to be the case study, and the optimal number of cases to include to be four. These decisions resulted in a research design described by Stake (1994) as a collective case study. Stake (1994) noted that collective case study has the maximum potential for providing insight regarding a phenomenon or building theory. Moon and Trepper (1996) identified the ability to conduct cross-case analyses as a strength of formal, multiple case study design. Thus, I am confident that the research design decisions--using the family as the unit of analysis and a collective case study approach--provided the maximum potential for learning as well as capturing and representing the stories of the families who comprised the cases.

Using the Family as the Unit of Analysis

According to Moon and Trepper (1996), the first step in designing a formal case study is to select the unit of analysis, and Rosenblatt and Fisher (1993) recommended the

inclusion of two or more family members when the family system is the unit of analysis. Because at least two individuals in each family included in Dr. Blanton's study have been interviewed, using the family as the unit of analysis was determined to be appropriate methodologically. Part of the rationale for identifying the family system as the unit of analysis was the paucity of research available on caregiving in which the family was the unit of analysis (Pyke & Bengsten, 1996; Rosenblatt & Fischer, 1993).

According to Stake (1994), the conceptual responsibilities of qualitative case study include great attention to defining the boundaries of the case (i.e., the conceptualization of the object of study). Based on Stake's (1994) cited definition of a case as a bounded, purposeful system (Smith, 1978), a definition that parallels a family systems perspective definition of family (Klein & White, 1996), the decision to use the family as the unit of analysis (i.e., as a case) made sense. Further, Stake (1994) elaborated on the definition of a case as a bounded system to include working parts, subsections, and shared events--language that parallels the conceptual language of family systems. To extend the elements of a case to those of a family system, the working parts of a case would be the functional roles of family members, the subsections of the case would be the relational subsystems within the family, and the shared events of the case would be the process of family caregiving. Thus, using the family system as the unit of analysis (Rosenblatt & Fischer, 1993) was a logical design choice to make sense of the large set of narrative data from interviews with the 11 individuals in the 4 families selected for study.

Using a Collective Case Study Approach

The rationale for selecting a collective case study approach was two-fold. First, the purpose of my inquiry was to explore the impact of Alzheimer's disease on families, certainly an area of interest larger than the experiences of one particular family. Second, I wanted to be able to conduct both within-case and cross-case analyses, a process that added to the potential of this research to contribute to advancing theory and generalizations for understanding the experiences of caregiving families. Thus, while I expected each case to be of inherent interest and value, my research intent was to understand the complexities of a phenomenon larger than the experiences of an individual family.

Stake (1994) described this type of broad intent as instrumental and suggested it as most appropriate when the research goal is either to provide insight into an issue or to build theory about a particular phenomenon, with the case itself being of secondary interest. With primary interest in understanding the phenomena associated with family caregiving when Alzheimer's disease is present, I wanted my findings to have the maximum potential for contributing to an understanding of the experiences perceived and resources needed by other families in these circumstances so that policies and practices may be developed to accommodate those needs. Thus, extension of the study to include multiple cases, an approach defined by Stake (1994) as collective case study, allowed the findings not only to reflect an understanding of the processes and patterns observed in the families studied but also, potentially, to enlighten and help other families embarking on similar caregiving paths.

Procedures

Stake (1994) asserted that placing the “best brains available into the thick of what is going on” (p. 242) was a good strategy for approaching qualitative case study research. The reflective thought processes of those researchers who observe the phenomena in the field and who listen to what the actors have to say about their experiences are critical to the process of interpreting and making sense of the data (Stake, 1994). According to Rosenblatt and Fischer (1993), the in-depth, personal interview is the most common method for collecting qualitative data. McCracken (1988) encouraged using a deliberate, inductive process to develop research involving the in-depth interview, which was the primary data collection strategy used in this research project. Another data collection strategy used was observation and field notes, with observations about the interview environment and process recorded in reflective notes written shortly after each interview session. In addition to the data collected directly from participant interviews and field notes, I drew on my subjective reactions to other field experiences in elder caregiving, which are bracketed in detail in Appendix B. Although these bracketed experiences were not directly reflected in the data, they have been, as expected, part of the interpretive process of analyzing the data (Denzin, 1989; Glaser & Strauss, 1968; Stake, 1994).

The set of data used in this study represents a subset of the data collected from May 1999 through February 2000 in Dr. Blanton’s Family Caregiving Research Project, described in more detail in Appendix A and summarized in the next section of this chapter. Because the data for the present study were drawn from Dr. Blanton’s larger project, procedures for gathering data were bound by the parameters of that study. However,

since I have been part of Dr. Blanton's research team throughout the process, I was familiar with the design and intent of the larger study as well as the present study. In fact, I have conducted most of the interviews for the larger project so far, including all of the family members in the cases selected for this study. In this section on procedures, I have included a description of Dr. Blanton's larger study along with the methodological considerations associated with the larger project, systematic procedures for selecting cases for the present study, and qualitative analysis strategies and standards of verification that were employed. In addition, I have discussed some of the basic assumptions of qualitative research that have guided my research approach.

Description of Dr. Blanton's Family Caregiving Project

The purpose of Dr. Priscilla Blanton's on-going, qualitative study of family caregiving, entitled "The Impact of Caregiving to the Frail Elders in Families," is to describe families' experiences with caregiving to frail elders. Through in-depth, person-to-person interviews with family members involved in the caregiving process, the research team is attempting to identify stresses and rewards generated by caregiving experiences. Also of interest in this research effort is discovery of family processes and resources utilized by families in coping with the challenges of elder caregiving. The project was implemented in May 1999 and is expected to be completed by December 2000. The research team is headed by Dr. Blanton, Professor in the Department of Child and Family Studies at The University of Tennessee, Knoxville, with research assistance provided by

graduate students (including me). Appendix A includes the official form submitted and approved by the Institutional Review Board (IRB) of The University of Tennessee.

Recruitment of Participants. Potential participants for the project have included any family members involved in the caregiving process for a frail elder. A one-half page summary of the research project, available for distribution to potential participants, has directed interested individuals to contact Dr. Blanton for additional information and for scheduling interviews. Participants continue to be recruited through various community agencies and programs providing services to elders and their families in Knox and Blount counties in Tennessee. As of April 2000, 16 families had participated, with audiotaped interviews of more than 38 participants conducted. By the close of the project, the research team hopes to include data from approximately 25 families, with a minimum of two interviews per family. Whenever possible (including three of the four cases selected for this collective case study), three individuals in each family will be interviewed.

Informed Consent Procedures. Standard protocol has been observed for obtaining informed consent and for maintaining confidentiality, as noted in Dr. Blanton's official proposal and Application for Review of Research Involving Human Subjects, Form B (see Appendix A). Before each interview, participants have been given the opportunity to read and ask questions about the statement of informed consent, and the researcher has explained verbally the purpose of the research project, the procedures for securing the data, and the option to withdraw from the project at any time. All participants included in the present study have indicated their understanding that their contributions to this project

were made willingly, and the interview process proceeded only if participants seemed comfortable in sharing their experiences and seemed interested in continuing.

Issues of Confidentiality. All interviews have been conducted face-to-face with individual family members. Participants have been assured that data from one family member would be kept confidential from other family members and that their personal or family identity will be concealed in any written or oral presentation of the findings. They also were assured that the audiotapes were strictly for the purpose of note taking and that the tapes and subsequent transcriptions will be managed with appropriate care to preserve confidentiality.

Interview Logistics. The interviews, ranging from 1 to 2 hours in length, have been arranged at a time and location convenient for the participant, including options of the participant's home, work place, or public setting like a library or nursing home. Basically, the interview environment has allowed for reasonable privacy appropriate for sharing sensitive information and has accommodated the researcher's need to observe the participant in his or her naturalistic setting. All interviews used in the present study have been audiotaped, transcribed, and checked for accuracy.

Cognitive Mapping Activity. Before each interview, participants were asked to complete a cognitive mapping activity that involved using concentric circles to reflect connections of family members in relation to the interviewee. The form used for this activity originated as a sociographic tool used in educational research and appears untitled in Appendix A. The research team first agreed to present this cognitive mapping activity as a way to show the family in relationship to the care receiver. However, when the first

two participants placed the care receivers in the middle, very little data about the family as a whole was elicited, perhaps because of the participants' perceptions about who would or would not be considered part of the caregiving process. As a strategy to obtain more data about the family system, the directions for the mapping activity were revised so that participants were asked to start by identifying themselves in the middle and then placing other family members, including the care receiver, in relation to themselves. This revised procedure resulted in more useful data and was more effective as a warm up activity in beginning the interview process.

Demographic Data. As a part of the interview process, demographic data were obtained from each participant. Because participants sometimes moved into the telling of their stories during this process, the gathering of these data was included in the audiotaping and subsequent transcriptions as well as recorded on the demographic information form by the researcher. Added to the form since the initial implementation of Dr. Blanton's project was a section for grandchildren (see Appendix A for the most current form in use by the research team).

Interview Format. The format for the interviews was relatively flexible, allowing participants' stories to guide to some extent the narrative flow. However, two protocols of questions were developed as interview guides, one for caregiving family members and another for care receivers who were available for interviews. These guides were developed on the basis of the areas covered by the questions and prompts listed in Dr. Blanton's project and were refined by the research team as interviews proceeded (see Appendix A for the lines of inquiry used by interviewers). In all interviews, the areas

related to challenges and rewards as well as other areas of interest included in the interview protocol were addressed--but not necessarily in the same order as they appear on the interview guides.

Observational Field Notes. After each interview was completed, the researcher wrote reflective notes about the interview process, including details about the setting, the comfort level of the participant, and any other relevant observations about interactions observed between family members before or after the interview session. These reflective notes included the interviewer's intuitions, thoughts, feelings, assumptions, or other subjective speculations about both the interview process and the environmental context.

Research Team Meetings. Weekly meetings of the two-person research team for the present study--Dr. Blanton and me--allowed for discussion of perceptions and sharing of experiences with the logistics of the interview process. Also, discussion of preliminary findings was included in these meetings to generate understanding of the phenomena, identify salient thematic elements, and encourage exploration of alternative approaches.

Sampling Procedures

The data available in Dr. Blanton's study through February 2000 (when case selection occurred) included 12 families with Alzheimer's disease present, thus defining the parameters of the sampling frame for the present study as those 12 families. To aid in the process of selecting cases, a matrix of family characteristics was created. As suggested by Stake (1994) in his discussion of systematic strategies for selecting cases that provide the most opportunity to learn, the selection matrix included demographic and

family characteristic variables for each of the 12 families: (a) identified stage of Alzheimer's disease, (b) gender of care receiver, (c) family role and gender of primary caregiver, (d) family roles and gender of other family members interviewed, (e) care setting, (f) identified socioeconomic status, (g) number of interviews, (h) number of generations represented, and (i) interviewers' subjective assessment of interest (i.e., potential for learning). In the process of selecting the four cases from the group that included all those identified as Alzheimer's families, the goal was to achieve maximum diversity across cases, especially in terms of severity of symptoms, care environment, family roles, gender, number of generations represented, and socioeconomic/cultural backgrounds.

Selection of Cases. One step in the sampling process was to decide how many cases would be included from Dr. Blanton's data set. Following Stake's (1994) recommendation to limit a collective study to four cases, a collaborative case selection process, using the 12-family matrix, was used by the research team to identify the four cases offering the maximum opportunity for learning about the phenomena associated with Alzheimer's caregiving in families: Families A, B, C, and E (see Table 1). In making the final selection of cases, Dr. Blanton and I independently chose the same four cases as being most appropriate for inclusion in the sample.

Characteristics of the Sample. In terms of severity of Alzheimer's symptoms and the care environment, the cases selected for this study included four families dealing with various stages of Alzheimer's disease and with care receivers in a variety of care settings, with each case representing a different stage of Alzheimer's disease. Presented

Table 1. Case Selection Based on Sample Characteristics

Family/ Characteristic	A	B	C	E
Alzheimer's Stage	early	middle	pre-diagnosis	late
Care Rec Gender	female	female	female	female
Primary Caregiver	d-in-law	cousins	daughter	daughter
Primary CG Gender	female	female	female	female
Other Family	son	cousin	s-in law/g-daughter	g-daughter
Others' Gender	male	female	male, female	female
Care Setting	own home	assisted living	adult child's home	nursing home
SES	working	professional	professional	upper
#interviews	3	3	3	2
# generations	2	2	3	3
Interest	medium	high	high	high

first, as Case One, Family A was in the early stages with the frail elder still living in her own home alone. Presented second, as Case Two, Family C was caring for their frail elder in the adult child's home and was dealing with apparent early to middle stage symptoms, but without a formal diagnosis of Alzheimer's disease. Third, as Case Three, Family B had a frail elder in the middle stages of Alzheimer's disease, recently transitioning to an assisted living facility. Fourth, as Case Four, Family E was in the late stage of Alzheimer's disease with the care receiver still in a skilled care section of an assisted living facility, anticipating transition to a nursing home setting. Including this range of stages of the illness and care settings permitted a view of the caregiving experiences across the course of the disease and in several types of care environments. Among these four cases were 11

females and only 3 males. All care receivers and primary caregivers were female. Two of the males involved were sons-in-law and one was a son. Of five females acting as primary caregivers, one was a daughter-in-law, two were daughters, and two were cousins acting together as co-primary caregivers. The other three women interviewed as family members included one granddaughter, one cousin, and one care receiver. The other three care receivers, all female, were not available for interview. A total of 11 interviews (coincidentally, all conducted by me as the interviewer) were included in the sample, with a minimum of 2 interviews per family. There were three interviews each from Families A, B, and C, and two from Family E. Including the frail elders, three generations were represented in Families C and E while only two were represented in Families A and B. In terms of socioeconomic backgrounds, one family was identified as working class, two as professional or middle class, and one as upper class, based on self-reported demographic data about education, income, and occupation obtained during the interview process. One participant's cultural background was South American, but all other participants' backgrounds were relatively homogeneous, reflecting contemporary United States culture. Of course, as in Dr. Blanton's larger study, identities of families and individuals were protected by the use of pseudonyms throughout this document and by using references to family demographic characteristics only as needed to explain decisions about case selection. Care was taken to disguise clearly identifiable attributes of specific families and also to ensure that potential exposure and/or embarrassment of the family would be avoided. As noted by Stake (1994) in his discussion of ethics in qualitative case study research, those of us who are permitted to enter these private spaces of the world

voluntarily should use good manners and a strict code of ethics. The ethical standards guiding the procedures of this study have been consistent with Stake's (1994) belief that opportunity to learn *never* outweighs the importance of protecting participants' rights to privacy.

Rationale for Sampling Criteria. The rationale for maximizing the diversity of these sample characteristics was based on Stake's (1994) discussion of opportunity to learn about the object of study as a sampling priority. Creswell (1997) also discussed purposive case selection and suggested that using a variety of attributes related to the issue under study allowed for informative cross-case comparisons. Although Stake (1994) discussed representativeness of attributes as a criterion for case selection, he indicated that, for case selection, ultimately, the *opportunity for learning* from a case was a superior criterion to *representativeness*. Both of these considerations were reflected in the matrix criteria used to select cases for this study. Because of my primary interest in the phenomena associated with caregiving in Alzheimer's families and the extent to which these phenomena may be observed across families, rather than an interest in the phenomena available within a single case or single set of family characteristics, a diverse sample was expected to provide the maximum opportunity for learning. One advantage of selecting a diverse set of cases was the ability to get a cross-sectional view of the caregiving process across the various stages involved in the course of the disease. Another advantage of maximizing variability across cases was some control for similarities among cases due to sample characteristics such as socioeconomic/cultural influences or type of care environment. Cases also were selected on the basis of the opportunities for

learning about Alzheimer's families available from observational and interview data, as well as the subjective interest of these data. Stake (1994) asserted that enduring learning from the presentation of case studies occurs with the process of *encounter* by readers. As he described encounter, it involves not only didactic leaning but also experiential learning. In other words, readers' abilities to be not only intellectually responsive but also emotionally responsive to the case study material is required. As asserted by Stake (1994) regarding learning from the particular, insights on the human condition are found even when readers are well aware of the atypical nature of the cases.

Limitations of Sample. Of course, however, with only four cases included, generalization of findings to other Alzheimer's families was somewhat limited. However, because the goal of the study was more exploratory than explanatory, a predictive or generalizable model was not expected to emerge. On this subject, Stake (1994) argued that generalizations stemming from one case are probably stronger than any that come from showing the differences between two or more cases because there are too many reasons why one case would be different from another, regardless of how many demographic variables are similar. In other words, an inherent limitation imposed on the study by the purposeful diversification of the sample was an increased possibility for sampling error. Thus, any identification of processes or patterns that cut across these four cases is tempered by the possibility that such findings could be accounted for by the characteristics of these particular cases. Another limitation worth noting, highlighted by Groger, Mayberry, and Straker (1999) in their description of the limitations of their sampling of African-American family caregivers, some of the data about the phenomena

under study will be missing simply because of who chooses to participate, or, rather, who chooses to not participate. In spite of these sample limitations, within-case and cross-case analyses of these data have the potential for acceptable standards of verification (Creswell, 1998; Stake, 1995) [i.e., credibility or internal validity (Maxwell, 1996; Rosenblatt & Fischer, 1993)]. Part of the argument for accepting the trustworthiness or authenticity (Lincoln & Guba, 1985) of these data was based on the richness of contextual descriptions of the phenomena observed as elements of the caregiving processes in Alzheimer's families. As Stake (1994) pointed out, making generalizations is not an activity limited to researchers. Readers of this case study will certainly generate some of their own generalizations as they encounter the data. Weiss (1994) also commented on the tendency for readers to assume generalizations based on their interaction with qualitative data:

Case studies regularly imply generalization.... Readers take from case studies a sense of the case as exemplary, with general lessons to teach.

They believe themselves to be learning not just about particular people but about people who are like them, not just about particular situations but about a class of situations. (Weiss, 1994)

Thus, regardless of whether the phenomena revealed in the present study mirror exactly the experiences of other families, other families have the potential to learn from the reflections of these family members on their experiences.

Qualitative Analysis Strategies

According to Weiss (1994), analysis and reporting of qualitative interview data involves some form of initial sorting, followed by more definitive analyses, which he described as local integration and inclusive integration. The analyses applied to the data in the present study reflected both of these analytic processes described by Weiss (1994) in terms of qualitative analysis in general, as well as the more specific application of these strategies to case study research (Creswell, 1998; Stake, 1994, 1995; Yin, 1989).

Weiss (1994) noted that qualitative reporting usually reflects primarily either an issue-focused or a case-focused approach in describing what has been learned from the participants. Because the intent of the present study was to explore issues beyond a single case, the approach to reporting findings was a combination of these case-focused and issue-focused approaches. Another study that reflects an effective combination of case-focused and issue-focused approaches was Fox, Von Bargen, and Jester's (1996) study of the concept of distal violence in understanding the responses of families to a violent murder occurring in their usually quiet neighborhood.

Similarly, in the present study, the primary emphasis was on cases when describing families, followed by identification of issue-relevant meanings. This emphasis was consistent with Stake's (1995) assertion that the case study researcher seeks a collection of instances, hoping that issue-relevant meanings will emerge. For each family, the analysis process was completed, including the writing of the report, before beginning analysis of the next case. Once analysis was completed for all four cases, issue-relevant meanings were identified via cross-case analyses.

Coding Processes

As described by Weiss (1994), the sorting process for each case began as a systematic reading of the set of the transcripts for each case while listening to the audiotapes, making marginal notes, and highlighting substantive quotes. Independently, Dr. Blanton and I both worked through this initial sorting process for each family, generally focusing on one family per week. From our combined impressions and notes, we developed groupings or categories for related excerpts, termed excerpt files by Weiss (1994). As categories became too large or remained too small, they were divided or combined to accommodate managing the volume of material.

Local Integration. Using these initial categories as the foundation for the next step of the analytical process, local integration (Weiss, 1994), we attempted to make sense of the relationships among categories, seeking structures to link or order these grouped sets of quotes. In relation to case study analysis, Stake (1995) described a process that he termed categorical aggregation, which is analogous to the process of local integration. He noted that this phase of analysis involves identifying patterns or themes and then looking for correspondence between categories. This process of grouping, or aggregating, then results in a reduction of the number of categories. In the present study, this phase was carried out both independently and collaboratively, as Dr. Blanton and I continued to discuss the findings and to consider ways to describe the larger structures they reflected. During this process of local integration, or categorical aggregation, we began to develop ideas about the significant marker events and dominant images of the family's caregiving

story. We also noted relational patterns and processes that appeared as themes in each family's experience.

Inclusive Integration. During the next phase of analysis, which Weiss (1994) termed inclusive integration, a framework for presenting the data as a coherent story is expected to emerge. Stake (1995) described this phase of analysis as the development of issues, during which details that support patterns and themes are identified. The process of drawing assertions entails the researchers' making sense of the data and providing interpretations of the lessons learned from it (Lincoln & Guba, 1985; Stake, 1995). Assertions may take the form of personal views as well as concepts from theories or constructs used in earlier scholarly works. Yin (1989) termed this type of process holistic analysis. He described this phase of analysis as involving an examination of the entire case followed by presentation of description, themes, and interpretations related to the whole case. Of course, the end result of the analysis process is represented by the presentation of a coherent report. My experience in writing each case report is consistent with Weiss's (1994) assertion that a good report makes the writing look easy even though it never is easy. The time I spent in the writing process for each case was more than the sum of the time needed to put the words together. Certainly, the writing process for the present study represented a significant portion of the analysis process. For each case, I drew on the collaborative thinking processes involved in local integration and inclusive integration activities to compose a coherent narrative that both captured the essence of the family experience and reported observations about thematic elements (i.e., issues) for the case. As the narrative summaries for each family were completed and revised via a collaborative

process, thematic elements were observed across families. As structures emerged to link these elements, they were incorporated into the discussion and interpretation of findings.

Diachronic Framework: Turning the Story

Weiss (1994) suggested that a coherent story may represent a diachronic movement of experience through time or a synchronic capturing of elements of experience as a moment in time. Because the emphasis of the present study was on the process of caregiving over time, with particular interest in the influences of the disease process on family caregiving experiences, I chose to describe the results from a diachronic perspective.

Yin (1989) suggested that the investigator might narrate the report by using a chronology of major events followed by a more detailed description of a few of these incidents. In our analyses of within-case data, we found creation of a time line display of each family's caregiving story to be an efficient and useful way to both summarize the narrative data and view the compiled perspectives of family members. By integrating the data in this graphic form, we were able to identify marker events described by multiple family members, note consistencies and inconsistencies, and get a sense of the family's experience over the time period of their caregiving experience. This phase was also a combination of independent and collaborative thinking about the possible structures for building a suitable framework for understanding and interpreting the story of each family. Further, the overall structure for presenting the results reflected diachronic movement across the course of the disease process, with the first case representing family caregiving

experiences during the earliest stages of the illness and progressing to the fourth case representing experiences in the later stages.

Stake (1995) offered a list of 20 criteria for assessing a good case report. Of those 20 criteria, 11 are focused on the narrative description of the case, the development of the issues, the effective use of quotations and “sense of story” (p. 123) in the presentation.

Standards of Verification

Stake (1995) observed that the ultimate question for case researchers is, “Do we have it right?” He suggested that the triangulation of information across data sources and investigators relates directly to the development of accurate description. Another procedure that Stake (1995) suggested as a standard of verification was member checking after data analyses had been completed. However, he commented that he usually received little back from participants in this process. Thus, I elected not to use this procedure.

Rather than mirroring the positivist language of quantitative study--validity and reliability--Creswell (1998) emphasized the array of strategies and alternate terminology available to qualitative researchers to establish and articulate corroboration for their findings. According to Dukes (1984), standards of verification are based on a combination of procedures that involve both the individual researcher and collaborative colleagues. The collaborative processes of data analysis of the present study supported the standards of quality and verification through the triangulation of information from multiple family members and from the perspectives of both individuals involved in the process of data analysis. The standards of verification used in the present qualitative

research effort included specific procedures for establishing credibility, including triangulation and prolonged immersion in the field of study.

Triangulation. Triangulation represents a standard of verification whereby researchers use multiple sources, methods, investigators, and theories to provide evidence of credibility (Creswell, 1998). In the present study, triangulation was achieved in several ways. First, the combination of independent and collaborative data analyses served as triangulation of investigators. Second, the use of observations and field notes to supplement interview narratives served as triangulation of methods and sources. Third, the local integration phase of analysis used in this study provided a means of constantly comparing information provided by one family member to that provided by other family members, a process that served as triangulation of sources.

Immersion in the Field. Immersion in the field of study is another strategy suggested to enhance the credibility of qualitative study (Creswell, 1994). Even before I became interested in gerontological research, my family experiences related to elder caregiving already were a significant part of my life (as detailed in Appendix B). However, my preparations for conducting formal research began when I entered the Family Studies program at The University of Tennessee. Though I found no specific program of study for gerontology available at The University, I consistently used both curricular and extracurricular opportunities to expand my experience in the field of elder caregiving. While enrolled in a graduate level sociology course, I conducted an in-depth study of the literature on issues of aging worldwide, a research process that stimulated my interest in cultural influences on the experience of aging. In every course I have taken

since then, I have focused my study as much as possible on applications to the field of gerontology, finally narrowing my research interests to the impact of Alzheimer's disease on families. For a qualitative research class project, I developed my initial proposal and conducted two pilot interviews, experiences that solidified my commitment to using qualitative methods. In addition, my pre-doctoral research involved interviewing professionals in their roles as elder care service providers, including representatives of administrative, clinical, and referral agencies. I continued to learn more about qualitative research by being active in the departmental qualitative research group for several months, and I volunteered to participate as an interviewee in a qualitative research project. The most dramatic learning events for me were hands-on caregiving experiences in the community, which included volunteer work in an Alzheimer's day treatment program. For almost a year I provided direct care to frail elders in their homes, from which I learned more about the human spirit for survival than I ever had realized before; and several months as a floor nurse in a nursing home, where I actually went through the training program and became a certified nursing assistant (CNA). All of these experiences boosted my confidence in my ability to connect with people suffering from the symptoms of Alzheimer's disease. In short, for the past 5 years, I have been immersed in the field of elder caregiving.

Qualitative Research Considerations

Inductive methodologies and data analysis techniques are perhaps the most appropriate approaches for addressing questions related to complex human experiences

like those of Alzheimer's families because the rich, thick data (McCracken, 1988) produced by inductive processes provide strong bases for understanding human experience (Fisher, 1989; Hendricks, 1996; Lincoln & Guba, 1985). Rosenblatt and Fischer (1993) contended that using qualitative methodologies to study families is grounded in the theoretical perspectives of symbolic interactionism and family systems, bases for understanding the essence of how families experience events. Certainly, the family systems theoretical perspective lends itself well to qualitative methodologies because the detailed narratives are helpful in understanding the complexities of family dynamics (Gubrium, 1988; Hendricks, 1996; Rosenblatt & Fischer, 1993), and the symbolic interactionist framework reflected in the work of Chicago school social scientists (Denzin, 1978, 1989; Thomas & Znaniecki, 1958) is inherently connected to some of the basic assumptions of the qualitative approach (Fisher, 1989; Maxwell, 1996).

Because of assumptions inherent in inductive design, it is clear that a qualitative researcher must be willing to take the time to listen and to understand the contextual details of participants' lived experiences. According to the principles of grounded theory (Denzin, 1989; Glaser & Strauss, 1968), some of the basic assumptions that drive the methodology of a qualitative research process include (a) that power in the research relationship is shared between the researcher and the participant, (b) that contextual elements of experience cannot be separated from the reality of the experience, and (c) that language of the participant is integral to understanding their experiences. In the process of considering these assumptions and how they relate to my research interests, I have discovered the nature of my attraction to qualitative research methodology. In this

section, I have explored these assumptions in terms of their methodological implications and have related them to the context of my own experiences.

Assumption that Research Power is Shared

A basic assumption of the qualitative research approach is that research power is shared, meaning that the researcher assumes a collaborative role with the participant in the research relationship (Denzin, 1989; Maxwell, 1996). Together, the researcher and participant endeavor to explore the phenomena of the participant's lived experience, unlike the researcher-subject relationship that is characteristic of a postivistic research approach (Rosenblatt & Fischer, 1993). The qualitative researcher does not know ahead of time what structures or meanings he or she is looking for but rather hopes to discover or understand the meanings or truths as they are understood and constructed by the participant (Glaser & Strauss, 1968). Ultimately, the researcher recognizes that he or she is not an expert but rather a novice, deferring to the knowledge available from participants' perspectives (i.e., allowing participants to take the lead most of the time).

The methodological implications of this assumption are reflected in the specific strategies used by qualitative researchers in accessing the data environment, including strategies like field observations (Jorgensen, 1989) and in-depth interviews (McCracken, 1988), as used in this study. These strategies are consistent with the phenomenological assertion that researchers should take care to minimize their disturbance of the research setting in order to preserve access to subjective data and to the dynamics of the phenomena as much as possible (Denzin, 1989). Because my perspective on life in general

is egalitarian, it makes sense to value a research relationship where the observer and the observed are equally important in the discovery process.

Assumption that Context and Experience are Inseparable

Another basic assumption of qualitative research is that the contextual elements of experiences are inseparable from the realities of those experiences (McCracken, 1988).

The interactive dynamics of lived experience imply movement through time, with development affected by contextual variables. In other words, a singular reality or truth does not stand still to be measured and described as it is perceived by a researcher. Instead, the phenomenological experiences of interacting people are inherently influenced by the context of those experiences (Denzin, 1978; Lincoln & Guba, 1985).

The methodological implications of this assumption include the need for the researcher to utilize subjective observations over a relatively long period of time and give attention to participant interpretation and insight (Denzin, 1989; Jorgensen, 1989). As a researcher, I am aware of my own need to operate with a sense of history, continuity, and movement in relation to experience. Consistent with the idea that context matters, I seek understanding the connections of my experiences over time and recognize patterns within the context of my life.

Assumption that Language and Experience are Integral

A third basic assumption of the qualitative approach is that language and experience are integral, which means that the human capacity for making sense of the

world is both restricted and symbolized by the parameters of language (Gubrium & Holstein, 1990; McCracken, 1988). In other words, the perspectives of participants, conveyed in the language of their own words, are essential to understanding the phenomenon of interest. If language is the vehicle by which human beings articulate the meanings associated with their experiences, it follows that making sense of the world is based on the words we use and that, therefore, reality is a social construction (Zeller & Farmer, 1999).

The methodological implications of this assumption are evidenced in qualitative researchers' respect for the exact words of participants (McCracken, 1988), most often insisting on audiotaping or videotaping to record precisely the words and contextual nuances of their interactions and relying on interpretative insights and intuitive thought processes to understand and present results of their studies (Denzin, 1989; Maxwell, 1996). I personally acknowledge the beauty and power of language, and I believe that language profoundly shapes meaning. Thus, seeking to understand phenomena through the exact words of the people involved appeals to me as a researcher.

In reporting the results of the present study, I hope that my best thinking has allowed me to tell the stories of these families well enough to convey the essence of the caregiving experiences and the lessons they may offer. However, I agree with Stake (1994) that the stories we hear as case researchers exceed anyone's knowing, *anyone's telling*, and that what we learn from these stories is always more than we report.

CHAPTER 4

RESULTS

The narrative data provided by informants in these four families were extraordinarily rich and productive as contributions to understanding the experiences of families involved in caregiving for a cognitively frail elder. Three interviews were conducted in three families and two in another for a total of 11 interviews. Because the unit of analysis used in describing and interpreting the findings is the family, articulation of the results begins with a contextual case description, followed by an expanded story of the family, and finally a thematic analysis of each family, or case, in terms of the relational experience of caregiving.

Contextual Description of Cases

As a brief preview of the four cases included in the present study, the following section provides a brief description of the contextual factors for each of the four families studied. Family demographic characteristics, such as age, gender, and family roles of caregivers and care receivers, as well as other contextual factors, such as stage of Alzheimer's disease and length of caregiving experience, have been included.

Case One: Alma's Family

Case One was the family of 82-year-old Alma, diagnosed as being in the early stages of Alzheimer's disease. Three informants--Alma, the care receiver; Lou, her

daughter-in-law; and Lou's husband Vern (Alma's son)--were interviewed in their homes, and the data represent the perspectives of two generations, including the care receiver. Alma was still living at home alone, but her symptoms of cognitive decline that started approximately a year earlier had become pronounced enough for Lou and her husband to agree that she needed to move in with them. With her in their home, they could make sure she ate "at least one good meal a day" and that she would have more social interaction with family members. They also agreed that Alma was too independent and strong-willed to move until she was ready. At the time of the interviews, they were hoping that Alma would agree to come stay with them for the winter. Lou projected that if she came to them and saw how well she was cared for, she would be willing to stay on after winter.

Case Two: Cora's Family

Case Two was the family of 75-year-old Cora, undiagnosed but reportedly suffering from significant symptoms of cognitive decline, "just like" those of her husband for whom she had cared first at home and then in a nursing home for several months before his death approximately 3 years before the time of the interviews. Three informants--Caroline, Cora's youngest of two daughters; Bob, Caroline's husband (Cora's son-in-law); and Maria, Caroline and Bob's adopted teenaged daughter--were interviewed, two at the public library and one at the place of work. The data gathered were from the perspectives of two generations--three counting the care receiver. Cora was living in her daughter's home at the time of the interviews, an arrangement intended to last only a few

weeks but which had turned into 7 months. Cora had fallen four times during the last several years, most recently at Caroline and Bob's house. After her last fall, Cora could not remember falling at all and insisted that her injuries suddenly appeared as she sat in her chair.

Case Three: Belle's Family

Case Three was the family of 84-year-old Belle, diagnosed with multiple health problems including leukemia as well as with middle-stage Alzheimer's disease. Belle was unmarried and both of her parents were dead, leaving her with only cousins as family. Three informants—Mattie, Belle's first cousin; Nancy and Becca, Mattie's adult granddaughters (Belle's third cousins)—were interviewed, two in their homes and one at a restaurant. Also, I had the opportunity to meet care receiver Belle. The data gathered were from the perspectives of two generations, including the care receiver. Belle had been in an assisted living environment for almost 1 year at the time of the interviews, with multiple moves from hospital to nursing home and back to assisted living. The unique aspect of this case was the identity of Mattie's granddaughters as co-caregivers, acting as a team to help their grandmother as much as to help their elder cousin.

Case Four: Elizabeth's Family

Case Four was the family of 82-year-old Elizabeth, diagnosed as being in the late stages of Alzheimer's disease, having been in an assisted living/skilled care environment for 15 years. Two informants—Liz, Elizabeth's only daughter (and only natural child); and

Lizbeth, Elizabeth's granddaughter (Liz's youngest of two daughters)—were interviewed separately but on the same day at their home. Three generations are represented in this case counting the care receiver. This family's experience offered ample opportunity for learning in that the perspectives of informants covered such a long period of involvement. To illustrate, 22-year-old granddaughter Lizbeth was in elementary school when her grandmother's symptoms first became apparent to the family, and she expressed her sense of loss for not ever having the chance "to be an adult" with her grandmother.

Case One: "My Very Best Friend"

"She's like a mother to me, she's not like a mother-in-law. I've been with the family since I was 16 year old, I mean, and we've been through a lot together, she and I both," recalled Lou, 50-year-old daughter-in-law with primary care responsibilities for her husband's 82-year-old mother, Alma, diagnosed as being in the early stages of Alzheimer's disease. When Alma's youngest son died two years ago from a heart attack at age 48, Lou "stayed right with [Alma]...crawled right up in the bed with her because she wouldn't rest and I told her, 'Come on, let's go to bed,' and I just crawled right in the bed with her and then we laid there in the bed and talked."

Although one of Alma's three daughters, 56-year-old Violet, lived in a nearby town and regularly came to clean her mother's house, and one of Alma's several granddaughters called her every day to check on her, Alma depended on her daughter-in-law Lou more than anyone else. As Alma remarked about her affection for Lou, "She seems almost like my young'un." According to Lou's husband, Vern, a 53-year-old sheet

rock contractor and the youngest of Alma's three sons still living, his wife loved his mother as much as he did, "maybe more." When asked who came to see her, Alma said, "My daughter, she...don't get up here too often, but she comes once in a while, and, of course, [Lou]...she comes pretty often...more than anybody, I guess." In fact, Lou was usually the one who took Alma to the doctor, handled her paperwork, and served as her main source of emotional support.

A day that Lou described as "the day that blessed me," Alma was sitting on the couch beside the desk where Lou was going through her bills and other paperwork when her mother-in-law remarked:

I need to tell you that you are my very best friend. There's not a child that I have that could tell you how important it is and how much you've meant to me. I need to tell you this. I've been thinking about dying. It's just something that I need to say to you, and I don't want, my kids couldn't say it like I can say it.

Lou recalled that she just had to turn away and wipe her tears because "it's like she said good-bye to me." Lou felt that Alma's recognition of their closeness and their bond of friendship "meant it all," explaining,

That was the day that I, that blessed me...and she's still in her right mind to the degree that she knew what she was talking about. If she died tomorrow, in a few hours, that's something that I'd know. I'd know beyond anything that she and I knew that, knew that me and her were really close and good friends. And I think she treats me like that.

When asked how she came to be the “one who’s responsible” for the caregiving, Lou’s response was, “I guess her, [Alma] herself...and just me being close...[Alma] just says, ‘The kids can say something and I’ll ask [Lou].’” Lou explained that she is not the “sole caregiver” but rather “just the person that does the messages,” keeping Alma’s six living children and their families informed of both any changes in Alma’s condition and any decisions that need to be made. Lou commented on her view of her caregiving role:

I just relay the message to everybody else. “This is what your mother is doing.” I call them when I’m taking her to the doctor, if there’s anything, any change. They get mad if I don’t call them. I just treat it like if it was my mother, and if I wanted, if I was a long way off and there was somebody here caring for my mother, I would want to know if you took her to the doctor, I would want to know this.

Alma’s son, Vern, who had power of attorney for his mother, described his role as the one who did “the muscle part, if there’s anything...she needed, anything, she’d call me, and I would try to do it immediately,” but that he did not see himself as “a caregiver.” He added that he also tried to “support [Lou] 100 percent.” He offered an example of how he saw himself in relation to his mother’s needs, “If she hollers, ‘I need my field bush-hogged,’ I go as quickly as I can and bush hog the field. If she needs firewood, I run over and get firewood and get it in the house.” He also made it clear that, if his wife asked him to take his mother to the doctor, he would “do it immediately” without question. Vern felt that the reason his wife was “as involved as deeply as she [was]” with his mother’s care was that “she’s close and she wants to do that,” and he referred to his wife as “the

Three Years Ago

This family's caregiving story began approximately 3 years before the time of the interviews, when Alma's second husband, Jay, died and Lou "became extremely close to [Alma]...stayed with [her] continuously and babysat her...helped her with all the paperwork," as reflected in Figure 4. When Alma's youngest son died only a year later, Lou "just ran right to her, to be with her," and since then has remained her closest confidante and friend, the one who "knows [her] as good as anybody." Being in such close contact with her mother-in-law, Lou has been the "one that notices anything, any change or anything," and, therefore, she has been the one most aware of Alma's cognitive decline, reassuring Alma that she will care for her as long as she is able and keeping the other family members informed.

Trip to Florida

According to Lou, Alma's cognitive problems became really noticeable about a year prior, just before Alma was to travel by air to see one of her daughters in Florida. Lou was worried about her mother-in-law's memory problems and how she would manage the unfamiliar circumstances of air travel, strangers, and changing planes. As she recalled her concern, "I knew her memory was really getting bad then, and I couldn't get anybody to really understand it. So I debated about getting a ticket myself and just going with her because that's how afraid I was." Instead, she arranged for the airline staff to provide special assistance in the process of changing planes in Atlanta and hoped for the best. Apparently this travel experience was confusing and frightening because, when Alma

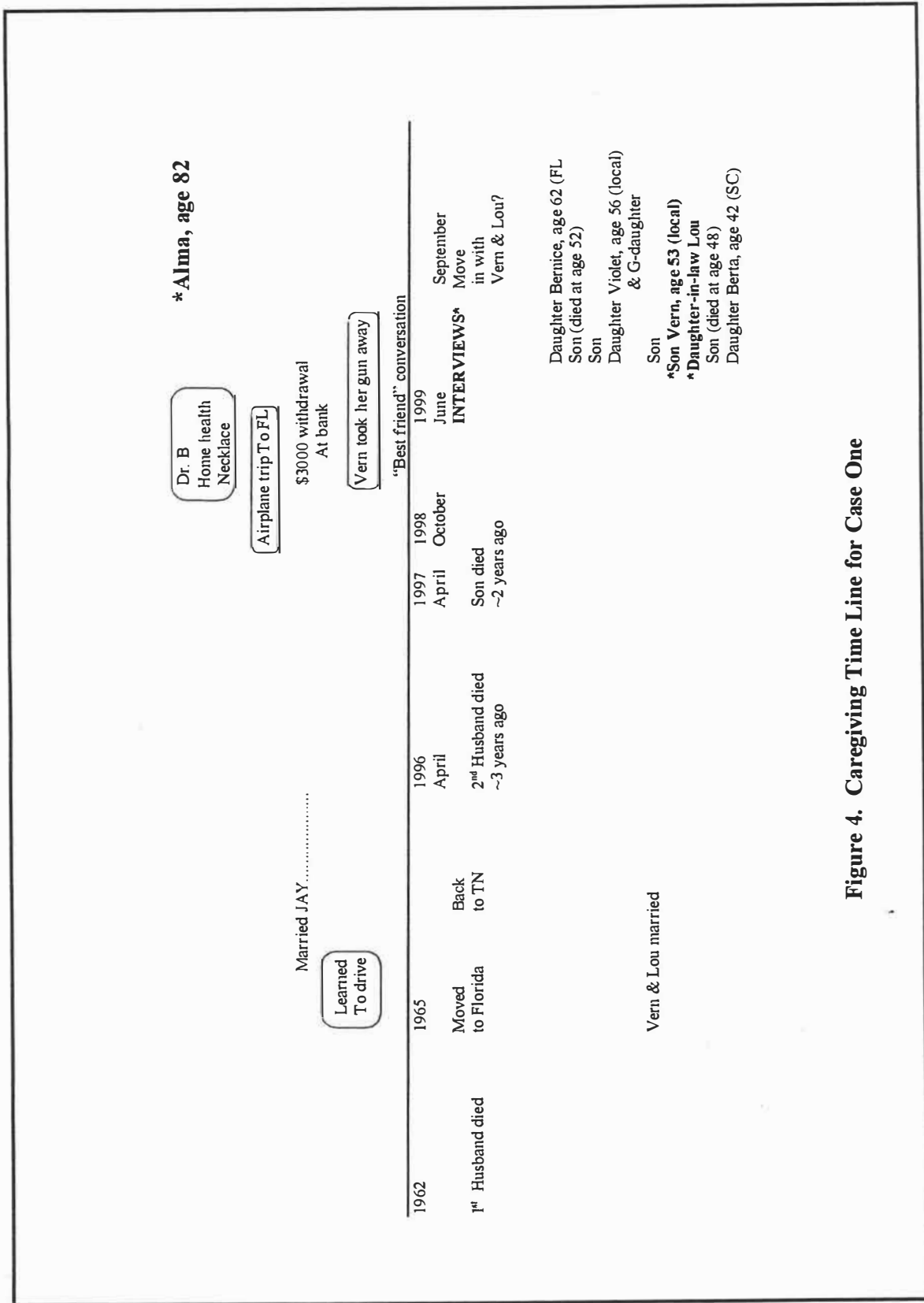


Figure 4. Caregiving Time Line for Case One

returned, she said to Lou, “I never want to go on a plane ever again.” It was then Lou realized that having to change planes on the way had been too much for her: “They took her and put her in this wheelchair and rushed her to another plane, and in between that time she’s forgetting where she, what her destination is, and she’s trusting total strangers.”

While she was with her family in Florida, they had a party to celebrate her upcoming 82nd birthday. They were puzzled when Alma insisted that she was going to be 83 years old, not “82” as written on her cake. They became frustrated when they realized that Alma could not be convinced otherwise, an experience that provided their first opportunity for insight regarding some of the cognitive difficulties about which Lou had been trying to tell them. When Alma returned to Tennessee, her first question for her daughter-in-law was, “How old am I?” and when Lou explained that she would be 82 in a few weeks and offered to get out her birth certificate to confirm the date, Alma relaxed and took Lou’s word as the truth. As Lou later explained to the daughter in Florida, who was upset that her mother would so readily believe Lou’s word after the frustrating process they had gone through in Florida to try to convince her, “I’m with her all the time, I don’t tell her things that’s not something really important. When we talk, things are pretty serious. And I never tell her a lie.”

She Needs to Come In Over Here

Since the trip to Florida, Lou had noticed a progressive decline in her mother-in-law’s ability to take care of herself in terms of eating, personal hygiene, remembering appointments, and other daily activities. Alma’s family decided that her confusion was

significant enough that someone needed to be with her all the time, so for a few weeks Lou and her husband and one of the daughters took turns staying with her at her house.

As Lou recalled:

But now [Violet] came and stayed with her when this first started happening, we had [Violet] come up and stay and I guess [Violet] stayed, what, two weeks? And we'd go down on the weekend and we'd stay on the weekends all the time. She had three meals a day. But she snapped out of a lot of it.

Even though Alma seemed more stable after a few weeks, and the family stopped staying with her all the time, both Lou and her husband felt that the best solution would be for her to move into their home where they could make sure she was eating at least one meal a day and having more social contact with other family members. As Lou remarked, "I know it would work if she was to come in over here, but we can't move in over there. She needs to come here." Lou recognized Alma's need to hold onto the familiar surroundings of her home, stating, "Her house is her haven." However, Lou demonstrated that she understood the doctor's advice to try to get her to move before she declined too far mentally, as Lou explained,

She needs to move into it while she's got some thought because if we take her from her environment and move her into my house and her not aware of everything around her, then it's going to be like, it's going to really be bad. She needs to be used to the place and start calling it home so that when she does go down, she's at home. I think if we get her here in the

winter and she sees how well she's cared for, she'll not go home. But I haven't got her here yet.

Being the "independent," "strong-willed," "home person" that she was, Alma continued to refuse their invitations, saying, "I don't want to leave home." Vern summed it up when he said, "I don't know how in the hell we're going to get her in here."

Trying to Get Some Help

Since Lou and her husband could not seem to convince her to come into their house, Lou hoped that Alma's doctor would provide the "dynamite" that Vern thought it would take to get her to move. The doctor's request that home health services visit Alma did not work to get her to move, but the home health representatives convinced her that she needed a telephone-based medical alert system.

The Doctor and Home Health. Lou called Alma the morning of her appointment with the neuro-psychologist to remind her to get cleaned up and to be ready, saying, "Now, I want you to go right now and get your shower and wash your hair. Because it's very important that you look as good as you can look, seeing Dr. B, 'cause that's how they evaluate." Even with Lou's phone call reminder, Alma did not remember to clean up and went to see the doctor with, as Lou described it, "a bad body odor." In a private conversation with the doctor, Lou explained that she had not been able to get her mother-in-law to take a bath, in spite of efforts to remind her and make sure she had hand rails in the tub as reassurance for her fear of falling. Lou said, "That's when they started the home health," but that strategy did not work the way Lou had hoped. Before the home

health visit, Alma's daughter Violet had come through and cleaned house and done laundry, leading the home health nurse to think, "This a woman who takes care of herself," and conclude that she was not beyond functioning on her own. Of course, Lou was frustrated with the process because she had hoped home health would tell Alma she could no longer stay there in her home alone.

The Medical-Alert Necklace. The one thing that was accomplished through the support of the home health group was getting Alma to agree to wear a medical alert necklace. Even so, Lou was not convinced that the necklace system would do much good, explaining that she felt that if Alma were having a problem serious enough to need help, she would be confused to the extent that she would not remember how to use it. Likewise, if her mind was clear enough to remember how it worked, her mother-in-law would be too cautious about asking for help and still not press the button. As Lou said, [Alma's] the type of person that, if she has any right mind at all, she'll think—she measures things on a low scale—that she doesn't need help. So, therefore, if she's not going to push it because she can do it, but if she needs help and she can't remember to push it, it's still not going to help.

Earlier, Lou had tried to convince her mother-in-law to wear a medical-alert bracelet to serve a similar purpose. Lou recalled her conversation with Alma about the bracelet:

And I already talked to her about putting the bracelet on her hand. That's before they come up with the necklace. And I said, "I do want to put a bracelet on you." And she said, "What for?" And I said, "Well, if this was to happen say, when you went to the grocery store, if this was to happen, I

would like to know—I would not want you to be frightened.” And I said, “It’s bound to be scary.” So I said “I just put my name and phone number and everything on the bracelet, and then if anybody—you know, anything, then someone will help you.”

However, since the home health nurse had convinced Alma that she needed the necklace and telephone system, Lou said, “That’s all I need to know. If you think you need it, then you need it.” Lou proceeded “to inform” Alma’s children about their mother’s wishes, and they agreed to share the expense of the medical-alert service, which came with a large-button, talking phone that Alma enjoyed demonstrating after her interview.

Family Caregiving Decisions

During the past year, the family had made several decisions regarding Alma’s care. Besides starting with a medical-alert telephone service, Lou and Vern had taken her gun away (on the advice of the neuro-psychologist). They had decided that they would not take away her car, even though they hoped she was not driving (at least not when she felt bad).

Taking Her Gun Away. Vern said he had caught his mother “in a weak moment” and talked her into letting him take her gun away. He said the doctor had warned them that her mental condition was unpredictable enough that she might mistake even a family member’s coming to visit as a dangerous intrusion and hurt someone. Apparently she subsequently had been upset about giving up her gun, complaining to other family

members that Vern had taken away “her only protection,” but Alma had not confronted either Lou or Vern about the gun again.

Not Taking Her Car Away. Even though Lou said she did not think Alma was driving anymore, Vern commented that he “saw her in town the other day,” and Alma, herself, claimed that she was still driving to go get groceries. Lou explained their thoughts about deciding not to take her car away yet:

We haven’t taken her car away from her. But she has, more or less, quit driving. And so she really doesn’t do the driving anymore. But, we just don’t take it away from her. She panics over that when she doesn’t have her car. I’ve been noticing that she just doesn’t drive when she feels bad.

Having the car in the driveway was a symbol of her independence, as it would be for many people. The car was especially significant for Alma because, after the death of her first husband, teenaged son Vern had taught her to drive, which he described as “an accomplishment for her really and truly.” As Alma bragged about how her son had helped her during that difficult period: “I don’t know what I would have done without him ‘cause, you know, when their daddy died, why shoot, I was left stranded. I couldn’t do nothing. Couldn’t drive a car or nothing.” Vern recalled his matter-of-fact feelings about helping his mother during this period:

At the time, my mother did not drive whatsoever. Well, I was 16. Just gotten my license, so I was the chauffeur. She said that I had to become the head of the house...but I don’t remember it. But at any rate, I do the

chauffeuring and probably in about a year, I said, “Hey, you’re going to have to learn to drive.” So I taught her how to drive.

Remembering Jay

Vern said he believed that his mother had been “happy” with her second husband, Jay, and that he had been “extremely, extremely good” to her. Vern and Lou agreed that Alma had begun to think and talk about Jay more lately, and she had shared with Lou that, even though she knew he was dead, she had sometimes been thinking “he’s actually there.” She said, “I know he’s not. I know that he is dead, I know all of this, but it’s so real, [Lou], and he’s there...I’m not crazy yet...but I do this so much.” Lou comforted her mother-in-law with the response, “Well, that’s because you loved him.” When Lou shared this event with the doctor, the doctor noted that Alma’s hallucinatory experiences were probably indicative of the Alzheimer’s disease process and that they might progress to the point that she would actually believe her husband was there.

“Usually whatever she wants to talk about mostly, and here lately she’s been talking about my stepfather and the good times they had,” was Vern’s perception of his conversations with his mother. When her first husband died, Alma still had three of her eight children at home, and even though she had not been looking to get married again, she said she “couldn’t have found anybody better” than Jay. She recalled her beloved Jay’s proposal of marriage and her response:

I love you but I can’t marry you, I’ve got all these kids and everything, and
I wouldn’t have them hurt for nothing and I wouldn’t want them to hurt

you and, you know, stuff like that. He said, “Well now, that’s not a problem. We ain’t going to hurt nobody.” He finally talked me into marrying him. And I’m glad he did.

In further evidence of her recent focus on Jay, she continued reminiscing,

I still miss him a lot. I don’t reckon you ever quit missing them. He was a good man, though, he was a good man. I’s laying in there last night trying to go to sleep and I couldn’t. I just kept a thinking, you know, and I was thinking about him and about how good he was to us all. Now he wasn’t just good to me, he was good to my whole family. He was.

Analysis of Case One

Three themes that emerged in the narrative data of this case included the themes of friendship between Alma and her daughter-in-law Lou, protectiveness of Alma’s sense of dignity, and recognition of Alma’s experiences of loss. The remarkable amount of data offered by this family reflected the influence of Appalachian mountain values on caregiving responses and revealed the sense of pride and closeness that characterized their family.

Theme of Friendship

The strongest theme that emerged in these interviews was the strength and closeness of the friendship that Lou and Alma shared. All three of the informants talked about this reality. Lou’s description of the conversation during which Alma told her that she wanted her daughter-in-law to know how much their relationship meant to her, that

she was her “very best friend,” as “the day that blessed me” illustrates the significance of their close friendship. Lou had been with her, comforting her with her words and her presence, through many difficult times over the years. Lou remarked,

I’m glad that I could help her and I’m glad that she has a person that she can talk to, really talk to that’s not family. It’s like that day that she told me that I was her very best friend. She meant that because she’s shared things with me that she hasn’t even shared with her children.

Anybody Can Break. Lou’s description of her relationship with her mother-in-law in terms of the closeness of friends emphasized the importance of being able to reveal her vulnerabilities in ways she could not with her children. To further explain, Lou said, “I mean she shares intimate feelings that she’d had about things, she shared with me, and she does not share with her family.” Alma revealed to Lou about the way her family perceived her, “They think I’m tough,” to which Lou replied, “Well, you’re tough, but you’re not that tough. Anybody can break.”

Nursing Home Promise. Another important aspect of their friendship was Lou’s honesty with Alma and the sense of trust that had been built in their relationship by that honesty. The daughter-in-law’s assertion that she would “never tell her a lie” was demonstrated in her interaction with her mother-in-law about the possibility of going to a nursing home. When Alma asked Lou to promise that she would never put her in a nursing home, Lou responded with genuine honesty, “As long as I can, I’ll take care of you, but if it’s something where you need special care, I may need to put you in a nursing home

because there are some things that I cannot do. And I need for you to understand that.”

Remarkably, Alma replied that she did understand and agreed to trust Lou’s judgment.

If You Had Cancer. Also a reflection of the level of trust in their relationship, Alma shared with Lou that she was afraid that she had cancer because of the pains she had been experiencing in her abdomen. Lou, in her straightforward and honest manner, assured her mother-in-law, “If you had cancer, I would tell you. If you had cancer, I would tell you because, if it was me, I would want to know. And I would tell you and I’ll treat you just like I would treat myself. That’s something that would be important to me.”

Empire State Building. As Vern spoke of his perception of the bond between his wife and his mother, he referred to his wife as “the most precious human on earth,” revealing a tender side not always apparent in talking to a middle-aged, male interviewee. Further, he demonstrated his genuine appreciation for his wife’s close relationship with his mother when he commented on one of the rewards he perceived about the caregiving experience:

Seeing her with my mother like that. If I owned the Empire State Building and you could say, “Well, which one’s better, owning that or knowing that your wife loves your mother that much,” it would be that, it’s incredible.

Vern admitted that he depended on his wife to motivate him to do what he knew he should do for his mother, saying that his wife had reminded him just that weekend: “Call your mother,” adding, “I count on my wife, now I do count on her a lot, and she carries the hard load, in other words, the chores that is hard for me a lot of times, she’ll carry that without me even asking her to.”

Theme of Protectiveness

A second theme that emerged was the protectiveness of both Lou and her husband toward Alma. While both of them spoke of how “strong-willed” and “independent” Alma was, they wanted to protect her from any experiences that they thought might diminish her sense of dignity. Lou described her husband’s role as power of attorney as the “overseer of the money and things like that” and described an incident where one of the grandchildren had taken Alma to the bank to withdraw \$3000 as a loan. Lou followed through with the bank, requesting to see the paperwork so that she could make sure that Alma had signed for the withdrawal, which she had, but Lou expressed her concern about Alma’s vulnerability in a situation like that and wanted to protect her from anyone who might take advantage.

We Haven’t Told Her. Lou said she had decided that it would be better to not tell Alma that she had been diagnosed with Alzheimer’s disease because Alma had told her once, “Of all things, I’d never want to get that. I never want to be that way and lose my mind.” The family had agreed to go along with Lou’s decision about keeping the diagnosis a secret. Lou recognized the difficulty of keeping this secret from Alma, but at the same time she felt the importance of protecting her dignity, stating that she was afraid knowledge that she had Alzheimer’s disease “would destroy her.” Lou spoke of Alma’s awareness of her cognitive problems and Lou’s explanation to her mother-in-law:

She knows something’s wrong and she knows that she has a problem with memory. But she asked me what it was. And so, I try not to lie to her, but

I don't tell her it's Alzheimer's. I explain to her that there are blood vessels in her brain that are rupturing, and...for a moment--she will forget.

Also evidence of their trying to protect Alma was that Lou and her husband both indicated that they never tried to tell Alma she was repeating herself, even though it sometimes seemed "like a broken record," not wanting to upset or embarrass this "tough" and "special lady."

Until She Says, "I Cannot." In relation to trying to convince Alma to move in with them, Lou and Vern had tried inviting her to supper or to stay overnight only and felt confident, if she would "come for the winter," they could get her comfortable with the idea of staying. Lou remarked, "Until she gets to that place where she says, 'I cannot,' we have to do it like it is," meaning allowing her to live in her own home and depending on them to check on her there. Lou stated that her greatest concern about this arrangement was

worrying that I'm not going to be there when she needs me the most. That bothers me and I have cried about that...I don't have time to do it all, I mean, you know, do it every day...stress-wise it would be better on me 'cause I worry even though I don't go by there, I still worry about her. I mean, it's on my mind all the time. I have to keep pushing it to the back, you know. She's being checked on. It's not like I'm totally out there with her all by myself.

Likewise, Vern recognized the importance of helping his mother maintain a sense of independence and stated that he was thankful that "she's still under her own steam." In

response to a question about the hardest part of the caregiving experience, he noted his identification with the losses that becoming dependent would represent.

Thinking about her going downhill to the point to where, in other words, where she's past going. But just the thoughts of her getting to the point to where she couldn't go on her own steam. I hope I live to be 70 or 80 or so if I can walk to the barn by myself.

Quit Asking Questions. As Lou has needed to give more direction to Alma about taking care of basic needs like going to the doctor or getting groceries, she said she had quit asking questions to avoid having to argue for compliance. She said about her new approach, "Well, I've started phrasing it now where I don't ask her if she would want to do certain things, I just say, we've got to do such and such and she'd say, 'Okay.'" Both Lou and her husband were focused on letting Alma remain as independent as possible but took appropriate actions to protect her from physical harm, as in removing the gun from her house, and from legal/financial harm, as in both removing the bulk of her money from her checking account and helping her with her bills. Consistent with protecting Alma's sense of dignity, for every check Lou wrote for one of Alma's bills, she would present it to Alma for her signature. Even when Alma noticed that her signature was beginning to look weak, Lou quipped, "That's okay as long as it's yours and not mine!" Lou said that then they both laughed about it. Indeed, more than once, Lou's sense of humor appeared to be a useful strategy both for coping with the losses resulting from the Alzheimer's disease process and for protecting Alma's sense of self-worth and dignity.

Theme of Recognition of Impact of Losses

The third theme that emerged from all three of the interviews was the recognition of the impact on her of the losses Alma was experiencing and the perceptions of all three as to how well she had coped with everything. When asked how getting older had changed her life, Alma remarked, “I don’t think it’s changed my life, it’s just I’m alone, you know, back then I had my kids and my husband and all, and now I’m alone. And that’s the biggest thing, it’s just that I’m just alone. Stay here by myself,” and, turning to Lou for confirmation of her self-assessment about how she was doing, said, “Pretty well, I guess, content, wouldn’t you say?”

Not a Giver Upper. Even though Alma had experienced numerous losses in her lifetime, including the deaths of two husbands and two children, her spirit of being “tough” came through in her statement regarding her goal in life.

I’ve had a strong will or whatever you call it and I’ve got a will to live, I’ve got a will to do my best. I’m not a giver upper. I make up my mind to do something and then I try my best. I’ve had a kind of a hard life, but...I thank the good Lord for my life because it’s meant so much with all my kids and my daughter-in-laws, and...especially [Lou].

Alma referred to her regret that she had had to drop out of school to help her family in the fields.

I never got to go to school much ‘cause we was having a hard time and they’d keep us out to work in the fields and we’d get behind, you know, and just it was aggravating and I finally just got fed up with it and I just

said, “I ain’t going back to school no more.” It was terrible that I couldn’t get more education than what I did.

Vern’s description of his childhood with his mother included how they had moved numerous times, evidence of his mother’s ability and strength to cope with the many changes: “We moved just every once in a while. Every couple of years we’d move from different place to place. moved continuously. But she adapted, she’s tough.”

Would Be So Sad. Lou and Vern demonstrated their awareness of Alma’s decline and the degree of sadness they felt for those losses associated with her disease. Lou said, “She puts on a front for a lot of people. Of course, she’s being tired all the time.” Vern echoed this concern in his statement about the prognosis for his mother’s future.

She still recognizes anybody that she knows. But it will get worse is what the doctors say. That’s the scary part to me. You know, she’ll be the same as a vegetable. That would be terrifying...to the point to where she is just reliant on someone to do everything for her. That would be so sad.

Vern’s sensitivity to the sadness of his mother’s decline was matched by his sense of humor, which he sometimes used to explain his feelings. He referred to a comment his mother made about not being able to walk to the mailbox anymore: “I’m getting so worthless,’ says, ‘I can’t hardly walk to the mailbox anymore.’” Vern laughed and said, “I don’t know if I would. I would drive to the mailbox. She’s got a long driveway!”

Armful of Baby. Alma reported that the high points of her life were “her little babies coming into the world” and that she thought she had been blessed with a “pretty

good family.” Vern’s earliest memory of his mother was when she had taken him and his baby sister to the doctor for their immunizations. Vern said he was brave just as she had requested but that he broke down when his baby sister cried. He recalled, “Here my mother was with a armful of baby, trying to comfort me, too, you know.... She’s had a hard life, in other words, she’s had to really grub to make it.”

Evidence that she passed on that ability to bear down and appreciate the available resources came through in her son’s statement about how hard it would be for him to lose his own physical and mental health.

Everything that happens to me I try to see some reason to be more content that I am able to do what I do because what I do is what I want to do. In other words, what I am trying to say, and I’m not going to bring religion into this, but it’s a fact. Whenever I talk to my maker, one of the things I discuss with him that I’m thankful for is that I have health and strength and *can do*. That’s what I am, in other words, all work and no play, that’s all I am. In other words, I want to be doing things with my hands and something that, at the end of the day, I can look back to and say, “All right.”

Not surprising was Vern’s simple wisdom for other families with someone with Alzheimer’s disease: “As long as you can, enjoy them.”

Case Two: “An Easier Pill to Swallow”

When 36-year-old Caroline was contacted with the message that her 75-year-old mother Cora had fallen, she left work immediately and met the ambulance at the hospital, assuming that her mother had broken her hip again. Caroline explained that, because of her mother’s history of osteoporosis, “When she falls, she breaks.” Because Cora had fallen twice in the past 7 years and had broken her hip each time, Caroline knew from experience that a broken hip would mean surgery and some time in the hospital (see Figure 5). Caroline was surprised when the x-rays did not show a broken hip but rather a broken pelvis. To her further surprise, the doctor did not admit her mother into the hospital and, instead, suggested a recuperation period of a few weeks at Caroline’s house since, obviously, she would not be able to manage at home alone. At that point, Caroline, the “responsible one,” felt she had no choice but to follow the doctor’s suggestion, especially since her only sibling, 49-year-old Cheryl Ann, lived out of state. Indeed, she felt she had no choice but to offer her home as a respite because her mom was “begging...with her eyes not to send her to a nursing home.”

The thought of bringing her mother into her house even for a short period filled Caroline with dread because she and her mother never had gotten along very well, and the short notice quickly turned her dread into panic. First of all, she wondered *where* she would put her mother—with four children, ages 17, 13, 12, and 8, already spread out in their large, two-story house. An upstairs bedroom would not work, at least not as long as her mother needed to use a walker to ambulate. The only choice on the ground level was the bedroom of their 8-year-old only son Christopher. Christopher’s small bedroom

Cora, age 75

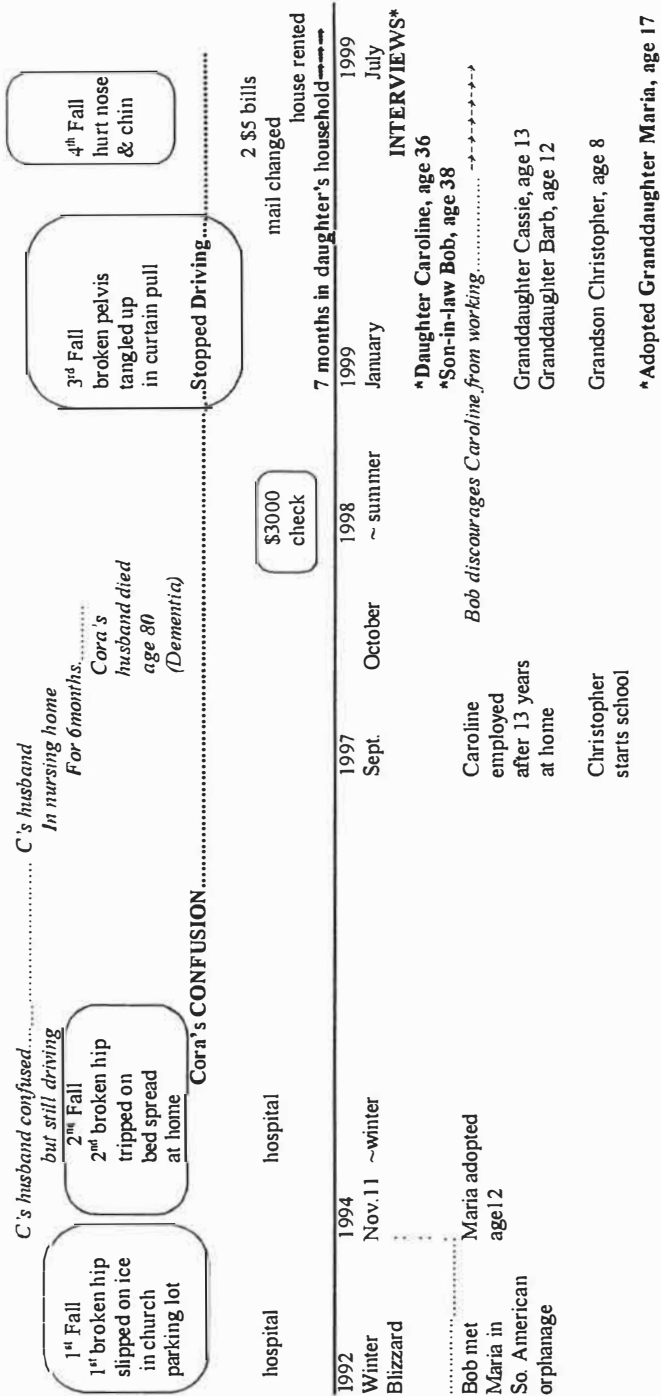


Figure 5. Caregiving Time Line for Case Two

shared a two-entrance bathroom with the master bedroom and was outfitted with bunk beds, which, Caroline reasoned, might be an advantage because the bottom bunk was low enough for her mother to get in and out of safely. Caroline wondered about the wisdom of sharing the downstairs bathroom with her mother, but, still, she felt she had no choice. Despite feeling uncomfortable with her quick decision, Caroline took a deep breath and said to the doctor, “Well, I’ll go and clean my son’s room up enough, get the [toys] out of the floor enough to where we can get her in.” Thus, she hurried home just moments ahead of the ambulance to clear a path into Christopher’s bedroom. In the meantime, she also was trying to contact her husband, whose job as a church youth minister kept them both busy, to inform him about Cora’s fall and the subsequent decisions about taking over Christopher’s room. Caroline recalled the pressure she felt in trying to get the room ready on such short notice. She said, “They were literally driving up and down my street in the ambulance, while I was on the phone with them, saying, ‘You can’t come yet, I haven’t cleared out the room yet, I’ve got to have a few more minutes!’” Once in the house, the ambulance workers helped Caroline get her mother settled into the lower bunk in Christopher’s room, which, at the time of the interviews, 7 months later, was still where she slept, while young Christopher continued to sleep “wherever he landed” each night and to insist that all he wanted was “to get [his] room back.”

First Few Weeks

During the first few weeks of Cora’s convalescence, Caroline indicated that she and her family had tried to be “really quiet” and “really change [their] life style” to make

her comfortable but that they soon decided that Cora would simply have to adjust to the noise and the extra activity of teenagers and their friends coming and going. Although they had decided to just go on with their lives in spite of the “temporary imposition” of Cora’s presence, the family found it difficult to avoid feeling intruded upon. As Caroline remarked,

The biggest inconvenience [was] just the lack of privacy and the fact that you can’t get away from--whatever. If we’re on the telephone, if she needs help with her checkbook or something, then she’ll stand there while we’re trying to have a conversation, and try to talk to us about whatever her problem is. And in the middle of the night, she’ll come in and turn on a light and not shut a door. Right now she’s right by our bedroom, so coming in and going out we have to pass her, and she can catch us.

Squeaking and Thumping in the Night. The participants each recalled how Cora’s walker could be heard throughout the house, noting that it was one of the older models without wheels and that it made a distinctive “squeak and thump” with each step she took. Bob said that hearing her with her walker trying to make her way to the bathroom during the night not only woke them up but also made them feel “on edge.” He said they would hear her and start “thinking, ‘Is she going to fall or can she make it in there?’ And every step, it was just so painful, every step, she’d just groan and moan. You couldn’t get back to sleep for thinking, ‘She is in such pain.’ You’d be mad because she woke you up and then you’d feel guilty because you were mad because she was in so much pain.” For Bob and Caroline, Cora’s proximity to their bedroom was problematic

because of having to share the bathroom with her and because of their loss of privacy as a couple. Bob compared his feelings during the first few weeks to those he had when they brought each of their three babies home from the hospital, recalling that it felt just like “having an infant in the house, when you are getting up every night in the middle of the night for one reason or another.”

Not Wanting to Go Home. After a few weeks of recuperation, Cora seemed well enough physically to return home but, to Bob and Caroline’s dismay, showed no signs of wanting to go. Caroline recalled her mother’s reticence to leave, “She really wouldn’t make a decision, didn’t want to sell her house, didn’t want to leave our house, either.” Caroline continued, “She healed real quickly and real easily from the break, and we kept saying, ‘Okay, are you about ready to go home?’ ‘Well, I think I will be in a few more weeks,’ and it just kept on and on, and we finally realized, ‘She’s not going home. She doesn’t want to go,’ you know, we can’t get rid of her.” From a perspective different from that of her parents, 17-year-old adopted granddaughter Maria recalled, “She had talked to my daddy about not going to a nursing home, no matter what. So she stayed here, and she got used to it, and so she doesn’t want to go back home.” Maria added that she was “glad that she’s not going back home because then I’d be missing having somebody to talk to or somebody to watch TV with.” Cora’s fears and worries about the idea of leaving were revealed in her comment to her son-in-law Bob after he had explained his idea of renting out her old house, “Oh, this is just perfect. This is just going to be the best thing. I’m going to be here, where I’m happy, and...I’m not lonely...and there’s going to be somebody else paying for my house.”

Signs of Cognitive Impairment. Although Cora had not been diagnosed as having Alzheimer's disease nor had her doctors identified any particular source of her cognitive difficulties, she was evidencing some of the same symptoms of cognitive impairment with which her husband had suffered for several years before his death two years prior. Cora's cognitive difficulties had been apparent to the family even before she broke her pelvis and came to their house to recuperate, but, as Bob noted, "It kind of took [this situation] to shock us into saying, 'Look, she can't live by herself anymore. She can't take care of herself.'" They offered numerous examples of her cognitive difficulties, such as trying to remember the word restaurant, having described it as that place where you get a hamburger and then you pay money to a person; having trouble with writing checks for the right amount, tending to add too many zeros (as she did with a check to Bob that she meant to be for \$300 but which she wrote for \$3000); asking the same question or bringing up the same concern over and over, apparently having no awareness of the repetitiveness of her behavior; and having trouble recalling how and why she fell each time, claiming that the most recent time she "did not fall" at all, that the "big knot came up on [her] chin and [her]...nose...bleeding" had simply appeared as she sat in her chair. Thus, Caroline and her husband realized on some level that, even if she were willing, it would not be safe for her to go home.

The Nomad. Displaced from his bedroom, grandson Christopher became known as the "nomad" of the family, sleeping with one sister and another sister or on the couch or on the floor with a bed roll, "wherever he lands" and with "no place to call his own." They "converted a closet" as a place to keep his toys and started keeping his clothes in a

laundry basket in his parents' bedroom. This temporary kind of arrangement for Christopher had become more and more uncomfortable for the family as the few weeks they had expected Cora to stay turned into several months. They were beginning to feel a sense of urgency to get him settled somewhere soon because school would be starting in another few weeks. All of the participants mentioned Christopher's habit of saying, "I just want my room back," indicating that his displacement was a concern for the whole family.

Juggling Bedrooms and Bathrooms. Another issue about household space seemed to be figuring out a way for Cora to have a bedroom and bathroom separate from the rest of the family, while preserving the bedroom and bathroom space already claimed by the parents and children. As Caroline noted in her thinking about how to juggle the bedrooms and bathrooms in a way that would be fair to everybody,

We have a big house. The children all have their own rooms, we have a bonus room, but then there's not a bathroom. Their bathrooms come off of their bedrooms, and not off of the hallway, so [Christopher] would have to go through their bedroom to get to their bathroom...and that doesn't solve the problem of Mother having a private bathroom, either.

Thus, the obvious solution--using the bonus room for Christopher--was not perceived as a good one because it did not solve the problem of bathroom access for either Christopher or Cora. Another solution mentioned by interviewees was the idea of building a small "mother-in-law apartment" onto the back of the house for Cora, making it possible for Christopher to have his room back and for Cora to have her own bedroom and bathroom space "on the opposite side of the house" from the other downstairs bedrooms.

Adjusting to Extended Time

Thus, the few weeks of recuperation that Caroline had dreaded turned into an indefinite, “apparently permanent” stay, at 7 months and counting. An adjustment strategy adopted by Caroline as well as by her mother was retreating to their own rooms and shutting the doors to avoid each other. Caroline observed, “The minute we walk in the door...she hits us immediately with whatever problem she’s worried about all day long.” and as Bob noted, “[Caroline] has gotten to where, when she hits the door, she’ll go and kind of hide in the bedroom. She just doesn’t want to deal with it. And I really feel like [Caroline] may be depressed right now over this whole situation.” Bob’s strategy for accommodating his mother-in-law’s need for his attention had been to “head it off at the pass” by making a point to greet his mother-in-law and give her an opportunity to ask him a question. He admitted that he got frustrated sometimes but “more in private than...to [Cora’s] face.” When he does not have time to sit down and work with her about her concern of the moment, he indicated he could get her to calm down and wait by saying, “I don’t have time right now. Let’s just wait. I’ll be back tonight, we’ll sit down and talk about this. But I just don’t have time to fool with it right now.”

Granddaughter’s View. Granddaughter Maria, in contrast to her parents’ strategies for avoiding or containing Cora, spoke of how she enjoyed her role in helping take care of Cora. “If I’m in my room, I’ll sometimes be on the phone or on the computer or doing something else, I come down and ask her if she needed anything, and sometimes she’ll be like, ‘I need some water.’ I’ll be like, ‘Coming right up!’ I don’t mind at all.” Even Maria, though, said that her grandmother’s repetitive behaviors sometimes “got

old,” and said that she might say something like, “[Grandmother], you already showed me that. I’m not trying to be mean or anything, why don’t you just throw it away because I don’t think we are going to need it...It’s not for us.”

The Family Till. In spite of some frustrations, Cora’s family had shown some evidence that they had begun to “come to grips” with the permanence of the situation in that they had asked a builder to estimate the cost of building a room onto the house, notified the post office to forward her mail to their address, and decided to rent her house for \$900 per month. By planning to use some of the \$900 of rental money for themselves, Caroline and her husband felt they would be operating in the spirit of fair exchange (i.e., getting “at least some compensation” for the disruption to their lives). However, Caroline’s 49-year-old sister Cheryl Ann, who worked full time, had a teenage daughter, lived out of state, and, of course, was unwilling for Cora to come to her house, had objected to the idea of renting her mother’s house and made it clear that she considered using the rent money unethical, “like charging your own mother for taking care of her.” Nevertheless, Caroline and Bob justified their position by pointing out that accommodating Cora at their home (with the rent money) would cost approximately one third of the cost of placing her in an assisted living facility. They projected that, by choosing this “least expensive way,” there would “be more to divide” after Cora is gone. Bob stated that he did not want “to sound greedy...but...a little bit of money coming in off of this deal...just makes it an easier pill to swallow.”

Around Much Longer? Overall, this family felt uncomfortable with but resigned to taking care of Cora in their home because they did not see any other options that they

could “live with.” Caroline remarked several times that Cora’s staying with them seemed to be “the best of all options, that are not very good.” Her husband explained that he realized Caroline’s worry about feeling guilty was part of why she hesitated to place her mother in assisted living, “to send her where she doesn’t want to be,” as he commented in his advice for other caregiving families.

You live the way you can...and don’t feel guilty about whatever you have to do. I think one of the reasons that [Caroline] won’t go ahead...is because she doesn’t want to feel guilty. One of the things I’ve heard her say is, “I know if she goes to [assisted living], I’m going to spend every day of my life feeling guilty because I’m not up there seeing her, I’m not visiting her often enough, or I’m not paying enough attention to her. So, I’d rather just have her here where I can see her every day and know that I’m taking care of her, helping to take care of her.”

Both Caroline and Bob commented that Cora had said that she “doesn’t think she is going to be around much longer” and does not want the family to “go to a lot of trouble” for her. In spite of her cognitive decline, Cora had remained in relatively good physical health, and her family believed that she was “probably going to be around a good many more years.”

Analysis of Case Two

As noted by in my field notes shortly after the first interview, Cora’s daughter Caroline seemed uncomfortable with the concept of caregiving and wished the task had

not fallen to her. Caroline did not seem to like her mother very much and would rather not have had to deal with these problems at all. She thought her sister would have been better “at the caring part” and commented about the unfairness of her getting “stuck” with it just because she is the one who lives nearby. This family seemed to be in some kind of holding pattern not unlike denial, waiting for something to jump start them into a decision about assisted living or even an Alzheimer’s diagnosis. My initial analysis of this unhappy caregiving situation revealed the three primary themes that did, indeed, surface over and over in analysis of the narrative data. First, the theme of perceived injustice was obvious as Cora’s daughter Caroline and son-in-law Bob expressed their sense of injustice regarding the caregiving situation, referring numerous times to how long their household had been disrupted and how unfair it was that the out-of-state daughter Cheryl Ann was not willing to help. Second, the theme of a legacy of distance in the mother-daughter relationship was illustrated through the characteristic distance between mother Cora and daughter Caroline as well as in the next generation between mother Caroline and adopted daughter Maria. Third, the theme of the process of denial was apparent in the family’s unwillingness to face Cora’s cognitive decline as a disease process, thus immobilizing their ability to make reasonable decisions and solve problems.

Theme of Perceived Injustice

The first theme that emerged was that of perceived injustice. Cora’s extended recuperation period at her daughter Caroline’s home was perceived by the family as an unfair situation that had become more than a temporary imposition on their family life, not

only displacing the grandson from his room for months but also destroying a sense of privacy for her daughter and son-in-law in their own home. This element of injustice surfaced in numerous ways throughout the caregiving story, being played out as strain in the marital relationship as well as in the adult sibling relationship between Caroline and her sister Cheryl Ann, especially over how their mother's money should be divided equitably. As Caroline remarked about her sense of injustice that this responsibility was falling to her at this stage in her family's life:

And I kept saying, I'm too young to have to deal with these. I still have children at home. I know a lot of people are taking care of elderly parents, but they're 60 themselves...and their children are gone...so it just kind of brings it into a whole new realm when...your children are still relatively small. They're involved in every activity. My husband and I are both very involved...so we're not at home a lot...to take care of her.

More Than a Temporary Imposition. The theme of perceived injustice also surfaced in Caroline's talking about how there was no time to prepare for moving her mother into their home and how they thought it would only be for a 4-6 week time period but it had now been 7 months. Bob described his initial reaction to his mother-in-law's moving in as a temporary inconvenience to the household. He stated, "I guess that was kind of my feelings when I first heard it...that it would just be a temporary imposition or something." Bob was also very definite about the strain he felt the situation had placed on his marital relationship but said, "I think we are getting through it." Although Caroline and her husband kept asking Cora if she was ready to go home, she did not want to go and

“You know, we can’t get rid of her.” One of the major inconveniences generated by Cora’s presence was the displacement of only son/grandson Christopher from his bedroom. Both Caroline and Bob spoke of this displacement as being troublesome, referring to Christopher as the family “nomad” because every night he had to find somewhere to sleep, but the family had made no specific arrangements for him to have another place to sleep once his room was taken. Caroline described his situation as “living out of a laundry basket and sleeping wherever--it’s really hard for him.”

Why Should I Be the One? The perceived unfairness of this caregiving situation also generated strain in the relationship between Caroline and her sister, Cheryl Ann. Caroline felt that her sister’s lack of involvement in caring for their mother was unjust: “I think [it is] a real unfair situation and there’s nothing you can do, but the fact that I’m the sibling that’s in town, and I can’t help that.” She also felt angry about her sister’s criticism of the plan to rent their mother’s house and use the money each month. Both Caroline and Bob talked about the injustice of Cheryl Ann’s calling their plan unethical in light of the fact that she was unwilling for mother Cora to come and stay with her. Further evidence of Caroline’s sense of unfairness about her filial obligations compared with those of her sister was reflected in her comment that she was a “late in life child,” implying that her parents might have been more considerate of the eventual developmental needs of the daughter born 11 years after the first one. As a full-time employed mother for four children and wife of a minister, Caroline was angered when her sister offered as her reason for refusing to take their mother into her home that she “operated as a single mom with a teenage daughter.” Caroline hung up the telephone and expressed her anger

and profound sense of injustice, “What does she think? Why does she think because I’m the local one that it’s my job to do this?” Bob reinforced his wife’s consternation over the situation in his answer to her question, “Why am I the one that gets stuck with this...responsible for this?” with a statement about his belief in his wife’s unquestionable sense of filial obligation and responsibility.

Because you are the one who is responsible. You are the daughter who is a responsible person and loves your mother and feels a responsibility toward her...because you’re not the self-centered. [Cheryl Ann] is the most self-centered person. You are a caring person who is going to make life bearable for your mom for her last, her final years.

Financial Inequities. Both Caroline and Bob referred to the fact that for the time period her mother had been with them they had not received any money directly for caring for her. Although the mother had given recently both of her daughters \$4500, it seemed unjust to Bob and his wife that the daughter who was not helping with the caregiving got the same amount of money. Bob talked a great deal about the injustice of “no money being added to the till of our family” since the care recipient had moved in with them. “But at this point, she’s contributed 10 bucks for the last 7 months. I’ve felt a little bit of animosity about that and you know there is all this money sitting there in her checkbook.” This financial inequity seemed to be a very important issue for the son-in-law, particularly since the care recipient had “plenty of money.” Also, daughter Caroline emphasized the injustice in her husband’s having so little voice in making decisions about his mother-in-law but having so much responsibility in providing for her.

He can sway me, as far as helping me to make decisions, but he knows, ultimately, like as far as selling her house and that kind of thing, that's got to be my decision and my timing...It's a little frustrating to him, I think, that he does give so much but yet has so little decision making.

Sandwiched Between Generations. Caroline and Bob both also talked about how unfair it was that they were faced with caregiving at such an early stage in their lives. Caroline talked about having young children and the unfairness of dealing with those demands along with dealing with elder caregiving demands. Caroline's sense of injustice about the situation is further illustrated by her comment about how unusual it is for someone as young as she to have these kinds of responsibilities: "I'm too young to have to deal with these.... I still have children at home." Bob echoed her indignation by pointing out that only some of their "older friends" (not their contemporaries) were having to deal with the frailties of their parents.

We have some older friends...that are starting to go through it, but, we look at our friends our age, especially [Caroline] three years younger than I am, you know, especially her age, the people she graduated from high school with...and she is going, "Nobody else is doing this but me."

Cultural Perspective. The adopted daughter/granddaughter Maria did not view the caregiving situation as unjust, however. She explained that in the South American culture where she grew up, the expectation is that the "kids take care of grown ups." Caroline acknowledged how much Maria did in caring for Cora, "just having to come up with something to feed her every night." Clearly, for Maria, having her grandmother in

the home was positive because she made her feel loved and appreciated. Maria remarked, “I like to be around her and talk to her a lot and take care of her...I don’t mind taking care of her. I really like it.”

Theme of Legacy of Mother-Daughter Distance

A second theme that emerged was legacy of distance in the mother-daughter relationship. Caroline’s placement of both her mother and her adopted daughter on the outer edges of the family map diagram signaled this theme of distance, as did Caroline’s early statement, “I know a lot of people are willing to care for their parents and that be their life and their job, but I’m real comfortable with the fact that that’s *not* what I want to do.” As daughter Caroline recalled the history of her relationship with her mother Cora: “I didn’t like living with her that much when I was in college, or you know,” and her husband, Bob, described their relationship in terms of their having “been frustrated with each other over a lifetime.” A continuation of this legacy of distance is reflected in the relationship between mother Caroline and adopted daughter Maria. Maria stated that she was a lot closer to her dad than her mom, and described her relationship with her mom by saying, “Sometimes we get along, and sometimes we don’t.” Indeed, there were several references across interviews that suggested Maria had a close relationship with her adoptive father and grandmother, but not with her adoptive mother.

Closed Doors. From the descriptions of all three participants, much of the time when Caroline and Cora were home without Bob, they stayed closed in their separate bedrooms to avoid one another. Maria also commented, “I don’t see my mom that much

because she's always in the bedroom." As Caroline put it, "She's my mother and I love her...but we all need our space." Caroline's awareness of the space between herself and her mother was also apparent in her comment about how she would feel guilty about "having to visit her" if her mother was in an assisted living facility, as if she knew in advance that she would not want to take the time and effort to go visit. Maria spoke several times of everybody, except herself, getting "tired" of grandmother's being there and wishing she was not there. She said her mother was "tired because she is not used to it," meaning that her mother had not adjusted to having Cora's being dependent and in such close proximity.

Substitute Relationships. Maria seemed to have a close relationship with her adoptive father and grandmother but not with her adoptive mother. Possibly Maria's perception of distance in relation to her adoptive mother influenced her to substitute a closeness with her father and grandmother for the closeness she was lacking with her mother. Thus, it was not surprising that Maria did not want to lose the love she felt when her grandmother welcomed her into the family and made her feel special by exclaiming, "Oh my goodness! Oh wow! This is my other granddaughter, I am so glad!" and by kissing her and hugging her. Nor did Maria want to lose the appreciation she received from her grandmother when she expressed delight over Maria's cooking, "Oh, this is the best meal I've ever had. You're a wonderful cook!"

Likewise, the care receiver, Cora, had substituted her dependence on her late husband with dependence on Caroline's husband, bypassing her distant daughter in filling the emotional void she perhaps felt after her husband died. Son-in-law Bob stated, "I

think she's always had somebody to come to and say, 'What is this? How do we take care of this? How do we handle this?' and so she has just kind of transferred that over to me." Caroline admitted that her husband was more patient than she and did a better job in working with her mother, stating, "My husband is who she goes to with problems, more so than me. He's just very patient with her...but if he doesn't take care of whatever fire is burning immediately, then she's going to follow him around and pursue it until he does."

Theme of the Process of Denial

The third theme that emerged was the process of denial, most apparent in the family's unwillingness to face Cora's cognitive decline as a disease process, immobilizing their ability to make reasonable decisions and solve family problems. As family members became aware of Cora's cognitive difficulties, in the form of repetitive and ritualistic behaviors, obsessive worrying about money or health, and inability to remember the details of her several falls, they noted these changes and could describe them in detail. Instead of framing these symptoms as part of a disease process, they tended to take them personally and feel annoyed by what seemed to be stubbornness and uncooperativeness. This process of denial--refusal to believe what one sees (Boss, 1988)--occurred both in dealing with the care recipient's symptoms of Alzheimer's disease and in terms of projecting the future of the caregiving situation.

Taking Symptoms Personally. Both Bob and Caroline avoided interpreting Cora's cognitive difficulties as symptoms of Alzheimer's disease. Rather than seeing her symptomatic behavior for what it was, they got frustrated with her and expected her to

remember things and to be capable of doing things that cognitively were probably beyond her abilities. Instead of acknowledging her repetitive questions, her obsessive worry, her ritualistic patterns of behavior as a reflection of the disease, Caroline described her mother as “rude” and “stubborn” and was angered by her mother’s sitting down at the dinner table as if she expected to have food placed in front of her. In response to her mother’s repetitive concerns about issues, Caroline would snap with impatience, “Mom, what are you talking about? You know exactly, we talked about this yesterday!” Likewise, Bob seemed to focus on Cora’s “obsessiveness” and her “anxiety” but would wait until he was alone with his wife to complain, as if her behaviors were purposefully annoying. “I will probably tend to wait until [Caroline] and I are in our bedroom, and then I’ll get upset...and go, ‘Golly, I wish she’d just remember some of this stuff.’” Bob’s denial of his mother-in-law’s behaviors as a reflection of a progressive disease was further illustrated by his belief that her seeking his assurance about how she had written a check meant she was “that much on top of the game.” Bob seemed unwilling to acknowledge the incongruence of her assurance-seeking behavior and her previous demonstrations that her judgment had the potential to lapse without warning. Similarly, the family had little concern about the potential for her to wander farther than the mailbox, notwithstanding the fact that her confusion was so profound that she needed the jar of peanut butter to be always on the right shelf in the pantry so she could fix a sandwich for her lunch. As Bob expressed their confidence about her level of cognitive functioning, “She’s pretty aware of where she is. I mean I don’t think she would...ever wander off and not know where she was. The farthest she will go out is to the mailbox.” Also probably unrealistic in terms of Cora’s condition

of dementia was Bob's attempt to convince Cora to use one of the daughters' upstairs bathrooms, at least while they were home in the evening. He recounted,

I took her up to [Cassie's] bathroom and said, "Why don't we do this...why don't we make it where you share [Cassie's] bathroom? And keep your stuff up." And she said, "Oh, I sure would like to just be able to get in there and be able to take a good, hot bath"and then when she got ready to...go to bed that night, she was right back in my bathroom.

She had forgotten all about that deal.

Clearly, if Bob or Caroline had viewed Cora's behavior as symptomatic of Alzheimer's disease, they would not be surprised that she could not *remember* to use the other bathroom. Instead, they seemed to take her symptoms personally and interpret her behaviors as intentionally uncooperative.

Avoiding Diagnosis. Neither husband nor wife reported being interested in pursuing further diagnostic work from the medical community. By avoiding a diagnosis, they used the process of denial to delay acknowledging the realities of the future in their caregiving situation. By not talking about the source of Cora's cognitive difficulties, they avoided thinking about the realities of Alzheimer's disease progression and, thus, delayed having to face the reality that all the future would hold was further deterioration. To illustrate the power of this process of denial, at the time of Cora's most recent fall, Caroline and Bob accepted the doctor's comment that there was a "mass on the CAT scan that was a little bit abnormal...nothing really unusual for her age." Further, they agreed

that her obsessiveness about running out of money might be no more than a “characteristic of a lot of old people.”

Immobilization. Going beyond providing a functional period of delay in getting used to the idea of a catastrophic illness (Boss, 1988), the process of denial in this family had become dysfunctional, resulting in immobilization--an inability to make reasonable decisions and take appropriate actions to solve problems. This immobilization was apparent in this family’s view of the future of the caregiving situation, especially from the perspective of the caregiving daughter, Caroline. It seemed that Caroline wanted to continue to view her mother’s needs as somewhat temporary, which may help account for her not creating a space for her son after his room was taken. In other words, if she took action to establish a new space for Christopher or to build a new addition to the house for her mother, she would have to acknowledge that she knew her mother would not be leaving in a few days or a few weeks. Another area where the process of denial seemed to prevent action was Caroline’s resistance to selling or renting her mother’s house. She said her husband was more ready to do something about it because he was not so “emotionally attached” to it as she was, having grown up in that house with the furniture still placed exactly as she had remembered. As long as the house remained as it was when Cora left it, perhaps Caroline, on some level, still believed her mother would go home and everything would be like it used to be, with her mother being the “selfless person” who always “waited on us” instead of “our waiting on her” (an unrealistic notion that describes the process of denial better than it describes nostalgia or sentimental attachment). Basically, Caroline seemed unable to acknowledge the permanence of the caregiving

situation and the fact that decisions would have to be made that neither she nor her mother wanted to face.

Case Three: “Cousins Are All She Has”

The caregiving situation of this family involved two sisters, Nancy and Becca, both career women in their early thirties, sharing primary responsibility with their paternal grandmother, Mattie, for managing the care of their physically and cognitively frail elder cousin Belle, who had been living in an assisted living facility for nearly a year. An unmarried, only child, Belle, at age 84, was in the middle stages of Alzheimer’s disease and had multiple physical health problems, including leukemia and bone cancer. The two sisters, Nancy and Becca, were third cousins to Belle on their father’s side of the family, taking on their roles as co-caregivers when they became aware that their 73-year-old grandmother, who was Belle’s first cousin, was having difficulties in managing the caregiving situation by herself. Thus, as illustrated in the Figure 6, this caregiving story has a sort of hop-scotch effect, with the two young women stepping in to help their grandmother, who for several years had been helping her cousin Belle by taking care of her bills, driving her wherever she needed to go, and checking on her regularly. Belle had “been anemic all her life,” having had poor health in general, but her problems with memory apparently started only a few years prior to her falling and breaking her hip, the crisis that precipitated the shift of primary caregiving responsibility from her first cousin Mattie to her two younger cousins Nancy and Becca almost one year prior to the time of the research interviews. The family members in this caregiving group clearly cared about

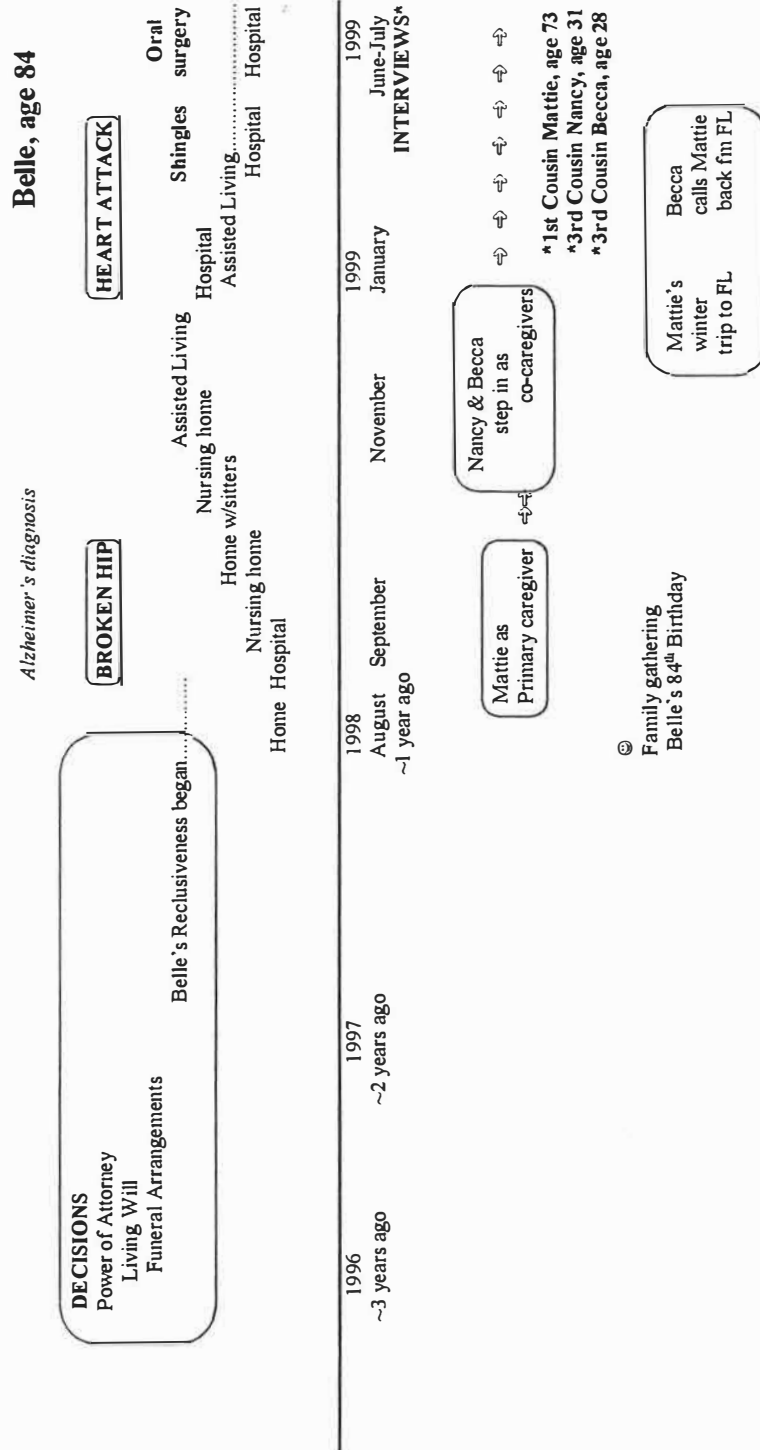


Figure 6. Caregiving Time Line for Case Three

Before Her Broken Hip

Although Belle and Mattie were just cousins, they had always spent time together and depended on one another like sisters or best friends would. They had been close as children but became even closer in adulthood, especially after Belle's parents died. Mattie had an older sister who had experienced mental illness during much of her adult life, and, thus, Mattie had turned to Belle for some of the companionship missing in her relationship with her sister. They both worked, Belle as a bookkeeper and Mattie as a sales clerk, but they planned their vacation time so that they could travel together, and when Mattie's husband was on night shift, Belle and Mattie spent their evenings together after work, teaming up to take care of major household chores like cleaning the carpet or putting up a new light fixture. They regularly went shopping and out to eat and even enjoyed Mattie's granddaughters together. Belle liked to buy little gifts for Mattie's granddaughters and always had a sweet treat to offer them. During the 20 years that Belle had lived alone since her parents died, her cousin Mattie had sort of "taken her under her wing" because Belle had no other family. As one of the participants noted, "Cousins are all she has," so, when she needed help, her cousins automatically were there for her because, from their perspective, "that's what families are for."

When She Broke Her Hip

One morning in September (about a year before the interviews), Belle's cousin Mattie was calling to check on her as usual but got no answer. Mattie worried a little because she knew that Belle did not drive and rarely left the house, but Mattie rationalized

that maybe someone from the church had taken her shopping. Later that day, still unable to reach her by telephone, she asked her husband to go with her to Belle's house to see what was wrong. Even though Mattie had a key to the door, she could not get in because Belle had locked it with an old-fashioned dead-bolt from the inside, as she sometimes did as an extra security precaution. When Mattie called out, Belle was able to respond to her cousin's voice but did not come to the door, so Mattie and her husband (and also, by that time, a neighbor) had to break the glass in the door to get into the house. Once in, they found Belle in the hallway in the floor, mentally confused and physically unable to get up. When they tried to help her get up, she groaned in pain, so they called 911, and Belle went to the hospital where x-rays showed that she had broken her hip. As part of her assessment at the hospital, doctors noticed her significant cognitive impairment and tentatively diagnosed her with Alzheimer's disease.

Belle's Symptoms in Retrospect

Apparently, Belle had had some awareness that she was losing control of her mental functioning for a period of time before the symptoms became apparent to others. About three years prior to her fall, Belle had asked Mattie to accept her power of attorney and to help her plan her funeral. Mattie, in turn, asked her own granddaughter Becca to share those responsibilities with her. Becca recalled that she automatically agreed to her grandmother's request without giving much thought to what it would eventually mean.

Belle also voluntarily had stopped driving and had become progressively reclusive, not wanting to go out of the house, even for their traditional family birthday gatherings.

However, she had attended her own 84th birthday celebration in August before her fall in September but, according to the informants, seemed depressed and withdrawn at that time. Further evidence of her mental decline surfaced later when Belle's cousins went to her house to clean up and get it ready for her to come back after rehabilitation for her broken hip. They found that she had stockpiled huge supplies of items like dishwashing liquid, had labeled canned goods with dates, and had written multiple notes to herself about various everyday tasks, such as how to clean the kitchen sink, including where the cleanser was stored and other details that ordinarily would be remembered without notes. In fact, in retrospect, Belle's cousins realized that her reclusiveness and other signs that something was wrong had been going on for several years, but they had not realized the extent of her cognitive problems until after the incident of falling and breaking her hip.

Caregiving Turnover

During the 2 months that followed her fall, Belle was transferred from the hospital to a rehabilitation unit at a nursing home, then back home for a week with 24-hour sitters, back to a nursing home, and finally to an Alzheimer's disease unit at an assisted living facility. During Belle's initial stay in the nursing home rehabilitation unit, Nancy and Becca had become aware of their grandmother's stress level in trying to manage all of the details of Belle's care by herself.

Help with Paperwork. Mattie had asked her granddaughters for help with the paperwork, and one evening after work the two sisters got together with their grandmother to sort out bills and insurance papers. In the process of going through the

stacks of old and new bills, torn envelopes, and other paperwork, they realized that Mattie was having significant difficulty with these tasks and needed help herself.

Trial Thing at Home. Their grandmother needed help not only organizing the bills and the insurance paperwork but also making decisions related to Belle's care. Mattie was very worried and upset about a social worker's advice to place Belle in a nursing home permanently after rehabilitation, and she insisted on bringing her back home with 24-hour sitter assistance. Thus, at Mattie's insistence, Belle returned to her own home, but, after a week with sitters trying to respond to Belle's stream of demands and her general agitation, not only were the sitters fatigued and frustrated but also Belle was unhappy, insisting that she was *not* at home. At that point, Mattie realized that having her at home with sitters was not going to work and arranged for her to return to the nursing home. Even though neither of the two sisters had thought "this little trial thing" of bringing Belle home with sitters around the clock was a good idea, they let their grandmother try it while they took that time to look around for assisted living options.

Including Mattie. When Nancy and Becca found a newly-opened assisted living facility that seemed like an ideal place for Belle, they took their grandmother to see it, included her in the process of deciding on it, valued her opinion about the facility, and took her advice to make sure Belle had a roommate. The two granddaughters began to take over responsibility for Belle's care, taking turns transporting her to doctors' appointments and responding to the requests of the staff at the assisted living facility, sharing the responsibility as equitably as possible. They both felt that it was important not only to include their grandmother in the process but also to protect her from unnecessary

worry, calculating the amount of detail their grandmother needed to be involved in without making her overly nervous and deciding together how to present choices so that she would feel comfortable about her role in the decision-making process. Clearly, their actions were as much in support of their grandmother as they were in response to the needs of their elder third cousin. Basically, when the granddaughters realized how much stress their grandmother was under, physically and emotionally, they decided together to help their grandmother help their frail elder cousin Belle.

All Her Houses

During the 9 months Belle had been in assisted living, she had been transferred to and from the hospital at least three more times. After only a couple of months in assisted living, Belle suffered a heart attack, an episode described by the youngest caregiver, Becca, as the most difficult challenge because the other two cousins were out of town and she was all alone, depending on the advice of the surgeon in making decisions about Belle's care. After the heart attack, Belle recovered well enough to return to assisted living. Next, she was in and out of the hospital for shingles and, of course, was taken to doctors' offices for various other needs. Even at the time of the research interviews, Belle was in the hospital again, this time apparently related to complications from the previous week's oral surgery.

I had accompanied Nancy to the hospital to visit the recovering Belle, who greeted me from her hospital bed with a smile and a gentle hand squeeze, as a nice hostess would, and, as Nancy adjusted her oxygen tube, Belle asked about her houses. According to her

cousins, she had started referring to the assisted living facility as home and worrying almost obsessively about “all her other houses.” Could it be that by being in and out of so many facilities in less than a year, she understandably was confused about the meaning and location of home?

Overall, Belle’s cousins expressed their belief that she had a “strong will to live” having surprised them several times with her recoveries. They felt assured that she had adjusted well to assisted living, commenting that she was eating better, socializing more, and enjoying life more since she had moved into the assisted living facility. They also noted signs that she was pleased with the facility and staff and that she was getting attached to her roommate, also an Alzheimer’s patient, whom she apparently identified as yet another cousin. Mattie, Nancy, and Becca all three felt that Belle’s potential quality of life was of primary importance in making decisions and expressed hope that she would be able to remain in assisted living. However, only a few months after my interviews with Belle’s cousins, I received the news that Belle had passed away--but only after another move to the hospital, then a nursing home, and finally the hospital again.

Analysis of Case Three

The major themes that emerged in the narrative data of Belle’s story included (a) carrying on family caregiving traditions, (b) protectiveness, (c) uncertainty, (d) creativity, (e) the importance of appreciation, and (f) the comaraderie of women.

Theme of Caregiving Traditions

This story of caregiving cousins reflects a family tradition of working together to help those in need, a phenomenon that seemed to run several generations deep. As Mattie spoke of this tradition, she noted that “they grew up to help each other.” Continuing this thought, she said,

My mother taught me to, she used to say, “Now [Mattie], you love your kinfolk.” And since I would see her help so many people, you know, that put something in my thinking, that if I see a need anywhere.

Referring to Belle’s mother, Mattie reminisced, “Her mother was like my mother, she was a really good person, always doing something for you.” Thus, it is not surprising that both Belle and Mattie cared for their parents when they became ill before they died.

Automatic Response. Interestingly, this recurrent theme of automatic response to family need was revealed in bold relief when the granddaughters stepped in to help their paternal grandmother manage the process of caring for their elder cousin Belle. As one remembered the sequence of events that precipitated their involvement,

But after she broke her hip...all this time my grandmother had been taking care of [Belle]. My grandmother, if she stays here in the winter, she gets really sick. So [we] were realizing, “This is getting more than [Mattie] can handle.” So that’s the point that [we] really stepped in.

In addition, the younger cousins Nancy and Becca had observed a similar response to need on their mother’s side of their family when their own mother took responsibility for managing care for their stepfather’s mother. As Nancy and Becca discussed their reasons

for taking on responsibility for Belle, they acknowledged the influence of role models in their family, including not only their father's mother (i.e., Mattie, a "care-taker kind of person") but also their own mother, whose caregiving experience served also as a resource of knowledge about the availability of assisted living as a care option.

From the Heart. Integral to their tradition of helping others, Belle's family stressed their belief that actions should be in the spirit of selflessness, "from the heart." As one participant said as she explained her motivations for helping Belle, "And I really get a blessing out of helping people. The main thing is, you know, I love her. I don't do it for show or I don't do it. I do it because there's a need there."

Theme of Protectiveness

Consistent with their traditions of pooling resources to help those in need, Belle's cousins acted in protective ways throughout the caregiving process. Whether they were responding to a crisis event or being assertive with service providers, they made their decisions on the basis of Belle's potential quality of life. Belle's cousins "wanted to watch over her health problems that made her the way she was," realizing her volatility, physically and mentally. One of the younger caregivers expressed her concern for Belle's condition, saying, "So she's weak, you know, and everybody would always say, oh, she's just anemic, 'cause she's been anemic all her life. But that's not, that's just a small part of the problem." In making caregiving decisions together, they focused on what would be in Belle's best interest and were thankful that in assisted living. "She obviously feels safe," "her diet had improved tremendously," and "her quality of life is a lot better...than it was

before she broke her hip.” Belle’s cousins’ protectiveness was apparent in the way they processed caregiving decisions, always focusing on maximizing her comfort.

Stolen Glasses. Whenever Belle had any need, her cousin(s) came to her rescue, working together to make decisions and taking turns getting her to the hospital or eye doctor or dentist. For example, when Belle became obsessed with thinking that her glasses had been stolen and that the pair she had was not hers, Nancy and Becca got together to find a creative solution that would keep Belle happy. They arranged for her to go to the eye doctor for new glasses, clearly monogrammed with Belle’s initials, and, to everyone’s delight, the strategy worked. Because she recognized her initials, she somehow was able to settle the question in her mind and stopped worrying about her glasses.

Pretty Forceful. Whenever the service provider system was difficult to deal with, Nancy and Becca supported each other in being assertive on Belle’s behalf. Ever aware of Belle’s physical and emotional well-being, they demonstrated that they could be “pretty forceful...to make something right,” doing whatever was needed to protect their elder cousin’s interests. For example, when a doctor insisted on further investigating a lump in Belle’s breast via a mammogram procedure, Nancy and Becca questioned the need for such a procedure and ultimately decided to change doctors. They reasoned that, even if Belle had breast cancer, she was too weak otherwise to have surgery or treatment for it, so there was no reason to put her through testing procedures that might be confusing or painful. Their advice to other caregiving families included the following directive.

Don't be afraid to disagree with people when they tell you stuff. After [Belle] had her heart attack, the doctors wanted to put her back into the nursing home for rehab and [we] told them, "No." It's really traumatic for [Belle] to go to another place, 'cause it was really hard when she went from the hospital to the nursing home, to her house, back to the nursing home, to [assisted living], all within four months. And she was really confused where she was. So [we] just said, "No, she's not." And the people there were just stunned. You have to just not be afraid to take charge and even disagree because you know the person better and you have a better feeling for their interests.

When protecting Belle's potential for quality of life, her cousins were not afraid to ask questions about procedures and about Alzheimer's disease, change service providers, or take a stand against what they perceived as arbitrary or unwise medical decisions. In this process of being assertive with service providers, they felt rewarded by having greater confidence in their ability to solve problems and deal with all kinds of people.

Theme of Uncertainty

According to her caregiving cousins, Belle's response to not being able to recognize her own home after the episode of breaking her hip indicated that she had some awareness of her mental decline. "She never had admitted that she knew she was in her house. She'd look up at me and she'd say, 'When am I going home?' And I'd say,

‘[Belle], honey, you are at home.’ And she said, ‘Isn’t this awful, I think my mind is gone.’ Now, she was thinking that way.”

Back and Forth. All three of Belle’s caregiving cousins expressed uncertainty about her ability to recover each time she experienced a medical crisis. They feared that they would have to place her in a nursing home after each hospitalization and, therefore, hoped that she would regain enough strength to be self-ambulatory, a requirement for assisted living. As one participant noted in relation to her ambivalent feelings about Belle’s condition,

We’re coming to the point, you know, I don’t hope that she dies, but I don’t want to see her suffer. And we are getting to that point now that, so far, so good, she’s been happy. I kinda’ go back and forth, you know, sometimes I think, well, and she says, “I want to get better.”

It’s Just Not Her. Again reflecting mixed feelings about Belle’s condition in relation to her quality of life, another participant stated, “So, it’ll be real sad when she does pass away, but it’s okay. She’ll be more at peace, and she’ll be herself again. ‘Cause that’s the hardest thing, is when she does have bouts of being not lucid at all, it’s just not her,” a statement that clearly recalls Boss’s (1999) discussion of ambiguous loss experienced by Alzheimer’s family caregivers as they try to make sense of their relationships with a person who is physically present but, progressively, psychologically absent. Commenting on how hard it is to know what is best, one of the participants described Belle’s cognitive improvement after being on an effective Alzheimer’s

medication as “a kind of Catch 22 because she was more lucid but she was more aware that she couldn’t remember things.”

Theme of Creativity

Consistently focused on Belle’s happiness, her cousins used creativity and humor to cope with the complexities of trying to interact with her. In explaining their rationale for going along with Belle’s version of reality, one of the participants said,

Most of the stuff with her having Alzheimer’s, if it’s not harmful, or if it’s not upsetting her, we go along with whatever she says. She’s decided she has multiple houses, and she’s all the time telling us she wants to go see them. So we’ve decided, because, we usually say, “Well, when you’re feeling better, you let us know, and we’ll go for a drive.” We’ve decided if it ever comes to that, we’re just going to drive around and let her pick some out. You know, as long as it makes her happy, we go along with whatever she says.

Belle’s cousins took into account the uncertainties associated with her Alzheimer’s condition in everything they did with her, including visits to doctors’ offices, her old house, her parents’ grave site, going out to eat, or shopping. For example, one time Nancy and Becca planned to take her shopping, but she did not feel good. Instead of trying to convince her to go or creating an issue out of it, the two sisters decided to go shopping *for* her, having great fun together picking out clothes they thought she would like and bringing them back to show her. Belle was delighted with this version of a

shopping trip and was apparently pleased with the girls' choices for her. Instead of trying to correct Belle or explain their version of reality to her (as sometimes Mattie tried to do), they found it best to go with the flow, letting Belle lead the way.

Theme of Importance of Appreciation

All three caregivers stressed the importance of appreciation in how they felt about their caregiving roles, noting how fortunate they were that the changes in Belle's personality had been in the direction of cooperativeness and graciousness and indicating that they would do it "whether she was appreciative or not, but it really helps."

They were grateful for her remarkable changes from being a picky eater to an easy-to-please person who would eat whatever appeared on her plate and from being a shy and reclusive person to one who, without argument or hesitation, would get on the assisted-living van and sit down "in the seat, just like a school child." Equally noted were congruencies with the past, including liking to go out to eat when she is out no matter what time of day, liking to read the newspaper and keep up with current events, and having a self-righteous, conservative attitude about how people should behave, especially in reference to her assisted living roommate's obsession with dancing and men.

Interestingly, her cousins tended to perceive Belle's newly-acquired appreciativeness and cooperativeness as lucid reactions, representative of her genuine feelings, while they tended to interpret the occasional appearance of her more familiar behaviors of being "snippy" or agitated as a reflection of her Alzheimer's illness. As the two younger cousins remarked about Belle's recognition of their efforts,

What's nice about it is she's very gracious about it, and I think that makes it worthwhile because if I was having, I don't have to do it, I choose to do it, but if I was doing it for somebody and they were rude and mean and hard to deal with. I don't know if I could handle that very well.

and

She is so sweet. She is all the time telling us how much she appreciates what we do, and she doesn't know what she'd do without us, that she just prays and thanks God that she's got us, and she'll get kind of emotional about it.

Completing the circle of appreciation, Belle's first cousin Mattie commented on her respect for what her granddaughters were doing, describing their efforts as extraordinary,

I said, "Anybody, two people, girls like [them] working...anybody that would take care of somebody for these four months that you have. I appreciate so much." I have never been around girls that, since she's just a third cousin, that has been as good to anybody as they have. I mean they are just right there and they're young and their mind is keen.

Also notable in relation to the process of appreciation in this family is the tradition of expressing appreciation through "giving little gifts." One participant, in describing Belle, said, "She's a gift giver. She loves to give us things, but she wasn't a real emotional person, you know, but she's real sweet." According to Mattie's granddaughters, whenever Mattie would go to visit Belle, or even if anyone would come to her house, she liked to have something to give, like an apple or a book. Not surprisingly, Nancy and

Becca seemed to have picked up on the gift-giving tradition as evidenced by their routine of taking flowers or small supplies like hand lotion or tissues to Belle.

Theme of Female Comaraderie

The theme of female comaraderie is the essence of this caregiving story in that the collaborative actions of these family members reflect the solidarity of intergenerational relationships among the women. The interviews revealed a pattern of women as the emotional support network of the family.

Tradition of Having Fun Together. The connections among the women in Belle's family were evident not only in the area of caregiving but also carried over into having fun. An important part of the comaraderie of these women was to have fun together, whether traveling, shopping, going out to eat, or doing household chores. Throughout their story, Belle and her cousins expressed their enjoyment of doing things together just for the sake of being together. As one of the participant's reminisced, "We'd go pick up [Belle] and go do something with her and my grandmother, just run errands or go shopping or whatever." Mattie and Belle "really got close after [Belle's] mother died," and "especially as young adults they did a lot of things together...but they've always been great friends."

Greatest Reward: Sense of Family. The two younger women interviewed described the primary rewards of the caregiving process as a strengthening of their family relationships, as illustrated by this combination of their comments in response to my question about what aspect of the process had been rewarding:

...the feeling of family, you know, I've gotten closer to my grandmother...and being family with [Belle] and doing things for her. My sister and I are real close. Now it feels weird if we go a day or so without talking during the day, then we'll talk at night. It's brought my sister and I a lot closer together. We talk to each other every day...every night this week we've talked for over an hour. I think I have a lot more sense of family, I'm a lot closer to [my sister] and I'm a lot closer to [grandmother] and I've become more interested in families ties. Overall, it's been, it's not been a negative experience for me. It's been positive because I feel closer to my family.

Their commitment to including their grandmother in the caregiving process is reflected in their appreciation for their grandmother's knowledge about the family, deferring to her judgment on issues like placing Belle with a roommate. Further, the following comment illustrates how they worked together to both include her in a respectful way but protect her from being overwhelmed: "[We] kind of consult each other and we decide what we're going to bring [Grandmother] in on. We'll talk about what we're gonna' do and what we're going to tell [Grandmother], you know, how we're going to involve her. We always involve her."

Greatest Challenge: Being By Myself. Further evidence that the bonds between these women were of prime importance were their responses to my question about the greatest challenges associated with their caregiving experiences,

When they came and told us that she's having a heart attack, we're going to give her the cauterization and I broke down, 'cause there I was, I thought I was by myself...and that was really hard...that situation when she had the heart attack and being by myself.

and

And it was real hard...when I was the only one with her at the doctor. She had fallen asleep...and when [the doctor] came in to give the diagnosis, said that he would be sure to put her resuscitation wishes very clearly on her chart. So it's kinda' sad. This could be it...and [the doctor] said she could very well pass away from this. And I got back in there and was holding her hand and everything...and it's kinda hard dealing with, you know, you asked me if I got upset about her and I do get upset. I don't know how one person does it. It has been a huge help that it's not one person.

For these caregiving women, connection to each other was so important that they considered the worst of circumstances to be those endured without physical and emotional proximity to one another.

Case Four: "I Don't Want to Give Up Yet"

In the late stages of Alzheimer's disease, unable to feed herself and almost nonverbal, 82-year-old Elizabeth brightens with her characteristic smile and says, "Well, look who's here!" as her 23-year-old granddaughter Lizbeth (the third Elizabeth) comes into view, apparently having no idea that Lizbeth had just been there, that she had left the

room to go to the bathroom only moments before. As Lizbeth related this story to me, she laughed heartily, her blue eyes dancing in delight that she could double or triple her grandmother's pleasure by such a simple act as going out and then coming back in. Even though her grandmother actually does not recognize her anymore, Lizbeth explained why she considered her visits worthwhile.

It's some kind of enlightenment to think that it's just the moment that matters...that you can make them happy in that moment, that it's not as sad. And there's something nice about it. If you can accept it for what it is and gain from it what you can. It's not the worst thing and it's not like you'd be better off dead. You can make her happy. It's not a terrible existence.

Lizbeth's remarkable, positive attitude about her relationship with her grandmother mirrors the example of her 52-year-old mother Liz (the second Elizabeth), who described how her beliefs about end-of-life issues had changed as a result of her experiences during the 15 years she had been dealing with her mother's having Alzheimer's disease.

Putting a value that you have to function *at this level* to be of any significance or whatever is something that I have changed my viewpoint on. If you can make the moment pleasant for another person, that's fine. I think the most profound feeling I have is that I feel strongly that people cannot be just discarded because they cannot function at a certain level. Certainly, in some aspects, Mother has lived beyond what most people would want our level of functioning to be, but...there is still value in that

life and it's not for me to say. I feel Mother and I have a wonderful relationship.

For both daughter Liz and granddaughter Lizbeth, caregiving experiences had contributed to their discovery of meaning in their lives and in their interactions with one another.

Lizbeth perceived her mother as intrinsically motivated to do what she does. "...[She] doesn't do it because she wants appreciation or she wants people to think that she's a great person, but she does it because that's what she feels that she needs to do." She added this philosophical comment, "I know now...why [my grandmother's] living the way she is. It gives meaning to my life, it gives my mom a lot of meaning for life."

Transition to Widowhood

The eldest Elizabeth grew up in a privileged environment, in many ways having opportunities to experience life that were not available to the average person, especially for a young woman "in the South." She made sure that not only her daughter (her only biological child) but also her granddaughters (Jo and Lizbeth) had access to some of the same advantages that she had, including going to private schools and traveling abroad. Her husband, described as "a great storyteller...an amazing storyteller," died unexpectedly when Elizabeth was in her mid-sixties, an event identified by her family as one of the initial events relevant to their caregiving story, as outlined in Figure 7. Left alone after over 30 years of marriage, Elizabeth began to spend more time with her daughter and her family, who lived within walking distance of her apartment. Elizabeth was described as a "strong woman...very independent...not a whiner," and, during the period of her transition to

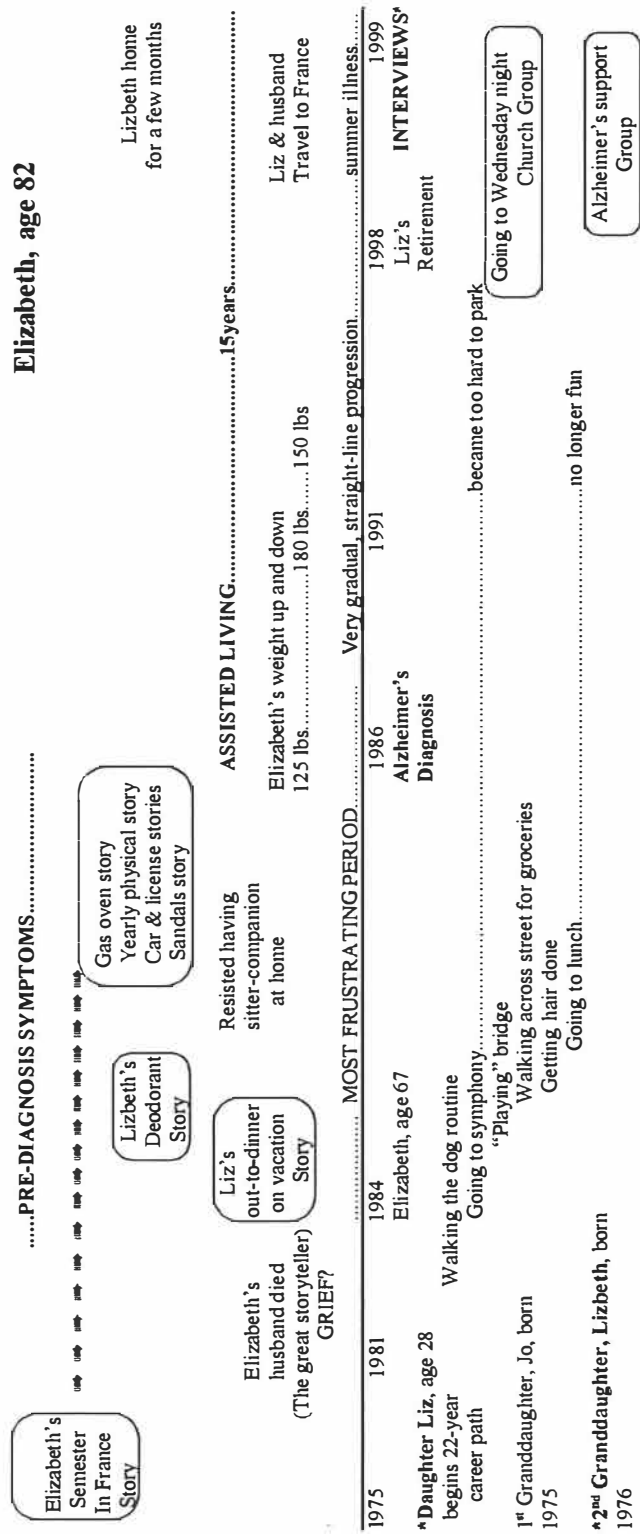


Figure 7. Caregiving Time Line for Case Four

widowhood, she began to spend more time helping her daughter, who was working full-time and caring for her two preschool daughters, by coming over to take the dog for a walk every day and by babysitting whenever she was needed.

Stiff Upper Lip. Liz appreciated her mother's help and accounted for some of the behavior changes she noticed during this transition period as her mother's way of expressing her feelings and working through her grief (i.e., her way of acting like everything was all right and "keeping a stiff upper lip"). For example, Liz had noticed that every time her mother came over, she would repeat her story about when she was in college and had the opportunity to travel to France for a semester. Liz interpreted this mildly annoying behavior as her mother's emerging desire to be the storyteller of the family (i.e., her turn to "take the floor" now that her husband finally had relinquished it). Elizabeth's semester in France was "purely her own story," an account of herself as a young adult before she married her husband and took on responsibility for his two small children (both boys) before having a daughter of her own. Liz also rationalized that maybe her mother's telling of this story helped by letting her dwell on a period of her life that she felt happy and proud about. Thus, Liz was patient with her mother's repetitive story telling, not thinking of it as a serious problem.

Deodorant Story. Lizbeth recalled her earliest memory of noticing that something was wrong with her grandmother as an incident that occurred while Elizabeth was babysitting with her and her sister while their parents were out of town. Only 8 or 9 years old, Lizbeth was in a dance ensemble and wanted to have deodorant in her bag like the other girls, so she put it on the grocery list for her grandmother to buy. Lizbeth

remembers arguing about the deodorant because her grandmother thought that she was too young to need deodorant. The odd thing about this incident was that the next morning, when her grandmother looked at the list, she said, “You need deodorant?” to which Lizbeth replied “Yes,” expecting an argument, and her grandmother just said, “Okay,” with no sign that they had had any argument or discussion about it the evening before. At the time, Lizbeth thought the interaction was odd but did not realize its significance until later when she understood more about Alzheimer’s disease.

Restaurant Incident. The first time Liz thought that her mother’s storytelling behavior might be more than a temporary coping mechanism was about 3 years later during their traditional vacation to their family cabin. They had gotten a sitter for the children, and the three adults went out to dinner. Of course, Liz and her husband were not surprised when Elizabeth started relating her usual story about her semester in France, but they were stunned when she finished it and then immediately began telling it again, completely unaware that she had just told it. Liz and her husband exchanged a look of amazed concern, and, as they continued to express their disbelief that this was happening, Elizabeth interpreted their amazement as heightened interest and embellished her story.

Most Frustrating Period

Liz described the two years that followed the storytelling incident in the restaurant as “the most frustrating period,” with the hardest thing being “wanting to get some agreement on her [mother’s] part for something.” Liz explained that “if something frightening happened, [Elizabeth] would be all agreeable, and it’d be all fine, and then

you'd go the next day, and it was like you'd never discussed it before." Elizabeth's symptoms of cognitive impairment became increasingly more apparent to her family and friends, but she continued to function fairly well living alone, perhaps facilitated by her "very regimented...structured" life style. Liz, looking back on how her mother managed to function as long as she did on her own, remarked,

She was very organized all her life, so that let her function in a familiar environment a lot longer than I think she might have been able to if she was more scatter-brained. You'd say, "Mother, what did you have for breakfast this morning?" I mean, if it's Tuesday, [she would say], "I [had] eggs and toast"...and, if it's Wednesday, [she would say], "it [was] this." She could walk across the street to the grocery store, and she ordered basically the same thing every day. These routines of what happened every day kept her going and able to live there [by herself]. She had a place where she put the bills and that kind of stuff...because they were such ingrained habits.

During this 2-year period, Elizabeth maintained her routines of walking the dog, going to the symphony with her daughter, playing bridge with her friends (who were very tolerant of her condition), walking across the street to get her usual groceries, and going on other outings to familiar places. Elizabeth recalled that during this period her grandmother "was still at the point of making choices, she didn't want to go into a home" and that she "would say 'I don't want to give up, yet, [Liz],' and that would really hurt my mom."

As Elizabeth's cognitive decline gradually progressed and her growing needs surfaced, daughter Liz assumed primary responsibility for taking care of her. Liz persisted in her efforts to get service providers to identify her mother's condition as a serious problem, in spite of a series of frustrating encounters. Among the events identified as being significant during this frustrating period were (a) changing the stove from gas to electric; (b) taking Elizabeth's car away, described as one of "the big issues;" (c) trying to get a referral for neurological evaluation; (d) trying a sitter-companion at home; and (e) deciding about placement in assisted living.

Changing Stove from Gas to Electric. Once, when Liz came to her mother's apartment for her usual daily visit, she almost fainted because the smell of gas was overwhelming. Apparently, her mother had turned on the gas stove but had forgotten to light it (or had forgotten what she was doing in general). Because Elizabeth could not smell the gas (an early sign of Alzheimer's disease), the potential for danger was significant, and Liz was alarmed. However, being her mother's daughter, Liz did not want to overreact, and so she simply had the stove changed over to electric, reasoning that electricity was less dangerous than gas and that her mother could still manage on her own.

Taking Her Car Away. Next, Liz had to figure out a way to get her mother to stop driving, but she did not want to be the one to tell her. She knew that her mother should not be driving because she knew of instances of her driving out somewhere and having trouble finding her way back home. But nothing "really bad" had happened yet, and Liz did not want to be the one to take away her mother's car. Twice she tried unsuccessfully to get help. Her first idea was to let her mother's license expire on purpose

so she would have to take a driving test, which Liz assumed her mother would fail. However, at the driver's license office, they did not pick up on Liz's signals to even give her mother an eye test. Instead they insisted that all she had to do was fill out a form to get a new license. Another time they actually gave her mother a driving test but declared that she was a great driver ("only went through one stop sign"). Finally, Liz took control when she discovered a big dent in her mother's car but her mother had no recollection of an accident. At that point Liz decided that she had to take the car away but recalled during the interview that her mother was "not happy about that." In fact, after Liz's taking away the car, her mother would sometimes come over to the house and start complaining about not having her car, and, according to Liz, the family would just disappear in all directions, not wanting to get involved in a discussion with Elizabeth about this sensitive issue.

Trying to Get a Referral. Having little doubt that something definitely was wrong, Liz continued to try to cope with her mother's symptoms of dementia and she realized the need to identify the source of her mother's cognitive problems. Again, she searched for a clever way to get someone else, this time Elizabeth's family doctor, to be the one to tell her what she had to do. However, she got no support there, either. She took her mother in for her yearly physical and spoke privately to the doctor about her concerns, asking him to refer her mother to a neurologist because Liz figured her mother would go willingly if her regular doctor said she should. Instead of understanding Liz's dilemma, this doctor indicated that, although he thought Alzheimer's disease might be the problem, there was no need to make a referral to a specialist, which, in his opinion, would

only mean spending more money to get the same diagnosis. Liz was frustrated by the doctor's unhelpful response.

Trying a Sitter-Companion. Because her mother was no longer cooking adequate meals or able to drive for herself, Liz decided to hire a sitter-companion to come in during the day to prepare meals, take her where she wanted to go, and make sure everything was safe. Of course, Elizabeth resisted that kind of attention, insisting that she did not need anyone with her and being unable to understand why a sitter was there, and daughter Liz acquiesced, respecting her mother's need to have some control. Liz commented on how her perception of danger had influenced her thinking in making decisions about her mother's situation,

You finally have something that pushes you, you know that it's coming, and, at the same time, I kept thinking that I didn't make the decision early enough, but the only reason you need to make it, in my opinion, is safety, and nothing bad happened to her.

Saying, "Okay, Mother. This is It." The incident that pushed Liz toward further action (i.e., getting her mother into the safer environment) was a deep-freeze, winter day when the temperature outside dropped to about 20 below zero, and her mother walked over to her house for a usual visit and to take the dog for a walk, wearing her "little sandals" and completely unaware that she was dressed inappropriately for the weather. At that point, Liz thought, "Okay, Mother, you've made the decision. This is it." Convinced that it was time to take control, Liz managed to get her mother officially diagnosed, placed in assisted living where she would be safe, and on medication for her

Alzheimer's symptoms. According to Liz, making the decision about assisted living was very difficult, but she "felt confident that [she] had made the right decision." Her mother had adjusted to the assisted living arrangement surprisingly well. As Liz noted, "By the time she started complaining. I could put up with, 'When am I going back to the apartment?' and this kind of stuff." She said that her relationship with her mother actually improved after the move to assisted living, because instead of spending her time arguing or feeling resentful, she could "go out and have a great visit because we are not trying to work something out." During the fifteen years Elizabeth had been in assisted living, she progressed from one level of care to the next as her condition worsened. Liz calculated that her mother would no longer qualify for initial placement in assisted living because of her level of need now that she was in the late stages, needing assistance in numerous areas of personal care. Liz expressed appreciation for the accommodations made by the assisted living facility to keep up with her mother's decline as much as possible, thereby avoiding having to move her to a nursing home facility, a decision not gladly anticipated but which Liz indicated may be the next transition for her family to face.

Analysis of Case Four

When the interviews with Liz and Elizabeth were completed, I accepted their gracious invitation to stay for a wonderful lunch of turkey, bagels and cream cheese during which the question was asked that, if these interviews had been conducted without knowing that the two were mother and daughter, would it have been evident that they were in the same family. My affirmative answer to this analytical query was met with

obvious pleasure, mother and daughter touching finger tips across the corner of the table as if mirroring each other's hands, so natural and in sync with one another in their conversation, eye contact, and hand-touching game that their intergenerational connections were almost palpable to me. Their genuine spirit of connection was consistent with their commitment to being real (i.e., not pretentious). As Lizbeth confessed, "I have a really hard time faking anything. It's all over my face. I would never *not* talk about [Elizabeth's Alzheimer's disease]." Likewise, Liz described her church group's unconditional acceptance of Elizabeth in contrast to the way her mother's high-society friends might have reacted to her somewhat disheveled appearance in the later stages of the disease. Reflected in the words of daughter Liz and granddaughter Lizbeth (which were sometimes almost the same words), several themes were apparent in the caregiving experiences of mother Elizabeth's family: (a) emphasis on structure, (b) importance of autonomy, and (c) awareness of intergenerational connections.

Theme of Emphasis on Structure

The theme of emphasis on structure was central to the caregiving process for this family. They took comfort in the elements of life that were somewhat predictable, pleasant and ordered, and viewed transitions as aberrations of time, to be endured without "whining." Liz described her mother's cognitive decline as a slow, steady progression, a straight line, and not too difficult or uncomfortable to deal with once you "get used to it." She commented that "the transitions are tough" but that she has "pretty well rolled with what the next thing has been." With an emphasis on structure as a way to understand

experience, participants explained their experiences using the language of structure, referring to elements of the caregiving process as being “in that period” or “at that point,” to the condition of care receiver as being “in the last stages” or having “a really bad period,” and to the discomforts of transitional events as being “a really hard time.”

Transitions are Tough. Lizbeth described her discomfort with being undecided about how to structure her life now that she had graduated from college, saying that she felt “really transitory.” Lizbeth spoke of how “soothing” it was to share her uncertainties about the future with her grandmother and have her seem to listen with unconditional acceptance. Lizbeth related how she was feeling lonely and lost one day when she went for a visit and just ended up “spilling it all” out to her grandmother, saying, “This is a hard time for me. I’m trying to figure out what I want to do.” This family also was aware of the importance of their access to abundant financial resources in keeping their lives in balance as they moved from one stage to the next, whether it was going away to college or moving to an assisted living environment.

Compartmentalizing. Not only did the participants describe their experiences in terms of their degree of comfort during various stages and transitions, but also they seemed to thrive on being able to compartmentalize (i.e., to keep the parts and pieces of their lives clearly defined, separate, and in perspective). As Liz noted as her recommended strategy for navigating the complexities of caregiving, “Try to get where there is a balance of meeting the needs.” Important to maintaining this order in their lives were (a) careful monitoring of physical well-being, as evidenced by participants’ references to nutritional standards, personal hygiene, and exercise; (b) attentiveness to

social and spiritual needs, as demonstrated by complex networks of friends and regular attendance at church; and (c) involvement by Liz in the Alzheimer's Association. Liz even related with delight the way Lizbeth recently had described her parents as being in a pleasurable stage of life,

Some good friends...had her over to dinner and she was saying, "You know, my parents are at such a good age." I know exactly what she's talking about because my mother and I had a period that was very wonderful as far as [being] mutually supportive.

Reliance on Routines. Consistent with the way Elizabeth had depended on the structure and even rigidity of her routines to continue living alone, her family had developed routines to maintain their interpersonal connections, each generation attributing the one before with more attention to structure and routine. Liz noted that her mother, the eldest Elizabeth, always had been very self-disciplined and rigid, lamenting that "there was no flexibility. You had to fit everything in and that was hard for me." Nevertheless, (according to granddaughter Lizbeth) Liz's caregiving routines were quite structured and even rigid. She visited Elizabeth at the assisted living facility *every* day after work no matter how tired she was, always had "the need to clean her up and tuck in her shirt," and never stayed "really long," never more than 30 or 45 minutes. Additional evidence of Liz's reliance on structure was reflected in her statement that she "felt for [her] personality...assisted living was just a wonderful thing, because when she was first there I would still take her to the symphony or we would go to church or whatever else and so we could do the things that we had enjoyed doing." With great admiration for Liz's

“incredible” tenacity and attention to detail in caring for Elizabeth, the youngest Elizabeth, Lizbeth, described herself as not thinking or caring about the details as much as her mother but wishing she could be even “half” as good a person as she perceived her mother to be. Lizbeth’s description of her *own* routines with her grandmother, nevertheless, reflected the family’s characteristic emphasis on structure and limits, when she said,

Those moments you can make her happy, and it can be for five minutes.

It’s so worth it for me. It doesn’t matter about if I was there yesterday or six months ago. She’s glad that I’m there for that time. I never want to spend too much time out there because then it takes away from that [pleasure] for me. ‘Cause once it starts getting...she gets grumpy. I just go out there, and if I can make her happy or make her smile, it makes me feel good when I leave.

Appreciating the Moment. Recognition of the moment as a valued element of time was an extension of this family’s emphasis on structure. Both interviewees spoke of how important it was to “realize there is just the moment” and not to look too far into the future. Liz labeled her emotional reaction to one doctor’s projection that her mother might die soon as anticipatory grief and said, “I was amazed at how emotional I felt about it.” Likewise, Lizbeth’s emotion surfaced at the thought of her grandmother’s eventual death, her eyes tearing as she stated, “She’s dying, you know.” She said she wishes she had been able to interact with her grandmother “as an adult,” and she advises her friends “to talk to your grandparents now if you can, [because] when it’s gone, it’s gone.” She felt that the eventual death of her grandmother would be a “different kind of loss,”

involving not only the loss of her grandmother physically but also as loss of the opportunities for sharing that the caregiving process offered both her and her mother.

Theme of Importance of Autonomy

Another persistent family theme was the importance of autonomy. No matter what happened, personal integrity and freedom were an unquestioned priority. This family's high regard for autonomy was reflected in Liz's waiting as long as possible to take over control of her mother's most obvious symbols of autonomy—her car and her apartment. Liz's attempts to get others to direct her mother to relinquish things rather than taking them away herself also illustrates the strength of her belief in her mother's right to keep her freedoms to go and to live where she wanted. She indicated that in some ways her mother became easier to deal with as the disease progressed because "she used to be so bossy before." In explaining the fact that she never considered bringing her mother to live in her house with her family, Liz makes it clear that such an action would have been an unreasonable encroachment on her life, her freedom to be her own person, saying,

As far as coming down to me solely, no one had to just give up their life to take care of her at that point, or for a long time. Never did. I never made myself feel very guilty about not moving mother in here. I just know for myself that...if I am resentful or frustrated...that is really not better for her or for me.

Lizbeth echoed this sense of self-preservation in relation to what she would do if faced with making choices about providing care.

It all depends on where we are, where my dad is...if my dad is not alive, then I would have to have her near me. I'd bring her some place where I could come and see her all the time. It just depends on your career...on so many things.

She added with youthful optimism that "hopefully my mom can remember all these things that she went through...and be cooperative." For a family who values autonomy to the extent that Elizabeth's family demonstrated, the idea of losing one's ability to make decisions, to make choices would be frightening, to say the least. Liz "hated making financial decisions for her [mother]" and delayed as long as possible taking away other basic freedoms, just as she hoped her daughters would do for her if the need ever came about. As she explained her rationale for delaying placement in assisted living, "So the fact that it wasn't an ideal situation is some ways...she should be able to stay there as long as she can, and hope my girls will let me stay where I want...maybe beyond when they think it is good."

Friends and Family as Support System. Having a support system that was wider than the boundaries of family seemed important in this family, as reflected in Liz's comment about the difference between biological family members and the several sets of friends she included on her family diagram at the beginning of the interview. "These are more *family ties* and then these are *choice ties*. I feel like people fill different parts of my needs category. I mean that I've always felt very fortunate that I just didn't have to go to my husband." Lizbeth made a remarkably similar comment as she explained her diagram,

This is just my support system in general...if I didn't know it was about [my grandmother] it would be very different...these are two really good friends of mine that I'll talk to about my grandmother...but then, I have friends that I'll talk to only about what I want to do or boy problems...different things. I have a huge group of friends.

Elizabeth's "only natural child" and only daughter, Liz automatically accepted her role as "sole caregiver," not even considering asking her only still living half-brother to help, partly because she appreciated the "advantage" of being able to make the decisions on her own and partly because he was, as she quipped, "just a guy." Instead, she depended on her daughters, especially her "best help" Lizbeth, her husband, a "great son" who had assumed primary responsibility for managing care for his own mother at another assisted living facility, and her wide circle of friends as her support system. Liz spoke of being aware of her husband's support in the context of the mutual respect they offered one another regarding the time and energy they each contributed to their own mother's care. They operated as autonomously as they could, not asking too much of each other in handling their respective caregiving responsibilities.

Walking, Singing, Driving, Traveling. Lizbeth found it "interesting" that her grandmother's "last stories that she remembered" were about traveling to another country and about getting her driver's license early (when she was only 13-years-old) and that the pleasures of walking and singing have been among her last activities to relinquish. Lizbeth said, "I always knew that kind of thing was important to her—travel...willing to take any life experience and try because that's what's important." Perhaps this family priority of

maintaining as much autonomy as possible is part of why both Lizbeth and her sister have traveled and lived different places, still teasing each other that eventually they will both “end up in the South because it seems like home.” When she talked about how she spent her time during a visit with her grandmother, Lizbeth said,

My mom wants her to walk, so I know that I want to walk her [while I am] there. From [when I was] a little kid, I remember her loving to walk. She walked all the time, and, when her and my mother lived together, they did, and so...that is what I know she would want to be doing, if she were making choices still. I like for her to laugh, and so that’s basically what I try to do, and we go walk...and I usually sing with her...she can usually put in the last word sometimes.

In the context of this family system, it makes sense that the process of taking away or giving up the most tangible symbols of her autonomy—freedom of movement and expression—was difficult. It is interesting that Elizabeth had been able to hold on to two of her greatest pleasures—walking and singing—and that she tried her best to remember the time in her life when she had the most autonomy—as a single, college girl finding her own way in a foreign country. That thought makes you wonder if her journey into Alzheimer’s disease feels somewhat like being lost in another country, like Pipher’s (1999) use of *another country* as a metaphor for movement into the uncharted territory of the disabled old.

Theme of Intergenerational Continuity/Exchange

Intergenerational continuity was another theme apparent throughout this family's caregiving story. Lizbeth, describing her perception of this continuity from one generation to the next, said her grandmother

always would be like, "three [Elizabeth's] right here in a row." My mom and her and I've always felt some sort of connection, I mean I feel like we look alike, and I look in her eyes and they look just like my eyes and her and my mom look so much alike, and I definitely identify with that side of the family so much more than with my father's side of the family.

She continued, wishing she had had a chance to be with her grandmother, "as an adult,"

at this age you really want to know. "Why am I the way I am, and am I connected to my family, and is there something about her that is in me?" I wish now that I could ask her these things. More about my mother as a child. Was she like me...what she thought about my father, what she thought about my grandfather...all these things that you just wonder about.

Interestingly, Lizbeth also said that although when she was younger she did not like her name, Elizabeth, believing that her sister "got the more beautiful name of [Josephine]."

Even so, she said she liked the feeling of connection with her mother and her grandmother represented by their sharing the same name through the three generations. Her feelings about this connection were strong enough that she admitted that she would seriously consider one day naming her own daughter Elizabeth.

Like Mother, Like Daughter, Like Granddaughter. Liz felt that it had been good for her girls to see the way she cares for her mother and to be exposed to old people in general at the assisted living facility, learning not to be ashamed and not to be afraid to be involved with older people. One time Lizbeth came home from college when her grandmother was hospitalized to “check on Mama, and she was having a hard time.” When she talked of the responsibilities her mother had accepted in caring for her grandmother, it made her think of the possibility that she might be in a similar situation someday in relation to her own mother. She remarked with admiration, “Just to see how much she has done for her mom makes me want to be like that, and I know I could never be as good as my mother, because, I mean, she is just incredible.”

Feeling Needed. Lizbeth also spoke of the importance of “feeling needed” for herself and her mother and of her anticipation of the loss of that feeling when the eldest Elizabeth dies. In projecting how she and her sister might approach caregiving roles in relation to their mother in the future, she said, “It’s more in my nature to be *that person* than my sister...she will do all the finances and make sure she is in the best place, but I am the people person. She is the organized one who is on top of things.” She added that thinking about “not having [her mother, Liz] around to talk to forever or the thought of her becoming like my grandmother and not being able to talk to her” made her feel “really nervous.” The atmosphere of mutual support among the women in this family was also evidenced by Liz’s heartfelt comment, “She is my best help, she really *is* my best help, she keeps me cheerful,” as she gave her daughter a waist-high hug before she got up from her chair to turn it over to her daughter between the two interviews.

Sharing Spiritual Dimension. Another element of the caregiving process that seemed to be significant for this family was their sharing the spiritual dimensions of caregiving, as reflected in Lizbeth's statement about the rewards of caregiving.

It gives meaning to my life and it gives my mom a lot of meaning for her life. In years to come, I'll look back on these months as a time of taking a break and being able to see my grandmother...and that's what it's all about, and it's one of the greatest things I've done.

Both participants agreed that significant rewards had come from taking Elizabeth to a special church service on Wednesday nights. According to Liz, the reactions of the people in that group to her being there with her mother had made it worth the effort to get her mother up out of bed and in and out of the car to attend. She explained,

The thing that has been best for me and I think for her is that there is a Wednesday healing service at the [church], and we have gone to that. I thought, "You know, they won't care that she's not dressed right, quite right". The whole group got so glad to see her. She would just smile and be so pleased and so happy about it...the person who was doing the service...would say, "It means so much to me to have your mother there," so even when it got very hard to get her in and out of the car and down there, I'd be saying, "Mother, you've got something you've got to do today." There's something about the relationship of seeing us there, a mother and a daughter, and what they maybe can do for their own and not be ashamed. I think that has been the biggest impact.

Alzheimer's Association Involvement. Also, Liz said her involvement in the activities of the Alzheimer's Association, as both a committee member and a caregiver support group participant, had been meaningful, giving her a chance to learn more about the disease itself as well as giving her an opportunity to help others by sharing her experiences as a long-term Alzheimer's caregiver. In fact, at an Alzheimer's Association function where I first met her, Liz related (with great animation) a story about how two assisted-living staff had insisted that they were not allowed to "help with transfers" but that she had managed to get her mother "transferred" into the car anyway by hailing a physician who happened to be passing by. As her punch line, Liz got the whole committee laughing when she described how fast the two aides got up and offered to help when they saw the physician taking his time to help. Thus, sitting across the meeting table from this obviously excellent story teller who seemed to be able to put a remarkably positive spin on trying circumstances, I welcomed Liz's enthusiastic offer to participate in this study and her assurance that also her daughter, Lizbeth, probably would participate. Indeed, I was privileged and enriched by the opportunity to hear the stories of these remarkable women, "three [Elizabeth's] all in a row."

CHAPTER 5

DISCUSSION

The discussion of the findings generated by the inductive research processes of this collective case study addresses the original lines of inquiry that formed the substantive frame of the study (i.e., the research questions stated in Chapter One and reflected as prompts in the Interview Guides). Next, the results are discussed in comparison to earlier scholarly research findings and in relation to theoretical concepts. Also, implications of the findings for methods, service providers, and caregiving families are identified, and suggestions are offered for future research. Finally, limitations as well as the strengths of the study are considered.

Conclusions from Cross-Case Analyses

The original lines of inquiry (see Chapter 1), now collapsed into three categories of family processes--(a) decision making processes, (b) relationship patterns, and (c) perceptions of challenges and rewards--have served as the framework for this discussion of conclusions for the present study. As outlined in Table 2, cross-case analyses resulted in identification of six thematic elements observable as patterns in the caregiving experiences of the families studied. The discussion of conclusions addresses these six thematic elements as observed across families in the context of the Alzheimer's disease process.

Table 2. Illustrative Quotes for Cross-Case Thematic Analysis

	Case One	Case Two	Case Three	Case Four
1. Theme of Protectiveness	Lou: We did take the gun away. Lou: I never tell her she repeats herself.	Bob: You couldn't get back to sleep for thinking, "She is in such pain." You'd be mad because she woke you up and then you'd feel guilty because you were mad and she was in so much pain.	Nancy & Becca: We're pretty forceful. [Mattie] can be pretty forceful, too, if she wants to. You have to just not be afraid to take charge and even disagree, because you know what the person better, and you have a better feeling for their interests.	Liz: You finally have something that kinda pushes you. I kept thinking I didn't make the decision early enough, but the only reason to make it...is safety.
2. Theme of Intergenerational Legacy	Lou: She's like a mother to me. I've been in the family since I was 16 year old...so we've been through a lot together.	Bob: We get frustrated... and I think [Caroline] gets more frustrated. They've been frustrated with each other a lot over a lifetime.	Mattie: Since my mother taught me to, she used to say, now [Mattie], you love your kinfolk.	Lizbeth: I feel like we look so much alike and...so it just like connection and wanting to know that [Elizabeth] feels that connection, too.
3. Theme of Ambiguity	Lou: And this winter, why, she might come over and stay. I think if we get her here in the winter and she sees how well she's cared for, she'll not go home. But I haven't got her here yet.	Caroline: She really wouldn't make a decision, didn't want to sell her house, didn't want to leave our house, either.	Becca: We're coming to a point, you know, I don't hope that she dies, but I don't want to see her suffer... 'cause that's the hardest thing, is when she does have bouts of being not lucid at all, it's just not her.	Liz: For a while, you thought, if I just tried a little harder. I [thought], "Is this my mother or is this the disease?" It wasn't my mother in many ways.
4. Theme of Men on the Periphery	Vern: I count on my wife. She carries the hard load...the chores that is hard for me.	Caroline: He can sway me...but he knows, ultimately...that's got to be my decision and my timing.	Becca: My boyfriend was real sweet to help me. He wrote out the directions [to the hospital].	Liz: It would never occur to [my half-brother] to do it. He's just a guy.
5. Theme of Perceiving Stress as Either Opportunity or Demand	Alma: I'm not a giver-upper. I've had kind of a hard life, but...I thank the good Lord for my life because it's meant so much with all my kids and my daughter-in-laws, especially [Lou]	Caroline: And I kept saying, I am too young to have... She's not going home. She doesn't want to go, you know, we can't get rid of her. Maria: I don't think it's really that hard to be taking care of a grandmother. I think it's pretty easy.	Mattie: And I really get a blessing out of helping people. Nancy: It's not been a negative experience for me. It's been positive because I feel closer to my family.	Lizbeth: If you can accept it for what it is and gain from it what you can.... It's not the worst thing, and it's not like you'd be better off dead. You can make her happy.
6. Theme of Comaraderie of Women	Lou: I just crawled right in the bed with her and then we laid there in the bed and talked.	Maria: I'm glad she's not going back home because I'd be missing having someone to talk to or somebody to watch tv with.	Nancy: We'd go pick up [Belle] and go do something with her and my grandmother, just run errands or go shopping or whatever.	Liz: She's my best help. She keeps me cheerful. Lizbeth: My mother and I had a period that was very wonderful as far as [being] mutually supportive.

The thematic elements observed across families, discussed within the framework of the original lines of inquiry, include

1. Theme of Protectiveness
2. Theme of Intergenerational Legacy
3. Theme of Ambiguity
4. Theme of Men on the Periphery
5. Theme of Perceiving Stress as Either Opportunity or Demand
6. Theme of Female Comaraderie

Decision-Making Processes

The decision-making strategies in these four families appeared to be founded on protecting the cognitively frail elder from physical danger, with attention to preserving autonomy and sense of dignity as long as possible.

Theme of Protectiveness. Most participants, though not all, reported that one of the most important elements in the decision process was maintaining the care receiver's sense of dignity and personal worth. To illustrate, in Case One, Alma's family removed her gun from her house, not because she could no longer handle it physically but because of the unpredictability of the disease process and their fears for her safety and the safety of others. Generally, families delayed taking control of finances, access to driving, and other symbols of autonomy as long as they could within the parameters of reasonable safety. Because cognitively frail elders physically may be very able, especially during the early and middle stages, the types of protective decisions presented across cases were primarily

influenced by the stage of the Alzheimer's disease process. All four families found themselves having to negotiate changes in daily activities and freedoms, including transportation, living arrangements, nutrition, money management, personal hygiene, social/spiritual needs, and medical needs. To some extent, concern for the physical safety of the cognitively frail elder was part of the rationale used for making decisions, especially during the early and middle stages of the illness. In later stages, concern for potential quality of life became the more critical factor influencing decision making.

Relationship Patterns

Decisions to take on caregiving roles were influenced by family traditions of helping family members in time of need. Also, families noted the uncertainties surrounding diagnosis as well as the relational ambiguities generated by progressive cognitive decline as significant factors in their caregiving experiences.

Theme of Intergenerational Legacy. A sense of filial obligation was reported in all four cases, with adult children, children-in-law, grandchildren, or cousins responding to perceived expectations for helping other family members. In all four caregiving families, participants reported multigenerational patterns in interactions among family members. Alma's family spoke of their history of making it through the hard times by being together, Cora's family revealed a legacy of mother-daughter distance, Belle's cousins' referred to their traditions of helping each other and having fun together, and Elizabeth's family talked about their strong sense of mother-daughter-grandmother connection. That these relational patterns were reflected in each family's approach to caregiving and that these

familiar patterns of connection or conflict continued to be emphasized in family relationships in subsequent generations were not surprising. These intergenerational legacies of emphasis on connection or conflict influenced how family members perceived disease symptoms, felt comfortable with their caregiving roles, and discovered ways to solve problems. Three families spoke of their awareness of other family members as caregiving role models and drew on the experiences of these models in finding ways to solve problems. However, the one family with a tradition of conflict and a legacy of distance found themselves caught in a process of denial, immobilizing the family in terms of their capacity to constructively make decisions or manage stress.

Theme of Ambiguity. The onset of Alzheimer's disease was characterized by ambiguity for all four families. Families felt uncertain about how far to go in making decisions and taking responsibility for the safety of the care receiver during the early stages. Families also reported feeling frustrated during early stages before they understood that the behavior and personality changes were part of the symptoms of the disease and during the middle stages when they felt the need to negotiate necessary changes and decisions with the care receiver. An advantage for caregivers during the later stages was that decisions no longer had to be negotiated because the responsibility for decisions was clearly held almost solely by the caregivers. During the late stages, relational issues surfaced as family members found ways to interact with care receivers who no longer recognized them, finding ways to appreciate the pleasure of the moment and focus on what remained rather than what had been lost.

Theme of Men on the Periphery. Apparent in three families was the tendency for women to take on primary responsibility for caregiving roles and for men to maintain peripheral, supportive roles. In one family, the son-in-law assumed more responsibility for negotiating with the care receiver than the daughter, whose relationship with her mother was strained. Nevertheless, he remained on the periphery in the decision-making process, deferring to his wife's legal status as power-of-attorney for her mother. All four families referred to the importance of the contributions of male family members to the caregiving situation, but those contributions were perceived as supportive rather than direct, involving instrumental assistance and/or emotional support for the female caregivers and/or care receivers. Overall, women, whether working closely together or in open conflict, were identified as the directors of the care process, givers of physical care and, ultimately, those responsible for decisions. Even in the family with the son holding positional authority as power-of-attorney, the daughter-in-law (Lou) held relational power regarding decisions because the son (Lou's husband) and the other adult children waited for her guidance about what action would be in their mother's best interest.

Perceptions of Challenges and Rewards

Families perceived the challenges or stresses of caregiving to some extent as both opportunities for personal growth and demands to be addressed. Families who viewed caregiving challenges as opportunities acknowledged several resources as being important factors in maintaining their positive perspective, including adequate or ample financial resources and availability of other family members to share in caregiving and decision-

making. Also important were their abilities to use humor and creativity as strategies for coping with the ambiguities of the disease and to preserve the care receiver's sense of dignity. To cope with the loss of mutuality and identity in relationships, they reported trying to focus on both the remaining and internalized elements of their earlier relationship rather than the lost elements of their present relationship with the Alzheimer's care recipient. At the same time, they also acknowledged their sense of loss and allowed themselves flexibility in their experience of grief. The emotional support family members were able to offer one another in this process seemed to be a crucial resource for managing the stresses of loss.

Theme of Perceiving Stress as Either Opportunity or Demand. In three of the four families, the emphasis seemed to be on the opportunities the caregiving process had presented to them. For the remaining family, the emphasis seemed to be on the burdens they were being required to endure in the process of caregiving. They could identify no positive gains from their caregiving experiences. In all cases, families referred to transition periods or anticipated changes in the caregiving situation as the most difficult times experienced in the processes of caregiving. The burdened family expressed dissatisfaction with the caregiving experience and viewed these difficulties as disruptive to their family life. Family members reported feelings of depression, agitation, frustration, or irritability for themselves and expressed concern about the emotional well-being of other family members. Clearly, this family emphasized the difficulties presented by the caregiving situation and expressed little hope for moving forward in a more positive manner. In contrast, the other three families felt confident in facing the challenges presented by the

caregiving process. While these families recognized the tasks before them as difficult and/or uncomfortable, they described these tasks as transitional difficulties and saw them as transitory periods of adjustment that must be worked through. Instead of feeling overwhelmed by the challenges, these families sought to marshal their resources to find ways to overcome difficulties and felt confident in their ability to move beyond the difficult period. They viewed the challenges not so much as burdens but as opportunities to solve problems and to support the needs of their cognitively frail family members and their wider family system.

Theme of the Comaraderie of Women. Families' perceptions of rewards in the caregiving process focused on seeking to achieve a sense of personal fulfillment. Participants who felt rewarded by their caregiving experiences spoke of feeling more self-confident and closer to other family members. Three of the families described traditions of comaraderie among women in the family. Participants in all families who felt rewarded by their caregiving experiences indicated that they viewed helping each other during difficult times as an extension of their sense of family cohesion. Two participants in the dissatisfied family reported experiencing no rewards in the caregiving process. As further evidence of the theme of comaraderie of women an important reward factor, it should be noted that this family whose members felt unrewarded reported a legacy of distance among women in their family. The emotional closeness among women sharing caregiving experiences was reinforced by mutual expressions of appreciation among caregivers and care receivers. Interestingly, family members consistently interpreted signs of contentment and statements of gratitude as moments of lucidity for their care receivers, whereas they discounted

agitation or expressions of hostility as a reflection of the disease process. This interpretation of graciousness as lucidity held true regardless of caregivers' knowledge of cooperative or hostile behaviors prior to the illness. Such attributions were, again, an important coping resource for families.

Comparison of Findings to Alzheimer's Family Literature

The three critical issues for Alzheimer's families previously noted from review of the literature--making caregiving decisions, adjusting to relationship changes, and coping with caregiver burden--were consistent with issues that emerged from the narrative data in the present study. Specifically, these data supported findings in the scholarly literature about (a) the motivations of daughters-in-law and sons-in-law for taking on caregiving roles, (b) the progressive involvement of family in decision making for cognitively frail elders, (c) the importance of appreciation and emotional support within the caregiving family, and (d) the influence of the uncertainties of the disease process on family members' perceptions of relationship changes and future challenges that their families might face. In contrast to the emphasis in the literature on caregiver burden, this study captured caregiving experiences characterized by personal fulfillment and opportunities for growth. Most remarkable about these data were the possibilities, if not probabilities, for rewarding, fulfilling, and positive caregiving experiences for Alzheimer's families.

Daughter-in-law and Son-in-law Motivations

Consistent with Globerman's (1996) findings on in-law motivations for caregiving, Case One daughter-in-law Lou and Case Two son-in-law Bob felt satisfied with their caregiving roles as part of their family role performance expectations. Lou's involvement in providing direct care, such as visiting and paying bills, also confirmed Globerman's findings that daughters-in-law were likely to be involved as primary caregivers. However, not consistent with the earlier findings was Bob's direct involvement with his mother-in-law through both instrumental and expressive support in addition to his indirect contributions through the support he offered his wife. The role of sons-in-law in caregiving relationships may be influenced, however, by the quality of the mother-daughter relationship, as was certainly the case for this family.

Progressive Importance of Family in Decision-Making

These data also reinforce High and Rowles' (1995) findings that family involvement with institutionalized elders did not end at the point of placement but rather increased as their cognitively frail elders progressively needed more assistance in decision making. Both families in this study who had placed elders in assisted living facilities had maintained high levels of involvement with the care recipients and increasingly had become more involved as surrogate decision makers. Certainly, the findings of the present study also supported what Brody (1990) termed the myth of abandonment upon residential placement of frail elders.

Importance of Appreciation and Emotional Support

The importance of appreciation among caregiving family members as well as between caregivers and care receivers was apparent in all of the cases in the present study. In Case One, daughter-in-law Lou recalled “the day that blessed me” as the time her mother-in-law told her that she was her “very best friend.” In Case Two, adopted granddaughter Maria described her delight in her grandmother’s compliments on her cooking. In Case Three, all three participants remarked on how important it was to feel like their care receiver appreciated the efforts as well as on how much they appreciated having the support of one another. In Case Four, granddaughter Lizbeth commented on how good it made her feel to be able to share the caregiving experience with her mother (Liz), a sentiment echoed in Liz’s comment that Lizbeth was her “best help.” The role of appreciation as positive factor in the caregiving process is not inconsistent with previous scholarly findings, but, certainly, it is not highlighted in the literature to the extent that it is in the present study. In fact, most of the literature on family caregiving has been problem-saturated, predominated by studies of caregiver stress and perception of burden.

However, consistent with scholarly reports, these data underscored the primacy of emotional support for female caregivers from male family members (Suitor & Pillemer, 1994). All of the female caregivers made references to the importance of emotional support from their partners [except for one (Belle’s cousin Nancy) who noted its absence and described her husband as “selfish,” not only in the context of caregiving but also in other situations that required her involvement with others], acknowledging contributions of instrumental support as important but not as significant as emotional support.

Influence of Uncertainties of Alzheimer's Disease on Relational Processes

Participants in the three families where a diagnosis of Alzheimer's had been made noted the importance of being able to understand their cognitively frail elders' behavior changes as part of the disease process, a phenomenon noted by Bleiszner & Shifflett (1990) in their study involving perception of closeness in Alzheimer's family relationships. Participants also reinforced the findings of Chelsa, Martinson, & Muwaswes (1994) that caregivers described their relationships with care receivers in comparison to their relationships with care recipients prior to the illness.

Theoretical Implications

The findings in this collective case study illustrated and reinforced several of the concepts associated with the theoretical perspectives of family systems, family stress, and symbolic interactionism. The additional concept of the process of denial, which stems from family stress theory in terms of barriers to coping in families, was illustrated by the caregiving dynamics in Case One. Worth noting, however, is the fact that this family was the only one of the four with the care receiver living *in their household*, a factor that may explain some (if not most) of their sense of burden (i.e., their perception of stress as demand rather than opportunity). These data appeared to support Boss's (1988) assertion that perception is the most influential element in the Reuben Hill's (1949) ABC-X model of stress. She asserted, however, that this element of the model has been studied less and described less fully than the other elements of the ABC-X model. Boss's (1993, 1999) extension of the concept of ambiguous loss to the experiences of Alzheimer's families was

supported by the present study, also. In addition, the findings from the present study supported the importance of intergenerational caregiving legacies suggested by Pyke and Bengsten's (1996) identification of family caregiving responses as reflections of either collectivist or individualistic traditions. Further, Bengsten's (1996) conclusions regarding intergenerational solidarity were also supported, as discussed in subsequent sections of this chapter.

Process of Denial/Family Immobilization

Boss (1988) noted the role of boundary ambiguity in family stress events as a barrier to effective stress management, creating a greater likelihood of dysfunctional, long-term denial being used by families. She suggested that the greater the boundary ambiguity surrounding the stressful event, the greater the probability that the family would fall into an extended and dysfunctional cycle of denial. This perspective apparently would explain some of the inability to solve problems and move forward experienced by the family in Case Two (Cora). Their immobilization was reflected in their delay in renting or selling the care receiver's house and in their resistance to creating a permanent place for their son to sleep. Further, their lack of interest in seeking a geriatric psychological assessment and their defining dementia as "normal aging" kept them from facing the realities of the situation they were experiencing. By continuing to deny the reality of their care receiver's cognitive decline, they were unable to take reasonable actions to address the challenges with which they were presented.

Influence of Perception on Experience of Stress

These data also reinforced Boss's (1988) assertion that perception is the most influential element of the double ABC-X model of family stress (McCubbin & Patterson, 1982). Sharing a seat with family stress theorist Pauline Boss on the airport shuttle shortly after her presentation at the National Council of Family Relations annual conference in November 1999, I took the opportunity to share my research interests and asked for her personal observations of Alzheimer's families. She commented that the most remarkable observation she had made so far was the tendency of caregiving families to perceive their experiences as either very negative or very positive, certainly an observation applicable to the families included in this study. Three of the four families considered their caregiving experiences clearly as more positive than negative, identifying the challenges as opportunities and remarking on the rewards of personal fulfillment from their caregiving experiences. On the other extreme, Case Two (Cora's family) viewed their caregiving experience as extremely negative, identifying the challenges as overwhelming stress and the rewards (other than the potential for financial compensation from renting the care receiver's house) as negligible. Even the participant in Case Two who felt rewarded by her caregiving activities (the adopted granddaughter) acknowledged the sense of dissatisfaction in the household as a function of the caregiving situation.

Patterns of Intergenerational Influences: Family Legacies

Bengsten's (1996) longitudinal study of families revealed intergenerational continuities in caregiving responses of families, a phenomenon supported by the findings

of this study. As stated in a panel presentation by Vern Bengsten and his research colleagues at the 1999 National Council on Family Relations Annual Conference, “What goes around comes around.” Bengsten (1996) used the concept of intergenerational solidarity to describe the elements of interaction, cohesion, sentiment, and support between parents and children or grandparents and grandchildren, and he used the concept of intergenerational conflict to describe the negative, conflictual, or nonaffirming elements in those relationships. Bengsten (1996) found that the best predictor of caregiving response from one generation to the next was relational legacies passed on by previous generations. In all four cases studied, legacies of connection or conflict and traditions of closeness or distance were apparent in their approaches to and attitudes about their caregiving experiences. Intergenerational solidarity was most notable in Cases One (Alma), Three (Belle), and Four (Elizabeth), while intergenerational conflict seemed to be the pattern in Case Two (Cora).

In addition, Pyke and Bengsten (1996), using the same longitudinal data, categorized caregiving families as either primarily individualist (i.e., minimizing care and relying on formal resources) or collectivist (i.e., using the care process to reinforce family ties), both concepts that are applicable to the findings of this study. Reflecting collectivist traditions, Alma’s daughter-in-law made it clear that not being alone was an important part of her caregiving experience, and Belle’s cousins worked so closely that no single person could be identified as the primary caregiver currently, although Mattie had assumed this role previously for several years. Reflecting individualist traditions, Elizabeth’s family held individual freedom and autonomy in highest regard, never considering giving up

totally “our lives” to be immersed in the important and rewarding but compartmentalized tasks of caregiving. Cora’s unhappy, individualist caregivers felt their privacy invaded, although her adopted granddaughter delighted in the companionship her grandmother’s presence in their home afforded her.

Methodological Implications

The findings of this study supported Rosenblatt and Fischer’s (1993) suggestion that the family system is the most appropriate unit of analysis for understanding family phenomena. In all four cases, the impact of multigenerational family patterns and problem-solving strategies influenced not only their approach to making decisions but also their perception of the potential challenges and rewards of their caregiving experiences. These family traditions seemed to make more difference than either the availability of external resources or the severity of the care receivers’ symptoms. Overall, these findings underscore the primacy of *individual family culture* in how families experience caregiving, a factor that seems to support the use the family as the unit of analysis in qualitative case study methodology.

On the other hand, extension of the study to additional cases representative of the various stages of the disease process (pre-diagnosis, early, middle, and late) would perhaps enhance understanding of family caregiving experiences at various stages of the disease process. From the perspective of Dr. Blanton’s larger study on family caregiving, within-case and cross-case analyses may reinforce the thematic elements that emerged in the present study or they may reveal new patterns. At the least, the larger study will

provide opportunity to compare cases involving similar stages of Alzheimer's disease as well as those involving similar care settings. Of particular interest would be comparing the experiences of several families in which the person with Alzheimer's was living in the same household. Another analysis that might be useful would be comparison of the experiences of spouse caregivers and adult child caregivers living in the same household as the person with Alzheimer's disease.

Suggestions for Future Research

More research attention should be given to the role of ambiguous loss (Boss, 1993, 1999) in the caregiving experiences of Alzheimer's families, a factor that may be an influential element for family caregiving with or without the presence of Alzheimer's disease or other dementias. The uncertainties that surround the diagnosis, prognosis, and disease process were mentioned as concerns in every family. Maureen Reagan commented in a recent television interview that her stepmother's greatest challenge in coping with former President Reagan's late-stage Alzheimer's disease was not knowing what to expect from one day to the next. Also, as noted on a recent Larry King show focused on President Reagan's recent birthday, for the first time in American history, there is a living former President who is unavailable to the American public. This reality has created some awareness of the experience of ambiguous loss for many in our culture.

Another area needing additional study is the role of Alzheimer's family caregivers as advocates for care receivers in dealing with medical and other service providers, as well as educating others about the realities of Alzheimer's disease. Families in this study often

reported frustrating attempts to get reinforcement from service providers in making decisions affecting care receivers' safety. Also, families referred consistently to instances where they needed to act as advocates on behalf of their cognitively frail care receivers. Lefley (1996), in her extensive study of families providing caregiving to mentally ill adults, spoke of the significance of *advocacy* as enabling caregiving families in this situation to have a sense of *taking control of their lives*. Further, she identified advocacy as the coping mechanism that most clearly distinguished families managing the stresses of their situations most effectively. Thus, further examination of advocacy as a coping mechanism for families providing care to elders cognitively impaired by Alzheimer's disease is needed.

Other areas for further study highlighted by the findings of the present study include the perceptions of caregiving roles performed by men in families and the inclusion of the perspectives of several generations in caregiving processes (e.g., the role of grandchildren, great-grandchildren). Also, of great interest for future study are the perspectives of cognitively frail care receivers, represented in this study by only one participant while in the early stages of cognitive decline. Much is lacking in our understanding of the narrative abilities of cognitively frail elders over the course of the disease process.

Suggestions for Interventions with Caregiving Families

Especially through the early and middle stages of Alzheimer's disease when the symptoms of cognitive decline outpace physical decline, frail elders most often are cared for by families at home. Even after placement in assisted living or nursing home

environments, families continue to be involved in making decisions and in providing emotional, social, and spiritual support for their cognitively frail elders. The findings of the present study of families coping with the challenges of Alzheimer's disease suggest that the following intervention strategies might be helpful in supporting the caregiving efforts of families:

1. Family-unit based consultation services, with professionals trained to facilitate family meetings, offer assistance in moving through transition periods, provide resources for creating a safer environment, and model strategies for interacting with cognitively frail elders.
2. Psychoeducational workshops/seminars about conditions of dementia and resources for family advocacy in the medical community.
3. Internet resources for information, referrals, and sharing experiences.
4. Outreach by the spiritual community to provide opportunities for spiritual growth for caregivers and care receivers.

Support for suggested interventions might come from the local Office on Aging, senior services departments of hospitals, grant funding promoted by the Alzheimer's Association, and volunteers or professionals from the service provider community.

Implications for Caregiving Families Themselves

As noted, service providers may use the findings of this study to develop programming that supports the needs of caregiving families, but also worth noting are the implications of these findings for caregiving families themselves. Many of the family

members who participated in this research commented on their positive feelings about being able to share their caregiving stories and expressed hope that other families might benefit from such opportunities for sharing their reflections and experiences. Several participants indicated that the interview process had prompted some discussion of issues as well as expressions of appreciation among caregivers within their families. Participants clearly felt positive about the potential for their contributions to the field of knowledge about Alzheimer's caregiving to help other families facing similar circumstances.

Present or future caregiving family members who encounter these data in either the present manuscript or other publication formats undoubtedly will interpret them within the context of their own experiences or anticipated experiences and hopefully will benefit from the perspectives of the families herein represented. Caregiving families struggling with the ambiguities of their cognitively frail elders' behaviors may view their own experiences in the context of these cases and learn from the applicable lessons or take away ideas for solving problems or making decisions. Others may realize the importance of recognizing intergenerational legacies that emphasize connection or conflict and be able to use that knowledge to make appropriate caregiving decisions. Generally, as caregiving families process the findings of the present study, perhaps their thinking about their experiences in relation to these findings will help them solve problems or feel more comfortable with their decisions.

Limitations of the Study

The purpose of this qualitative, collective case study--to explore and describe how families perceive their experiences in caring for a cognitively frail elder relative--was achieved. However, achievement of that purpose was limited by the extent to which the experiences of the four families studied resonate with those of families not studied. Of course, these data did not present a predictive model, nor were they intended to do so. However, the findings appeared to parallel explanations offered by both family stress theorist Pauline Boss (1988, 1999) and intergenerational researcher Vern Bengsten (1996).

Several factors related to sampling issues limited the transferability, or generalizability, of the findings in the present study. First, no spousal caregiving dyads were selected for study, limiting caregiving perspectives to adult children, children-in-law, grandchildren, and cousins. Second, all care receivers were female and all primary caregivers were female, limiting exploration of the roles of male family members to those perceived as supportive to the female caregivers. However, though these two factors are limitations, they do reflect the demographic characteristics of the caregiving population, at least in terms of gender. Third, only two or three family members' perspectives were elicited, thereby limiting the story of each family to the views of those interviewed. Fourth, financial resources were available in all families to some extent, with perceived abundant resources in one family. Fifth, comparison cases of caregiving families without presence of dementia were not included in the present study. Weiss (1994) indicated that

the inclusion of a small number of such comparison cases strengthens the basis for generalizing results from qualitative research.

Another limiting factor is that only four cases were selected, each representing a different stage of the disease process, thus limiting data regarding each stage across families. This cross-sectional snapshot of the disease process was useful but not as process-across-time focused as would be longitudinal data on each case.

Strengths of the Study

The most notable strength of this study was the methodological decision to focus on the family as the unit of analysis. Using the family as the unit of analysis allowed for the description of multigenerational family patterns and processes and their influence on families' approaches to caregiving. In addition, using the family as the unit of analysis provided opportunities for triangulation of data related to the family systems.

The diversity of the sample was also a strength. Each case's representation of a different stage of the Alzheimer's disease process suggested that the perception of good caregiving changes with the progression of the disease. The issues for families at the time of onset, such as negotiating freedoms and worrying about safety, appeared to change dramatically by the late stages, such as finding ways to enjoy what remains rather than grieve over what is lost in the relationship. For the phenomena under examination, the diversity of the sample provided maximum opportunity to learn from a relative small number of individuals.

Another obvious strength of the study was capturing caregivers' perceptions of the rewards of caregiving. Opportunities for personal fulfillment and enrichment of family relationships were abundant in these families, a finding not usually reflected in the scholarly literature. Family caregiving processes revolved around themes of protectiveness, mutual appreciativeness, motivations for caregiving "from the heart," and the camaraderie of women. Perhaps the findings of the present study can provide a basis for moving somewhat away from a problem-saturated perspective on the experiences of Alzheimer's families.

REFERENCES

REFERENCES

- Agee, A., & Blanton, P. W. (in press). Service providers' modes of interacting with frail elders and their families: Understanding the context for caregiving decisions. Journal of Aging Studies, forthcoming in 2000.
- Allen, K. R., & Walker, A. J. (1992). A feminist analysis of interview with elderly mothers and their daughters. In J. F. Gilgun, D. Daly, & G. Handel (Eds.), Qualitative Methods in Family Research. Newbury Park: Sage.
- Allen, S. M., Goldscheider, F., & Ciambone, D. A. (1999). Gender roles, marital intimacy, and nomination of spouse as primary caregiver. The Gerontologist, 39 (2), 150-158.
- Amaducci, L., Falcini, M., & Lippi, A. (1993). Descriptive epidemiology and risk factors for Alzheimer's disease. In B. Corain, K. Iqbal, M. Nicolini, B. Winblad, H. Wisniewski, & P. Zatta (Eds.), Alzheimer's disease: Advances in clinical and basic research. New York: John Wiley & Sons Ltd.
- Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlach, C. J. (1995). Profiles in caregiving: The unexpected career. San Diego: Academic Press.
- Aronson, M. K. (1992). Reducing stress in caregivers of dementia patients. In J. E. Jackson, et al. (Eds.), Alzheimer's disease: Long term care. San Diego: San Diego University Press.
- Barusch, A. S. (1991). Elder care: Family training and support. Newbury Park: Sage.
- Bengsten, V. L. (1996). Continuities and discontinuities in intergenerational relationships over time. In V. L. Bengsten, Ed., Adulthood and Aging. New York: Springer.
- Bengsten, V. L., Rosenthal, C., & Burton, L. (1996). Paradoxes of families and aging. In R. H. Binstock and L. K. George (Eds.), Handbook of aging and the social sciences, 4th edition. San Diego: Academic Press.
- Binstock, R. H., & Murray, T H. (1998). Genetics and long-term-care insurance: Ethical and policy issues. In S.G. Post & P. J. Whitehouse (Eds.), Genetic testing for Alzheimer disease: Ethical and clinical issues. Baltimore: Johns Hopkins University Press.
- Blieszner, R., & Shiflett, P. A. (1990). The effects of Alzheimer's disease on close relationships between patients and caregivers. Family Relations, 39, 57-62.

- Boss, P. (1988). Family stress management. Newbury Park: Sage.
- Boss, P. G. (1993). The reconstruction of family life with Alzheimer's disease: Generating theory to lower family stress from ambiguous loss. In P. G. Boss, W. J. Doherty, R. LaRossa, W. R. Schumm, & S. K. Steinmetz (Eds.) Sourcebook of Family Theories and Methods: A Contextual Approach. New York: Plenum Press.
- Boss, P. (1999). Ambiguous loss: Learning to live with unresolved grief. Cambridge, MA: Harvard University Press.
- Brody, E. M. (1990). Women in the middle: Their parent-care years. New York: Springer.
- Brubaker, T. H. (1990). Families in later life: A burgeoning research area. Journal of Marriage and the Family, 52, 959-981.
- Burke, J. R., & Morgenlander, J. C. (1999). Update on Alzheimer's disease: Promising advances in detection and treatment. Postgraduate Medicine, 106 (5), 85-96.
- Caron, W. A. (1997). Family systems and nursing home systems: An ecosystemic perspective for the practitioner. In T. D. Hargrave & S. M. Hanna (Eds.), The aging family: New visions in theory, practice, and reality. New York: Brunner/Mazel.
- Carroll, D. L. (1989). When your loved one has Alzheimer's: A caregiver's guide. New York: Harper and Row.
- Carter, B., & McGoldrick, M. (1989). The changing family life cycle: A framework for family therapy, 2nd ed. Boston: Allyn and Bacon.
- Chamberlain, C. (1999). Alzheimer's inevitable path: The disease gradually robbed Reagan of memory. ABC News Internet Ventures, ABCNEWS.com.
- Chelsa, C., Martinson, I., & Muwaswes, M. (1994). Continuities and discontinuities in family members' relationships with Alzheimer's patients. Family Relations, 43, 3-9.
- Choi, N. G. (1996). The never married and divorced elderly: Comparison of economic and health status, social support, and living arrangement. Journal of Gerontological Social Work, 26, 3-25.
- Cicirelli, V. G. (1984). Marital disruption and adult children's perception of their siblings' help to elderly parents. Family Relations, 33, 613-621.

- Cicirelli, V. G. (1991). Family caregiving: Autonomous and paternalistic decision making. Newbury Park: Sage.
- Cohen, D., & Eisdorfer, C. (1988). Depression in family members caring for a relative with Alzheimer's disease. Journal of the American Geriatrics Society, 36, 885-889.
- Coleman, M., Ganong, L., & Cable, S. M. (1997). Beliefs about women's intergenerational family obligations to provide support before and after divorce or remarriage. Journal of Marriage and the Family, 59, 165-176.
- Cowgill, D. O. (1974). Aging and modernization: A revision of the theory. In J. F. Gubrium (Ed.), Late life communities and environmental policy.
- Creswell, J. W. (1998). Qualitative inquiry and research design: Choosing among five traditions. Thousand Oaks, CA: Sage Publications.
- Cutler, N. R., & Sramek, J. J. (1996). Understanding Alzheimer's disease. Jackson: University of Mississippi Press.
- Dempsey, N. P., & Pruchno, R. A. (1993). The family's role in the nursing home: Predictors of technical and non-technical assistance. Journal of Gerontological Social Work, 21, 127-145.
- DeGenova, M. K. (1997). Families in cultural context: Strengths and challenges in diversity. Mountain View, CA: Mayfield Publishing.
- Denzin, N. K. (1978). The research act: A theoretical introduction to sociological methods. New York: McGraw-Hill.
- Denzin, N. K. (1989). Interpretive interactionism. Newbury Park: Sage Publications.
- Denzin, N. K., & Lincoln, Y. S., (Eds.). (1994). Handbook of qualitative research. Thousand Oaks, CA: Sage Publications.
- Dervarics, C. (1999). The coming of age of older women. Population Today, 27(2), 1-2.
- Dillehay, R. C., & Sandys, M. R. (1990). Caregivers for Alzheimer's patients: What we are learning from research. International Journal of Aging and Human Development, 30(4), 263-285.

- Dilworth-Anderson, P., Williams, S. W., & Cooper, T. (1999). The contexts of experiencing emotional distress among family caregivers to elderly African Americans. Family Relations, 48, 391-396.
- Dobrof, R., & Ericsson, K. (1993). The role of formal organizations in the provision of care for people with Alzheimer's disease. In B. Corain, K. Iqbal, M. Nicolini, B. Winblad, H. Wisniewski, & P. Zatta (Eds.), Alzheimer's disease: Advances in clinical and basic research. New York: John Wiley & Sons Ltd.
- Doty, P., Jackson, M. E., & Crown, W. (1998). The impact of female caregivers' employment status on patterns of formal and informal care. The Gerontologist, 38(3), 331-341.
- Dukes, S. (1984). Phenomenological methodology in the human sciences. Journal of Nursing and Scholarship, 18 (2), 39-43.
- Dupuis, S. L., & Norris, J. E. (1997). A multidimensional and contextual framework for understanding diverse family members' roles in long-term care facilities. Journal of Aging Studies, 11 (4), 297-325.
- Erlanger, M A. (1997). Changing roles and life-cycle transitions. In T. D. Hargrave & S. M. Hanna (Eds.), The aging family: New visions in theory, practice, and reality. New York: Brunner/Mazel.
- Fisher, L., & Lieberman, M. A. (1994). Alzheimer's disease: The impact of the family on spouses, offspring, and in-laws. Family Process, 33, 305-325.
- Fisher, L., & Lieberman, M. A. (1999). A longitudinal study of predictors of nursing home placement for patients with dementia: The contribution of family characteristics. The Gerontologist, 39 (6), 677-686.
- Fisher, W. (1989). Clarifying the narrative paradigm. Communication Monographs, 56, 55-58.
- Fox, G. L., Bargen, J. V., & Jester, M. (1996). Managing murder: Parents as mediators of children's experiences. Journal of Family Issues, 1, 91-100.
- Frederickson, K. I., & Scharlach, A. E. (1997). Caregiving and employment: The impact of workplace characteristics on role strain. Journal of Gerontological Social Work, 28 (4), 2-22.
- Friedland, R. B., & Summer, L. (1999). Demography is Not Destiny. New York: National Academy on Aging.

- Gallagher, S. K. (1994). Older people giving care: Helping family and community. Westport, CT: Auburn House.
- Gauthier, S. (1999). Managing expectation in the long-term treatment of Alzheimer's disease. Gerontology, 45 (1), 33-38.
- Glaser, B. G., & Strauss, A. L. (1968). The discovery of grounded theory: Strategies for qualitative research. London: Weidenfeld & Nicolson.
- Globerman, J. (1996). Daughters- and sons-in-law caring for relatives with Alzheimer's disease. Family Relations, 45, 37-45.
- Greenberg, V. E. (1996). Children of a certain age: Adults and their aging parents. New York: Lexington books.
- Groger, L. (1994). Decision as process: A conceptual model of black elders' nursing home placement. Journal of Aging Studies, 8 (1), 137-153.
- Groger, L., Mayberry, P. S., & Straker, J. K. (1999). What we didn't learn because of the people who wouldn't talk to us. Qualitative Health Research, 9 (6), 829-835.
- Gubrium, J. F. (1988). Family responsibility and caregiving in the qualitative analysis of the Alzheimer's disease experience. Journal of Marriage and the Family, 49, 773-786.
- Gubrium, J. F. (1991). The mosaic of care: Frail elderly and their families in the real world. New York: Springer.
- Gubrium, J. F., & Holstein, J. A. (1990). What is family? Mountain View, CA: Mayfield.
- Hargrave, T. D., & Hanna, S. M. (1997). Aging: A primer for family therapists. In T. D. Hargrave & S. M. Hanna (Eds.), The aging family: New visions in theory, practice, and reality. New York: Brunner/Mazel.
- Harlton, S., Keating, N., & Fast, J. (1998). Defining eldercare for policy and practice: Perspectives matter. Family Relations, 47, 281-288.
- Harris, P. B. (1998). Listening to caregiving sons: Misunderstood realities. The Gerontologist, 38 (3), 342-352.
- Henderson, A. S. (1990). Epidemiology of dementia disorders. In R. J. Wurtman, et al. (Eds.), Advances in Neurology, Vol. 51: Alzheimer's disease. New York: Raven Press Ltd.

- Hendricks, J. (1996). Qualitative research: Contributions and advances. In R. H. Binstock and L. K. George (Eds.), Handbook of aging and the social sciences, 4th edition. San Diego: Academic Press.
- High, D. M., & Rowles, G. D. (1995). Nursing home residents, families, and decision making: Toward a progressive surrogacy. Journal of Aging Studies, 9 (2), 101-117.
- Hill, R. (1949). Families under stress. Westport, CT: Greenwood.
- Holstein, M. (1997). Alzheimer's disease and senile dementia, 1185-1920: An interpretive history of disease negotiation. Journal of Aging Studies, 11 (1), 1-13.
- Horowitz, A. (1985). Sons and daughters as caregivers to older parents: Differences in role performance and consequences. The Gerontologist, 25(6), 612-617.
- Ikkink, K. K., Tilburg, T. V., & Knipscheer, C. P. M. (1999). Perceived instrumental support exchanges in relationships between elderly parents and their adult children: Normative and structural explanations. Journal of Marriage and the Family, 61, 831-844
- Janesick, V. J. (1994). The dance of qualitative research design: Metaphor, methodolatry, and meaning. In N. K. Denzin & Y. S. Lincoln, Handbook of Qualitative Research. Thousand Oaks: Sage.
- Jett, K. M., Coward, R. T., Schoenberg, N. E., Duncan, J. W., Dwyer, J. W. (1996). The influence of community context on the decision to enter a nursing home. Journal of Aging Studies, 10 (3), 237-254.
- Jorgensen, D. L. (1989). Participant observation: A methodology for human studies. Newbury Park: Sage Publications.
- Keith, C. (1995). Family caregiving systems: Models, resources, and values. Journal of Marriage and the Family, 57, 179-189.
- Keysor, J. J., Desai, T., & Mutran, E. J. (1999). Elders' preferences for care setting in short- and long-term disability scenarios. The Gerontologist, 39 (3), 334-344.
- Kivnick, H. Q., & Jernstedt, H. L. (1996). Mama still sparkles: An elder role model in long-term care. In J. F. Gilgun & M. B. Sussman (Eds.), The Methods and Methodologies of Qualitative Research. New York: Haworth Press.

- Klein, D. M., & White, J. M. (1996). Family Theories: An introduction. Thousand Oaks: Sage Publications.
- Kriseman, N. L., & Claes, J. A. (1997). Gender issues and elder care. In T. D. Hargrave & S. M. Hanna (Eds.), The aging family: New visions in theory, practice, and reality. New York: Brunner/Mazel.
- Lefley, H. P. (1996). Family caregiving in mental illness. Thousand Oaks, CA: Sage Publications.
- Lieberman, M. A., & Fisher, L. (1999). The effects of family conflict resolution and decision making on the provision of help for an elder with Alzheimer's disease. The Gerontologist, 39 (2), 159-166.
- Lincoln, Y., & Guba, E. (1985). Naturalistic inquiry. Beverly Hills, CA: Sage Publications.
- Long, J. (1997). Alzheimer's disease and the family: Working with realities. In T. D. Hargrave & S. M. Hanna (Eds.), The aging family: New visions in theory, practice, and reality. New York: Brunner/Mazel.
- Mace, N. L., & Rabins, P. V. (1999). The 36-hour day (3rd ed.). Baltimore: Johns Hopkins Press.
- Maxwell, J. A. (1996). Qualitative research design: An interactive approach. Newbury Park: Sage Publications.
- McCracken, G. (1988). The long interview. Newbury Park: Sage Publications.
- McCubbin, H.I., & Patterson, J. M. (1982). Family stress, coping, and social support. Springfield, IL: Charles C. Thomas.
- McGowin, D. F. (1993). Living in the labyrinth: A personal journey through the maze of Alzheimer's. New York: Delacorte Press.
- McGrew, K. B. (1998). Daughter' decisions: From an impulse to a balancing point of care. Journal of Women & Aging, 10(2), 40-65.
- McKeith, I. G., et al. (Eds.). (1999). Outcome measures in Alzheimer's disease. London: Marin Dunitz.
- Mead, G. H. (1934). Mind, self, and society (C. Morris, Introduction and Ed.). Chicago: University of Chicago Press.

- Mellins, C. A., Blum, M. J., Boyd-David, S. L., & Gatz, M. (1993). Family network perspectives on caregiving. In M. A. Smyer (Ed.), Mental Health and Aging. New York: Springer.
- Miles, M. B., & Huberman, A. M. (1994). Qualitative data analysis: An expanded sourcebook, 2nd edition. Thousand Oaks: Sage.
- Miller, S. C., Prohaska, T. R., & Furner, S. E. (1999). Nursing home admission for African Americans with Alzheimer's disease. Journal of Gerontology: Medical Sciences, 54A (7), M365-M369.
- Moon, S. M., & Trepper, T. S. (1996). Case study research. In D. H. Sprenkle & S. M. Moon (Eds.), Research Methods in Family Therapy. New York: Guilford Press.
- Mui, A. C. (1995). Multidimensional predictors of caregiver strain among older persons caring for frail spouses. Journal of Marriage and the Family, 57, 733-740.
- Naleppa, M. J. (1996). Families and the institutionalized elderly: A review. Journal of Gerontological Social Work, 27(½), 87-111.
- Neal, M. B., Chapman, N. J., Ingersoll-Dayton, B., & Emlen, A. C. (1993). Balancing work and caregiving for children, adults, and elders. Newbury Park CA: Sage Publications.
- Olson, L. K., ed. (1994). The graying of the world: Who will care for the frail elderly? New York: Haworth Press.
- Pearlin, L. I., Aneshensel, C. S., Mullan, J. T., & Whitlach, C. J. (1996). Caregiving and its social support. In R. H. Binstock and L. K. George (Eds.), Handbook of aging and the social sciences, 4th edition. San Diego: Academic Press.
- Pipher, M. (1999). Another country: Navigating the emotional terrain of our elders. New York: Riverhead Books.
- Pohl, J. M., Collins, C. E., & Given, C. W. (1998). Longitudinal employment decisions of daughters and daughters-in-law after assuming parent care. Journal of Women and Aging, 10(1), 59-74.
- Post, S. G., Whitehouse, P. J., & Zinn, A. B. (1998). Introduction: Genetics and the moral future of dementia care. In S.G. Post & P. J. Whitehouse (Eds.), Genetic testing for Alzheimer disease: Ethical and clinical issues. Baltimore: Johns Hopkins University Press.

- Pyke, K. D., & Bengtson, V. L. (1996). Caring more or less: Individualistic and collectivist systems of family eldercare. Journal of Marriage and the Family, 58, 379-392.
- Reagan, M. (1999). Maureen Reagan says father's world getting smaller. Interview, 10-21-99, ABC News Internet Ventures, ABCNEWS.com.
- Reinhard, S. C., & Horowitz, A. V. (1995). Caregiver burden: Differentiating the content and consequences of family caregiving. Journal of Marriage and the Family, 57, 71-750.
- Riddick, C. C., Cohen-Mansfield, J., Fleschner, E., & Kraft, G. (1992). Caregiver adaptations to having a relative with dementia admitted to a nursing home. Journal of Gerontological Social Work, 19 (1), 51-76.
- Rosenblatt, P. C., & Fischer, L. R. (1993). Qualitative family research. In P. G. Boss, W. J. Dougherty, R. LaRossa, W. R. Schumm, & S. K. Steinmetz (Eds.), Sourcebook of Family Theories and Methods: A Contextual Approach. New York: Plenum Press.
- Rubin, E. H. (1990). Psychopathology of senile dementia of the Alzheimer's type. In R. J. Wurtman, et al. (Eds.), Advances in neurology, Vol. 51: Alzheimer's disease (pp. 53-59). New York: Raven Press, Ltd.
- Schoenberg, N. E., & Coward, R. T. (1997). Attitudes about entering a nursing home: Comparisons of older rural and urban African-American women. Journal of Aging Studies, 11 (1), 27-47.
- Smith, L. M. (1978). An evolving logic of participant observation, educational ethnography and other case studies. In L. Shuman (Ed.), Review of Research in Education, Vol. 6, pp. 316-377. Itasca, IL: Peacock.
- Snyder, L. (1992). Strategies for providing special services to Alzheimer's patients: Nursing home placement and family concerns. In J. E. Jackson, et al. (Eds.), Alzheimer's disease: Long term care. San Diego: San Diego University Press.
- Stake, R. E. (1994). Case studies. In N. K. Denzin & Y. S. Lincoln, Handbook of Qualitative Research. Thousand Oaks: Sage.
- Stake, R. E. (1995). The art of case study research. Thousand Oaks, CA: Sage Publications.

- Starrels, M. E., Ingersoll-Dayton, B., Dowler, D. W., & Neal, M. B. (1997). The stress of caring for a parent: Effects of the elders' impairment on an employed, adult child. Journal of Marriage and the Family, 59, 860-872.
- Strauss, A. L., & Corbin, J. (1994). Grounded theory methodology: An overview. In N. Denzin & Y. S. Lincoln (Eds.), Handbook of qualitative research (pp. 273-285). Thousand Oaks, CA: Sage.
- Suitor, J. J., & Pillemer, K. (1994). Family caregiving and marital satisfaction: Findings from a 1-year panel study of women caring for parents with dementia. Journal of Marriage and the Family, 56, 681-690.
- Terry, R. D. (1992). Why do an autopsy? In J. E. Jackson, et al. (Eds.), Alzheimer's disease: Long term care. San Diego: San Diego University Press.
- U. S. Bureau of the Census. (1989). Projections of the population of the U. S. By age, sex and race: 1988-2080. Current population reports. Series P-25, no. 1018, U. S. Department of Commerce.
- Vetter, P. H., Krauss, S., Steiner, O., Kropp, P., Moller, W. D., Moises, H. W., & Koller, O. (1999). Vascular dementia versus dementia of Alzheimer's type: Do they have differential effects on caregivers' burden? Journal of Gerontology: Social Sciences, 54B(2), S93-S98.
- Waters, R. (1997). Estrogen to prevent Alzheimer's? Health, January/February, 40-42.
- Weiss, R. S. (1994). Learning from strangers: The art and method of qualitative interview studies. New York: The Free Press.
- West, M. J., Coleman, D. G., Flood, & Troncoso, J. C. (1997). Is Alzheimer's disease accelerated aging? Different patterns of age and Alzheimer's disease related neuronal losses in the hippocampus. In B. T. Hyman, C. Duyckaerts, and Y. Christen (Eds.), Connections, cognition, and Alzheimer's disease. Berlin/Heidelberg: Springer.
- Whitehouse, P. J. (1998). Therapeutic interventions in Alzheimer disease: Implications of genetic advances. In S.G. Post & P. J. Whitehouse (Eds.), Genetic testing for Alzheimer disease: Ethical and clinical issues. Baltimore: Johns Hopkins University Press.
- Wright, L. K. (1993). Alzheimer's disease and marriage. Newbury Park: Sage Publications.

- Yin, R. K. (1989). Case study research: Design and methods. Newbury Park: Sage Publications.
- Zarit, S. H., Orr, N. K., & Zarit, J. M. (1985). The hidden victims of Alzheimer's disease: Families under stress. New York: New York University Press.
- Zarit, S. H., & Whitlach, C. J. (1992). Institutional placement: Phases of the transition. The Gerontologist, 32, 665-672.
- Zeller, N., & Farmer, F. M. (1999) 'Catchy, clever titles are not acceptable': Style, APA, and qualitative reporting. International Journal of Qualitative Studies in Education, 1, 3-19.

APPENDICES

APPENDIX A

PRISCILLA BLANTON'S FAMILY CAREGIVING RESEARCH PROJECT

CONTENTS–APPENDIX A

A-1. Institutional Review Board (IRB) Application for Review of Research Involving Human Subjects, Form B	191
A-2. Summary of Family Caregiving Research Project	201
A-3. Informed Consent Form	202
A-4. Cognitive Mapping Activity	203
A-5. Demographic Information Sheet	204
A-6. Interview Guides	205

IRB# _____
Date received in OR _____

FORM B

THE UNIVERSITY OF TENNESSEE

Application for Review of Research Involving Human Subjects

IDENTIFICATION OF THE PROJECT:

A. PRINCIPAL INVESTIGATOR(S) and/or CO-PI(s):

Dr. Priscilla Blanton, Faculty
Department: Child & Family Studies
Address and Phone Number:
115 Jessie Harris Building
974-6270
e-mail: pblanton@utk.edu

B. PROJECT CLASSIFICATION:

Faculty Research Project

C. TITLE OF PROJECT:

The Impact of Caregiving to the Frail Elderly in Families

D. STARTING DATE:

Upon approval by the Office of Research

E. ESTIMATED COMPLETION DATE:

December, 2000

F. EXTERNAL FUNDING:

n/a

II. PROJECT OBJECTIVES:

The purpose of this project is to describe the impact of caregiving to the frail elderly on families through interviewing those involved in the caregiving process. Specifically, I am interested in identifying the stresses and rewards family members perceive as being associated with the experience of caregivers. Further, the ways in which caregivers manage the caregiving process and the coping resources they utilize will also be explored.

**A-1. Institutional Review Board (IRB) Application for Review of Research
Involving Human Subjects, Form B**

III. DESCRIPTION AND SOURCE OF RESEARCH PARTICIPANTS:

Participants in the study will be those individuals involved in caregiving to the elderly in their families. Potential participants will be informed about the study via a one page description (see Appendix A) of the project. This description of the study will be distributed to community agencies and programs providing services to the elderly and their families. These agencies will include adult daycare programs, assisted living facilities, nursing homes, senior citizen centers, the Alzheimer's Association, the Office on Aging, and home health programs. Agencies in both Knox and Blount County will be given descriptions of the study to distribute to clients they provide services to who are involved in providing care to frail elderly family members. Agencies were selected because they frequently have contact with such families. There will be approximately 25 families selected for participation in the study with 2-3 members of each family being interviewed. Criteria for inclusion in the study is the experience of being involved in providing care to a frail elderly family member. There are no criteria for exclusion from the study.

The description for the research project will instruct anyone interested in participating to contact Dr. Blanton by telephone at her university office. When potential participants call, they will be provided additional information about the project and any questions they have will be answered. If they indicate a willingness to participate, a time will be set for them to be interviewed at a private location of their choosing. They will be provided with an informed consent form at initial contact with them at the agreed upon appointment time (see Appendix B). Only after they have read and signed the informed consent form will the interview be started.

The consent form makes it clear that their participation is strictly voluntary and that they are free to withdraw their consent at any time during their participation without any loss of benefits or penalty. Interviews will be audio-taped and, if they withdraw consent, the tape of any conversation with them will be erased in their presence.

Subjects will be asked to provide the names and telephone numbers of 1-2 family members that they feel are most involved in the process of caregiving with them. These additional family members will be contacted by telephone to request their participation in the study also. The same procedures used with the first family member will be followed with subsequent family members if they are interested in participation in the study. Each family member will be assured of the confidentiality of the information they provide in the interview process and will be assured specifically that the information they share will not be communicated to other family members.

In addition to the participants identified through community agencies, a snowballing technique may also be used to identify potential participants. At the end of each interview, participants will be asked if they would like to provide names and telephone numbers of other families they know who are also involved in caregiving to elderly family members. It will be explained that these potential participants will be called and only told that their name was given to me as someone who might be interested in being interviewed by the person who supplied their name and telephone number. The fact that the person supplying the name and telephone number was a study participant will not be revealed.

IV. METHODS AND PROCEDURES:

Overview: Interviews will be conducted by myself and graduate students who will be trained and supervised by me in conducting interviews. Participants will be provided with the credentials and qualifications of their interviewer during their initial telephone contact with me. Interviews will be an one and a half to two hours in length. Examples of the questions to be posed during the interview are in Appendix C. Interviews will be relatively open-ended and appropriate probes and follow-up questions will be utilized by the interviewer. The open-ended interview format was selected to allow both the interviewer and interviewee flexibility in steering the direction of the interview which contribute to an emergent design. The interview will open with the interviewer asking the interviewee to, "Tell me about the situation in your family that involves you in helping to provide care to an elderly family member." The interviewer will probe with appropriate, subsequent questions based upon the interviewee's response to this first question. Interviews will be audio-taped with a hand-held recorder and tape recordings will be transcribed by clerical staff in the CFS department office. The research team (myself and graduate students involved in doing the interviewing) will analyze the transcriptions of the interview to identify themes most salient to the topic of investigation. Data analysis will be on-going during the research project.

Participants in the study will also be asked to fill out a one-page questionnaire providing sociodemographic information about themselves and their families. A copy of this questionnaire is in Appendix D.

After each interview is completed, the interviewer will within the following twenty four hours, write out reflective notes about the interview process. The focus of the reflective notes will be on the interviewer's intuitions, thoughts, feeling, assumptions, and somewhat subjective speculations about the interview process. Reflective notes will provide subjective influences that may help the research team form a more complete picture of the interview process.

V. SPECIFIC RISKS AND PROTECTION MEASURES:

The identity of all participants will be kept confidential through the use of pseudonyms in all transcriptions of interviews and reflective field notes. The consent forms will be stored in a locked cabinet in Dr. Blanton's locked office (421 JHB) for three years past completion of the study, after which they will be shredded by Dr. Blanton.

After transcription and analysis, data will be stored in the locked office of Dr. Blanton along with reflective notes. Only pseudonyms will be used on the transcriptions of interviews and reflective notes.

There are relatively minimal risks associated with participation in the study. Participation is voluntary and it is anticipated that those individuals who might find the content or process of the interview unduly threatening will probably self-select themselves out of the study. It is anticipated that participants may find it helpful to talk about their experiences in caregiving to elderly family members. However, if the interviewee evidences undue anxiety or other negative emotional responses to the interview process, they will be informed that the interviewer can provide them with the name and telephone number of the mental health center that provides services in their catchment area if they would like the opportunity to talk further about their concerns.

All data will be kept confidential. The minimal risk of breach of confidentiality will be controlled through the consistent use of pseudonyms for names and locations in all written materials. If there is descriptive information revealed in the interview about their family situation which might be recognized by others, it will be changed so that confidentiality is maintained. All data will be stored in a locked file cabinet in Dr. Blanton's locked office (JHB 421) separate from the consent forms which will be kept in another locked file cabinet in the same office. The data will be used for research purposes only and no names will be associated with any published findings. Data will be prepared in manuscript format and may be published in professional journals or books. The data may also be presented at professional meetings and used for educational purposes. All data will be archived in Dr. Blanton's locked office for a period of five years after which it will be destroyed.

VI. BENEFITS:

The anticipated benefits of participation in the study include the possibilities of a greater awareness and understanding of the participant's experiences in providing care to an elderly family member. In addition, each interviewee will be provided with a copy of the Directory of Services available for the elderly compiled and published by the Office on Aging in their county of residence (Knox or Blount). These directories may help them identify services they need for caregiving to elderly family members.

A-1, IRB, continued

This study will help social science professionals become more aware of the impact on the family of the process of caregiving to an elderly family member. More and more families in our society will be involved in this process as the length of the lifespan increases and the proportion of our population that is elderly also increases. Currently it is estimated that families provide caregiving that is more complex and extends for a larger period of time than ever before in our society. This research contributes to our understanding of how families deal with the demands of caregiving and can provide information about the ways in which families could be supported in providing care.

VII. METHODS FOR OBTAINING INFORMED CONSENT:

Use of a written consent document will be used to obtain informed consent from study participants. The informed consent form has been attached (Appendix B) for IRB review. The informed consent form will be hand delivered to participants at the first face-to-face contact between the interviewer and the potential participant. The informed consent form outlines the purpose of the study and describes the means of data collection. It includes the eight elements of informed consent. Participants will sign two forms and be given one of the forms to keep.

Participants will be told that the researchers are interested in collecting information about their perceptions of the process of caregiving to an elderly family member. Thus, the researcher will use audio-taped interviews as a means of collecting data. Interviews will take place in a private location selected by the participant. The participants will be told that all members of the research team may read the transcribed interview, but that no names will be used in the transcriptions and that pseudonyms will be used instead. Participants will also be told that the data collected is for research purposes and may be presented at professional meetings or published in professional journals or books.

Additional elements of informed consent include informing the participants that their consent forms will be stored in a separate locked file cabinet in a locked office for three years and that they then will be shredded. Interview transcripts will be archived for five years and then shredded. Participants will also be informed of the potential risks and benefits involved with participation in this study. The informed consent forms also clearly states that participation in the study is completely voluntary and that participants can withdraw at any time and the tape of the interview will be erased in their presence. Their withdrawal is without any penalty or loss of benefits. Participants will also be informed that myself and/or their interviewer will address any questions or concerns they might have.

VIII. QUALIFICATIONS OF THE INVESTIGATOR:

Dr. Blanton has been conducting research dealing with families for 28 years. She teaches courses on later life families and family stress. She has conducted numerous other qualitative studies with families during the last ten years. Graduate students selected to conduct interviews will have course work in gerontology and family studies. Further, they will be trained and work under the direct supervision of Dr. Blanton.

IX. FACILITIES AND EQUIPMENT TO BE USED IN RESEARCH:

No special facilities or equipment are required for the study.

X. RESPONSIBILITY OF THE PRINCIPAL INVESTIGATORS:

By compliance with the policies established by the Institutional Review Board of The University of Tennessee, Knoxville, the principal investigators subscribe to the principles stated in "The Belmont Report" and standards of professional ethics in all research, development, and related activities involving human subjects under the auspices of The University of Tennessee. The principal investigators further agree that:

1. Approval will be obtained from the Institutional Review Board prior to instituting any changes in this project.
2. Development of any unexpected risks will be immediately reported to the Compliance Section.
3. An annual review and progress report (Form R) will be completed and submitted when requested by the Institutional Review Board.
4. Signed informed consent documents will be kept for the duration of the project and for at least three years thereafter at a location approved by the Institutional Review Board.

XI. SIGNATURES:

Principal Investigator Priscilla Blanton, Ed.D.

Signature Priscilla Blanton Date 5/27/99

XII. DEPARTMENT REVIEW AND APPROVAL:

☐ Expedited Review - Category(ies): _____

or

☐ Full IRB Review

Chair, DRC _____

Signature _____ Date _____

Co-Reviewer _____

Signature _____ Date _____

Department Head _____

Signature _____ Date _____

A-1, IRB, continued

APPENDIX A

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 hopefully identify ways in which caregiving families can be helped and supported. Participants will be interviewed for 1½ - 2 hours at a time and private location of their choosing. She hopes 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-1, IRB, continued

APPENDIX B

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.

Priscilla Blanton
Department of Child and Family Studies
College of Human Ecology
The University of Tennessee, Knoxville
Knoxville, TN 37996-1900
(423) 974-6270
pblanton@utk.edu

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-1, IRB, continued

APPENDIX C

Examples of Interview Questions

Describe a typical day for your family.

Describe how people in your family are involved in providing care to your elderly family member.

What do you experience as the most challenging aspects of caregiving?

What gratifications do you experience in the process of caregiving?

What resources do you use to assist you in providing care to your elderly family member?

Who do you rely on for help with caregiving?

What community services and/or agencies have you gone to for help with caregiving?

How do others in your family react to your involvement in caregiving?

What could be done to help you provide the best care you could to your elderly family member?

How are decisions about the process of caregiving made in your family?

What has been the most demanding situation you have faced in the process of caregiving?

How has your involvement in caregiving affected your job?

How has your involvement in caregiving affected relationships in your family?

A-1, IRB, continued

APPENDIX D

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: _____

Grandchildren: _____

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

<u>Gender</u>		<u>Age</u>	<u>Lives with you</u>	
M	F	_____	Yes	No
M	F	_____	Yes	No
M	F	_____	Yes	No
M	F	_____	Yes	No
M	F	_____	Yes	No
M	F	_____	Yes	No
M	F	_____	Yes	No
M	F	_____	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.

<u>Gender</u>		<u>Age</u>
M	F	_____
M	F	_____
M	F	_____
M	F	_____
M	F	_____

Does the elderly care recipient have insurance other than Medicare? Yes ____ No ____

A-1, IRB, continued

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 hopefully identify ways in which caregiving families can be helped and supported. Participants will be interviewed for 1½ - 2 hours at a time and private location of their choosing. She hopes 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. Summary of Family Caregiving Research Project

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.

Priscilla Blanton
Department of Child and Family Studies
College of Human Ecology
The University of Tennessee, Knoxville
Knoxville, TN 37996-1900
(423) 974-6270
pblanton@utk.edu

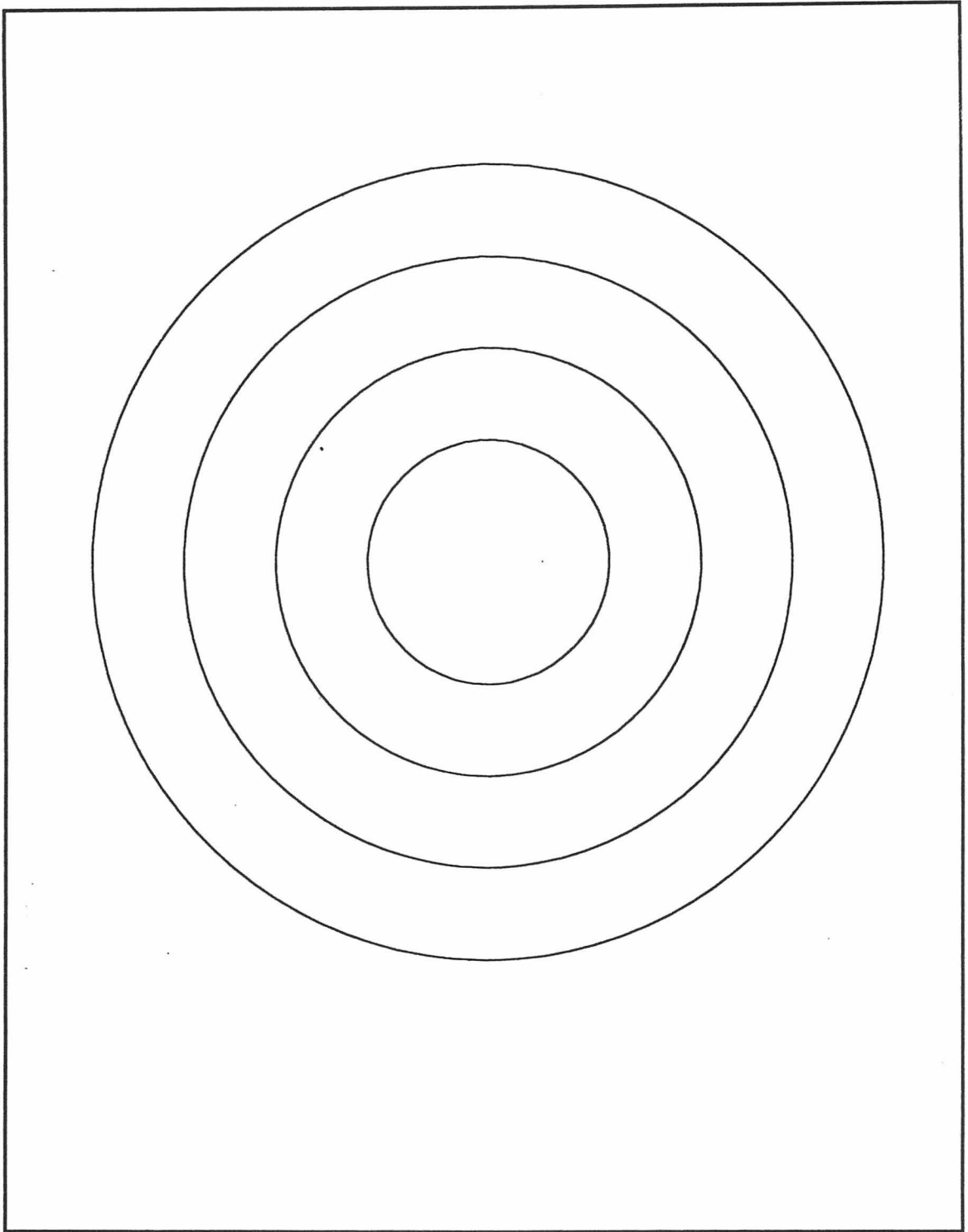
Your signature below indicates that you have read the above information, agree to participate in this study, and have received a copy of this form.

Participant Name (print) _____

Participant Signature _____

Date _____

A-3. Informed Consent Form



A-4. Cognitive Mapping Activity

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: _____

Grandchildren: _____

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

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

Does the elderly care recipient have insurance other than Medicare? Yes _____ No _____

A-5. Demographic Information Sheet

Interview Guide for Family Caregiving Qualitative Study -- Form A

_____ 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?

A-6. Interview Guides

Interview Guide for Family Caregiving Qualitative Study -- Form B

- ☐ Informed Consent
(Turn on recorder)
- ☐ Demographics (Omit financial and resources questions as appropriate)
- ☐ 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/position in your family?
 - Who do see the most often? Least often?
- Describe a typical day/morning/evening for you?
- What is it like when _____ comes to see you or help you with something?
 - What do you talk about? What do you do? What do you enjoy the most?
- What are some places that you go with family members? Grocery shopping?
 - Doctor's appointments? Out to eat? Hair appointment?

THE STORY

- Tell me a little about how your family works. What are some of your family traditions?
 - In what ways is your family unique/different from others? Similar?
- Who in your family knows you the best? How would that person describe you?
 - What would you say is your most cherished possession?
 - What have been some of the major turning points in your life?
 - What do you do to relieve stress?
- In what ways has getting older affected your life? Your job? Your family relationships?
 - Your marriage? Your leisure/recreational time activities?
- What is the most difficult/challenging aspect of getting older 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?

WRAP UP

- What is your goal in life?
 - What do you think your life will be like during the next few months? Years?
- What advice would you give to other people as they get older (and wiser, like you)?
- 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
BRACKETING ACTIVITIES

CONTENTS--APPENDIX B

B-1. My Family Caregiving Experiences	209
B-2. My Experience as a Participant in Qualitative Research	212
B-3. Lessons from Ella Sue	213
B-4. My Nursing Home Story	216

My Family Experiences with Long-Term Care *

In order to understand where I am coming from regarding this topic, I should bracket my own family experiences in making decisions about long-term care for family members, including:

Aunt Jo-- my dad's 82 year old sister who is still living in a nursing home;
Mimi -- my mom's mom, who died at age -- after several years of care at home;
Earl -- my mom's stepfather, who died at age -- in a nursing home after suffering from Alzheimer's for several years.
MomMom -- my dad's mom, who had diabetes and was blind when she died in the hospital at the age of--; and
Granddaddy -- my mom's dad, who died at age -- after suffering from Alzheimer's for several years;

Aunt Jo: My dad's 82 year old sister, who has been in a nursing home for seven years, has had several strokes, needing 24-hour care at home for a couple of years before going to the nursing home. She has some dementia, but she is often alert and cognizant of her environment and world events. Aunt Jo was a career officer in the army, taught Catholic school for years after retiring from the army, married her true love (the boy she loved as a teenager but was not permitted to marry) late in life (after his wife died), and became a widow only a few years after she married. She always valued her independence and still looks in the paper for a job sometimes, not realizing how far from reality she is straying. Though I have not been to see her in a few months, I have routinely visited her once a week for several hours at a time. I keep saying that I need to get back into my routine. It helps me center my life and get perspective on what is really important about life. So, I can't say that I do it so much for her as I do it for myself. When I am feeling the lowest, I can go to her bedside and tend to her many needs.... everything from massaging her dry hands and feet with lotion to finding her sweepstakes entry form. Sometimes I take her some fast food fish dinner, which she loves, especially if I remember to get fresh lemon on the side. She also likes chocolate ice cream when I will share it with her.

My dad has basically been in charge of all the decisions regarding Aunt Jo's care, within the context of family needs and resources. Since she never had children, he is her only living family, her seven-years-younger little brother, to whom she looks for emotional and physical support. When she has been hospitalized for her strokes, he has been the point person to deal with the medical staff; when she needed care at home, he arranged for sitters to be with her 24 hours a day; and he still manages her finances and sees to her needs at the nursing home. My sister who lives in Florida calls her about every day, I go see her (I should) regularly, my brother goes to see her occasionally, and my mom talks with her on the phone if my dad is out of town. It would appear that my dad carries the full responsibility for her care decisions, but the family context within which he makes those decisions is significant. For example, if my mother had been willing to have her live at their home and had been willing to devote her time and energy to Aunt Jo's care, she would likely be at their home now, driving both my mom and dad crazy with taking care of her needs 24 seven. I am confident that my mom and dad are better off with her at the nursing home. I intend to interview my dad as part of my research process to better understand how the family context influenced his decisions and to get a fuller picture of his experience in making those decisions. In addition, I want to interview my dad from his perspective as a medical professional who deals with families making serious decisions about long-term care.

B-1. My Family Caregiving Experiences

Mimi and Earl. My mom's mom, who suffered from heart disease and some dementia, took care of her husband Earl for a few years at home after his Alzheimer's problems began. After she fell during the night going to the kitchen to make sure Earl had not turned on the stove and after her carotid artery surgery, my mom and dad moved Mimi to a house next door and placed Earl in a nursing home. Earl was very confused and tended to wander off, finally having to be restrained at the nursing home before he died. My mother had a sitter with Mimi 24 hours a day and visited her once or twice a day. When Earl died at the nursing home, Mimi was not able to go to the funeral, and I am not sure she ever realized what happened to him after he went to the nursing home. I continued my Thursday lunch time visits with Mimi that I had started a few years before while she and Earl were still at their own home, and I listened to the same stories over again each week as if I had never heard them before. When I first started my visits, Mimi would cook lunch for us -- usually fried chicken, green beans, fried corn, and tomatoes from Earl's garden. In the later years when she was no longer able to cook lunch, we would sit and have coffee and talk about life and family and memories.

Though I was not directly involved with making any of the decisions regarding Mimi or Earl, I was aware and supportive of the struggles my mother went through in deciding what to do, feeling guilty for not wanting to be the 24-hour caregiver, and deciding to keep or not keep an I-V going to make her death less painful when the time came. My mother was basically in charge of the decisions made about Mimi and Earl, though my dad's support and opinions were important I'm sure. My mother's only living brother left the responsibility to her, providing little or no emotional or financial support. I believe my mother felt very alone in making decisions related to Mimi and Earl. I intend to interview my mother as part of my research process, not only to gather data about her experience but also to fill in some of the gaps in my understanding of my own experiences associated with care for Mimi and Earl.

MomMom. My dad's mother discovered that she had diabetes when she was about 30 years old, and my dad can remember his dad telling him that his mother would not live too long because of it. However, because insulin use in controlling diabetes was discovered about the same time, MomMom was one of the first individuals to benefit from daily insulin injections, outliving her husband by about 50 years. Besides her diabetes, her only other disability was never completely recovering from breaking her hip in a passenger train accident, so she had to use a walker and/or a wheelchair during the last 15-20 years of her life. She lived with Aunt Jo, and they had a sitter come in during the days, to cook and take her shopping or to get her hair done. I guess I did not consider her needs to be in the category of long-term care, because I was not directly involved and because she never went to a nursing home.

All I remember is when she died in the hospital. I don't even know what illness or problem she was having, except that the doctor said her cardiovascular system was in perfect shape, like that of a sixteen year old, which was apparently due to the low fat diet she adhered to for so many years as a "brittle diabetic." Anyway, I remember that she was in ICU, and I (and others, one at a time) went in to speak to her. She was asleep, and I do not remember what I said but that the equipment and technology were all around her small body. I concluded later that my dad and his sister and cousin had gotten together to make the decision to turn off the equipment, but it was not discussed openly in front of me. I just overheard some of the guilt and the rationale for how "this was the best decision" and that "it had to be this way." Perhaps, when I interview my dad, I will get a clearer picture of how her death happened and who was involved in deciding.

B-1, My Family, continued

Granddaddy. My mom's dad (Mimi's first husband who she divorced after my mother married and left home) stayed at our house for awhile after he developed Alzheimer's, but that was after I had left home, so my experience with his care is indirect. My mother tells a story about once when they were in the kitchen together, and my mother thought they were having a good conversation about old times when Granddaddy asked her about her father, not realizing that he was her father. In growing up, I saw less of Granddaddy than of Mimi and Earl, apparently due to the strain of relations with his new wife and her family. But my visits to his house are vivid, and I remember when he had "the shingles" and was in the bed, cared for by his wife full-time. I hope to learn more about the context of family decisions regarding Granddaddy through interviews with my mom as I continue my research.

My Research Insights as a Result of Bracketing

What I have discovered from this process of bracketing my own experiences is that, even though I have no direct experience in providing long-term care for a family member, I have been part of the family context within which decisions have been made. As a child and as a young adult, I was aware that decisions were being made, and my understanding of those decisions is limited. Perhaps part of my interest in researching this issues is associated with my need to understand how these decisions were made in my own family. In addition, perhaps I am recognizing that my own parents are aging (~~78~~ and going strong), and I may be realizing that I am the most likely person to be in charge of deciding what to do, trying to communicate and coordinate with my two sisters and one brother about who is responsible for what.

11

*These notes were made in the summer of 1997 as part of an assignment in a qualitative research course. Since then, my Aunt Jo^{has} died and I have had opportunities to talk with my parents, ^{now} more about the questions I had related to ^{each of} these family caregiving experiences. (Note added 2-10-00.)

B-1, My Family, continued

My Experience as Participant in Qualitative Research

From my experiences as the interviewee in a qualitative research project, I learned, first hand, that it is a vulnerable feeling to be in the interviewee role, especially when the subject of the research is of a sensitive and personal nature. At the beginning of the process, which involved over five hours of interviewing over a period of about a month, I was relieved by the way the interviewer took care to establish a sense of trust and genuine relationship with me. I felt respected, which was a vital element in achieving a sense of connection and openness.

Another thing I learned from this interview experience was that the cognitive processes involved in reflecting on my experiences and in articulating them to the interviewer had a powerful effect on my understandings and perceptions of those experiences. In other words, as I shared my experiences in the interview process, I learned more about the experiences themselves. I was surprised that I had more to learn about my private experiences, and the effect was therapeutic.

I felt valued and validated as a person, and I enjoyed the close personal bond that developed between the interviewer and me. Every time I approach an opportunity to conduct an in-depth interview, I remember how vulnerable I felt as the interviewee, and I proceed with the kind of care and warmth that I needed when I was in that position.

B-2. My Experience as a Participant in Qualitative Research

Lessons from Ella Sue

By far, the most dramatic learning experience related to family caregiving was taking care of Ella Sue from October 1998-August 1999. This is my story about how I learned about what a frail elder experiences when her family does NOT provide adequate care. This story is much too long to tell it all (ever), but it is far too important to leave it out. So, I will try to convey the essence of my experience with Ella Sue, and I will try to put into words what I learned so well from the woman whose spirit touched mine and changed forever my perception of family caregiving for frail elders.

Here is how it started. As a creative way to make some money while being a student, I advertised myself as a sitter for elders. Even though I knew nothing about the technical aspects of caregiving, I figured that I could use my social science background as a basis for caregiving and learn the nursing part as I went. My first and only regular job came in the form of taking care of Ella Sue, an 83-year-old, mountain-born woman who had been disabled by a broken hip for 20 years. My assignment was to come twice a day, 1 ½ hours each time, and get her in and out of bed with a Hoyer lift, prepare her meals, and make sure she got her medicine. She was alone all day and all night all the time except for my twice daily appearances.

The first morning, I met her adopted son Boyce at her trailer on the ridge of a mountain 12.5 miles farther back in the country than the farm where I live. Within 15 minutes, he had changed her diaper, hoisted her up from the bed and into her chair, microwaved a cup of coffee and a pre-fab sausage biscuit, given her her medicine, and fixed a peanut butter sandwich on a paper plate. Wham bam, thank you, ma'am, as it were. And he left me there with her.

B-3. Lessons from Ella Sue

I knelt down beside her wheelchair, not knowing what I would say or do but knowing I had to connect with her somehow. I said, "Are you okay?" and she replied that she was "Itching." Then I realized that her arms and shoulders were covered with scabs and small lesions, and I could see why she was itching, to say the least. I asked her how it felt to itch so bad and she said that she was "Terrified." She said she was through with her breakfast and was only interested in her coffee. When I left, I felt terrified, too.

To say that figuring out what to do to take care of Ella Sue was a challenge is too mild. To figure it out was literally a matter of life and death, punctuated by excruciating pain, both physical and emotional. I do not believe that she had Alzheimer's disease, but she was cognitively disabled, apparently as the result of the extreme isolation she had experienced for 20+ years. She could not use a telephone, a television, or a radio. She could not open the refrigerator or reach the sink. She could not open the door to her trailer or get her wheelchair into the bedrooms or bathroom of the trailer. She could not reach any cabinets in the kitchen area. She could not microwave a cup of coffee. But she could tell me about how her daddy used to walk down the road with her and play his fiddle, and she could ask me if I was feeling better than before. She could ask me why things were like this for her, and she could tell me about the day her husband dropped dead from a heart attack. And she could tell me about how she took Boyce in as an infant when his mother abandoned him. She told him on the phone once that she still loved him and she had loved him "since a little baby." Another time she said to me, "He don't care. I promise you, HE DON'T CARE." Meanwhile, Boyce, who lived next door in a nice brick house with his third wife and three children, might as well have tied up the person he knew as his mother out back like an unwelcome dog.

B-3, Lessons, continued

Our first goal was to cure her itching. With a twice daily routine of hygiene and clean bedding, hydrocortisone and antibiotic creams, and cocoa butter lotion, we won. Her family said they were pleased with my work. Our second goal was to heal the deep bed sore on her right heel. Her family doctor said not to worry about it. The scab finally sloughed off in December, leaving a small crater-like hole. Our third goal was to find her long, lost little brother Terry. Her family would not help me locate him, so I searched the archives at the courthouse and the library and finally the world wide web to find him. She got to talk to him twice on the phone. Our last goal was to take care of the pain in her right leg that radiated from the newly developed lesions between her toes and caused her to draw her knee up to her chest and not be able to straighten it. Her family refused to get tests done to evaluate the circulation in her leg. Finally, adult protective services was able to get her to the hospital, and they amputated her leg because the infection was in the bone. After the surgery she told me the pain was gone. I am not sure if the pain she now had was nothing in comparison to the months of agony she had endured or if this mountain lady had decided to never complain again. She died a week after the surgery.

You might say that I fell in love with Ella Sue on the first day I met her. I truly believe that we were meant to spend that year helping each other. We laughed together, and we cried together. And she thanked me for bringing so many memories and feelings back to her. I thanked her for teaching me about what really matters in this life. So, whenever I feel like feeling sorry for myself about anything, I am reminded that at least in my life I am not stranded in a single-wide trailer with a peanut butter sandwich.

B-3, Lessons, continued

My Nursing Home Story

After Ella Sue died, I looked for another opportunity to expand my knowledge about frail elders and their families. I wanted more experience with Alzheimer's families, and I knew from my daughter's brief experience as a nursing aide that most elders in nursing homes have some degree of dementia. So, off I went to try to get a job at a nursing home. I figured that it would be as valuable to me as doing volunteer work somewhere, and I needed the money, not that it would be that much. Every little bit helps when you are going on your third year as a starving graduate student. I went to my friend Brenda, who is a nursing home administrator, and told her my situation and that if she would give me this opportunity to learn, I would do any job she needed me to do and that I would do it to the very best of my ability. She said okay and asked me if I knew what I was getting into to which I replied that I knew it was hard work. I like to work. And I needed the money. So, I took a deep breath as if I knew the kind of plunge I was about to take, and I became the oldest nursing assistant in training they had.

Before this experience I believed, like the nursing home administrator, that the problem with turnover in nursing aides was based on low pay, hard work, and bad attitudes. After all, I know about teenagers and other young adults who do not seem to want to work. And I knew this was a harder job than flipping hamburgers. I knew you had to change diapers and clean up all manner of other messes. But I was wrong. Those are not THE reasons for the high turnover.

Here is why people do not stay. The job as it is set up within the system is

B-4. My Nursing Home Story

virtually impossible to do. No, I do not mean that it is too hard. And I do not mean that there is not enough time to do it. It cannot be done. On one eight-hour shift the job (as I understood it) was an assignment of caring for 12-18 residents most unable to transfer from chair to bed alone. First order of business was to change everyone, including clothes and bedding if needed. I was not fast at this part, but, for the fastest person working alone it might take ten minutes per person, counting at least one trip to the clean linen closet and another to the dirty linen closet. So, one round of changing at best would take two hours, and since you have to do (chart) three rounds of changing, that eats up six hours. Second priority is to get your showers done, which means you are responsible for the twice weekly opportunity for three or four residents to get cleaned up thoroughly. The fastest person working alone reasonably could shower a person and do routine skin care (not counting nail or oral care, of course) in twenty minutes. So there's another hour shot, at the very least. And, oh, there are the 3:00 snacks to distribute and feed, supper to get residents dressed and up and into the dining room for, the 9:00 snacks, and of course the vitals that have to be done before the charge nurse can administer the blood pressure medicine. And of course the list goes on and on and on. Sometimes weights need to be done (I never did figure out the schedule on that part). For snacks and meals, about half the residents needed to be fed their pureed delights and the rest needed some encouragement or help. The charge nurses insisted that all residents must be in the dining room with bibs on and ready to eat by 5:30 and finished and back to their rooms by 7:00. To feed one person (or three at a time in a circle as I learned to do) it took a minimum of twenty minutes. Oh my, where has the time gone? I have not stopped long enough to get a drink of water, sit down, catch my breath, or even think one second about my feet being

B-4, Nursing Home, continued

on fire. At 8:30 the charge nurse scolds me for not taking my thirty minute supper break at the right time. I take a deep breath and try to figure out how to get a handle on my priorities. Mr. Jones' wife is still waiting for me to get his pajamas on him and get him into bed. Donnie is still holding his mother's hand and watching tv with her, waiting for me to come get her cleaned up and ready for bed. I stayed for four months. I became a certified nursing assistant. But I would never stay on as a nursing assistant at a nursing home, even one of the best like this one.

Of course, the job looks like it has been done from the perspective of the charge nurses, who are quick to notice the most minor infraction like carrying fresh linen in the hallway without a bed sheet draped over the stack to protect from air-born germs. And it looks like the job has been done when the head of nursing reads the detailed patient care chart that shows that every patient received oral care before bedtime and that the new residents' input and output numbers look good. And it looks like the job has been done when residents are wearing regular clothes to the dining room rather than pajamas. The catch is that what looks like the job is not the job. What happens with the linens in the residents' rooms matters more than what happens in the hallway, charting what is done is not the same as its being done, and having on a sweat suit does not mean the resident feels dressed.

Some people who stay are good. They hate the corners they have to cut. They are overworked and underpaid (new meaning for me after this job!). But this is no ordinary job. They feel good about being able to make a difference, one person at a time. Some people who stay move up to be charge nurses. Some people who stay learn how to cut enough corners to make the job look good enough. But the JOB cannot be done. I

B-4, Nursing Home, continued

am a hard worker and I am smart, but the majority of the time I was on the clock I felt incompetent, inadequate, and plain stupid. If I felt that way, the other souls who walked in the door and applied for this extraordinary job also felt that way or worse. At least I knew the problem was not me.

B-4, Nursing Home, continued

VITA

Annabel Lee Agee was born on August 13, 1949, in Denver, Colorado, where her father was completing his medical residency at the University of Colorado. Her family settled in Maryville, Tennessee, by the time she was ready to start kindergarten. The second of four children and the middle daughter, she enjoyed her visits to see her grandparents in Knoxville and, especially, has fond memories of times spent at her paternal grandmother's old, two story house on Highland Avenue where her father was born as well as at her maternal grandmother's similar, old house on Chicago Avenue.

She attended Maryville City Schools through high school graduation in 1967 and proceeded to attend college at the University of Tennessee, Knoxville. She earned a B. S. degree in English Education in 1971 and taught 11th and 12th grade English at Madisonville High School in Monroe County, Tennessee, before eventually returning to the University of Tennessee to earn an M. S. degree in Educational Psychology in 1976.

She began her career in higher education as an adjunct instructor at State Technical Institute at Knoxville in the fall of 1976, teaching technical writing, speech, and human relations and continuing her tenure with State Tech through its transition to community college status. It then was renamed Pellissippi State Technical Community College (PSTCC), and expanded to branch campus locations. During her 20-year tenure with PSTCC, she served as an assistant professor, director of student development, associate professor/departement head for the English, reading and study skills component of the remedial/developmental program, and, finally, assistant dean and director of the

college's branch campus in Blount County. During her eight years as assistant dean, the branch campus enrollment grew from an initial enrollment of 500 students to a stable enrollment of 1500 students per semester. She received awards for Outstanding Faculty in 1981 and Outstanding Administrator in 1989 and was elected to Leadership Blount, Class of 1993.

Ms. Agee returned to The University of Tennessee as a full-time student in the fall of 1997 to pursue a PhD degree in Family Studies in the College of Human Ecology, with a research focus on gerontology. While completing her academic program, she augmented her learning experiences in gerontology as a volunteer in an Alzheimer's day treatment program, a nursing assistant at a nursing home, and an entrepreneur in elder care community services. Ms. Agee has shared her research findings through various professional organizations and community seminars and has co-authored with Dr. Priscilla Blanton a manuscript forthcoming in the fall of 2000 in the Journal of Aging Studies. Also, Ms. Agee is a student member of the Gerontological Society of America and the National Council on Family Relations and an associate member of the American Association of Marriage and Family Therapists. Upon completing her doctoral program in May 2000, Ms. Agee plans to serve as a private consultant, helping families working with later life issues, including family caregiving and experiences with Alzheimer's disease.

In the summer of 1993, Ms. Agee married process engineer David Ted Zwolinski, with whom she lives on a small farm in Blount County and enjoys camping, kayaking, barn building, and restoring old tractors. Together, they have four young adult children (and their significant others), ages 20-25, and three grandchildren, ages 2-8.