A Qualitative Study of Non-Caregiving Adult Children's Experiences of a Parent's Alzheimer's Disease

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Abstract

Although there is abundant research on the etiology of Alzheimer's disease and its impact on primary caregivers, there is relatively little research that examines the consequences of the disease for entire families, and no literature that exclusively studies the experiences of non-caregiving family members. Seeking to explore the experience of non-caregivers, this qualitative study examined how adult children of an Alzheimer's patient who were not the caregiver for their parent experienced the onset and progression of the disease. Using the guiding theoretical frameworks of phenomenology, family systems theory, and ambiguous loss, in-depth interviews were conducted with three individuals and were coded for themes. The main themes found included externalization of symptoms, belief in the Alzheimer's diagnosis, acceptance, flexibility, sibling and parental relationships, communication, planning, shared family philosophy, family of origin roles, and boundary ambiguity. Implications for clinical practice and suggestions for future research are included.

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Table of Contents

ABSTRACT ii

ACKNOWLEDGEMENTS iii

CHAPTER I: Introduction 1

- The Problem and its Setting 1
- Alzheimer's Research: A Focus on Caregivers 1
- Significance 4
- Rationale 6
- Theoretical Framework 6
  - Phenomenology 6
  - Family Systems Theory 7
  - Ambiguous Loss 9
- Purpose of the Study 11

CHAPTER II: Literature Review 12

- The Growing Problem of Alzheimer's Disease 12
- Effects of Alzheimer's on the Family 13
- Research on Caregivers 16
- Alzheimer's Disease and Ambiguous Loss 23
  - Coping With Ambiguous Loss 23
  - Boundary Ambiguity and Depression 26
  - Studies Extending Beyond the Primary Caregiver 29
- Research Questions 32

CHAPTER III: Methods 33

Qualitative Study 33

Participants 33

Procedures 36

Instruments 37

Design and Analysis 37

CHAPTER IV: Results 39

Introduction 39

Interview One: Summary 39

Interview Two: Summary 40

Interview Three: Summary 41

Phenomenology 42

Externalization of Symptoms 42

Belief in the Diagnosis of Alzheimer’s Disease 45

Acceptance 48

Resources 50

Detail 51

Focus 51

Worry 52

Distance and Involvement 53

Communication: Having a Plan 55

Experience of Burden 58

- Family Systems 60
    - Sibling Relationships 60
    - Shared Family Philosophy 63
    - Parental Relationships 64
    - Family of Origin Roles 66
    - Change and Flexibility 70
    - Intergenerational Transmission 73
    - Roles versus Self-Care 74
    - Environment and Roles 75
    - Necessity of Family Involvement 76
    - Control versus Resignation 77
- Ambiguous Loss 78
    - Time 78
    - Role Reversal 80
    - Resources and Coping with Boundary Ambiguity 81
    - Detachment and Ambiguous Loss 82
    - Acknowledgement of Boundary Ambiguity 82

CHAPTER V: Discussion 86

- Introduction 86
- Summary of Findings 86
- Links to Previous Research 89
    - Experience of Burden 89

        Distance 90
        Family Roles 90
        Family Conflict and Cut-Off...93
        Coping with Ambiguity through Acceptance versus Avoidance..................96
        Stages of Ambiguous Loss...97
        Reciprocal Coping 98
        Mastery 99
    Study Limitations..100
    Clinical Relevance 102
    Suggested Future Research 105
REFERENCES...108
APPENDIX A 113

CHAPTER I: INTRODUCTION

The Problem and its Setting

Recent advancements in medicine and standards of health-care have resulted in a phenomenon known to many as the graying of society (Walsh, 1998). At the beginning of the twenty-first century, people are living longer, healthier lives than ever before. Despite all its advantages, this extended life expectancy has serious implications for the increased development of those diseases that become more prevalent with age. This is especially true of Alzheimer's disease. Its characteristic slow progression and chronic degeneration, coupled with the fact that there is currently no cure, make it one of the most debilitating and devastating disorders of our time (Cummings & Jeste, 1999). Unfortunately, as the graying of society continues, the projected prevalence of Alzheimer's will also continue to increase. This has tremendous implications not only on a societal level, but on a family and individual level as well.

Alzheimer's Research: A Focus on Caregivers

While an abundance of family research on Alzheimer's disease exists and has demonstrated that Alzheimer's disease has consequences for whole families, the focus of much literature has principally been on primary caregivers—those persons who are essentially responsible for most aspects of the Alzheimer's patient's daily care (both activities of daily living, such as toileting, bathing, and feeding, as well as instrumental activities of daily living, like shopping, budgeting, and cooking, according to Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). While exploring the implications of Alzheimer's disease for primary caregivers is certainly important, there is little research that addresses how family members other than the primary caregiver experience and make meaning of the disease. Globerman (1994) writes that "many studies examining 'dementia and the family' are in reality studies about dementia and these primary caregivers" (p. 212). Only a few published articles have been uncovered thus far that acknowledge this gap in the research or attempt to address it in some way.

The first study found was Lieberman and Fisher's (1999) research on family conflict resolution in families dealing with the Alzheimer's disease of a loved one. This article focused on how family care of an Alzheimer's patient was impacted by the decision management and conflict resolution styles of the families. Though the authors do not explore the experience of non-caregiving family members per se, their research focused on family units rather than on individual caregivers. They provide justification for moving away from research that focuses solely on the primary caregiver when they say:

> If the importance of second generation decision making and conflict resolution can be demonstrated, then the justification can be offered for programs to move beyond the primary caregiver to address the family as a unit. (Lieberman & Fisher, 1999, p. 159)

These authors go on to note that caregiving is a developmental task of entire sibling groups over the life cycle, and not of specific individuals (Lieberman & Fisher, 1999).

A second study by Harvey and Burns (2003) was undertaken to study the traits and experiences of different types of caregivers (primary, nonprimary, and lone). Though this research was conducted in the broader field of mental illness and was not focused specifically on caring for patients with Alzheimer's disease, it demonstrates that a focus on the primary caregiver exists in the broad research on caregiving as well. These authors highlight some interesting points, the most salient of which is the need for a clear definition of what caregiving is and who can be considered a caregiver. They also point out the need to broaden the scope of caregiving to include more than one person, as it is often the case in families that many members share caregiving duties. They articulate the importance of research into these areas when they say that:

> If the assumption that one individual tends to be more adversely affected than others is correct, then it is necessary to find ways of identifying that person, otherwise the extent of a family's difficulty may be underestimated. If, on the other hand, the assumption is incorrect and the demands of caregiving extend to the wider family, interventions aimed at supporting all involved relatives need to be designed. (Harvey & Burns, 2003, p. 326)

The final article found was Judith Globerman's (1994) research on balancing tensions in families coping with Alzheimer's disease. Her qualitative study explored family members' experiences and descriptions of the dispersion of responsibility and participation in caring for a relative with the disease. Globerman (1994) highlighted the aforementioned gap in the literature by stating that "few studies have examined the experience [of Alzheimer's disease] from the perspectives of family members other than the designated primary caregiver" (p. 212). Accordingly, her study looked at the ways both primary caregivers and other family members discuss, understand, and organize their lives around the disease; furthermore, it explored what family tensions they experienced and how they dealt with them throughout the course of the disease (Globerman, 1994). Her primary finding was that all family members experienced a loss-of-self related to the inability to renegotiate relationships, both with the Alzheimer's patient (due the progression of the disease), as well as with other family members. Most participants talked about feeling consumed by their families of origin in times of crisis, and described a pattern of resuming family of origin roles in order to navigate the crisis. Globerman (1994) concluded that:

> How families apportion and experience caregiving may be more related to their legacies than we have considered to date, and in crisis they may find their known and “safe” roles and relationships inflexible and non-negotiable. *The loss-of-self evident in research on caregivers is present in non-caregiving relatives whose apparent involvement can appear minimal and insignificant to an outsider* [italics added]. (p. 227)

There are several implications of this conclusion, the most alarming of which is the possibility that research on families coping with Alzheimer’s disease could be severely limiting what we know about the disease and its effects on families by only studying primary caregivers, when some evidence suggests that coping with the disease is just as difficult for those who are not primarily responsible for care. These three articles coupled with the absence of extensive research on non-caregiving family members all seem to point to the need for further analysis of this group of people. This study will attempt to bridge this gap in the literature by examining non-caregiver’s experiences of Alzheimer’s disease in the context of available research on how Alzheimer’s disease is commonly experienced by primary caregivers and families as a whole.

Significance

This type of study is important for several reasons. First, focusing on one person as the designated primary caregiver assumes that only one person is responsible for care, and could possibly fail to acknowledge the ways in which other family members contribute to the care of a relative (Harvey & Burns, 2003). Second is the problem of the "shrinking family" (Davidhizar, 1999, p. 10). Whereas families formerly had an average of five or six children, the typical modern family averages one and a half children, and it is becoming more common for those children to settle far from home (Davidhizar, 1999). In light of this, it makes sense that a number of adult children of Alzheimer's patients would be prevented from providing care for that individual due to geographic distance, and that this could foster an experience of the disease that is quite different from that of primary caregivers.

Third, focusing on only the primary caregiver in research on Alzheimer's disease means that the results of that research only capture the experience of one group of people and can only be extrapolated to one member of each family as opposed to several. The scope of people that benefit from the study of the disease, the number of resources available to families and individuals, and the knowledge available to clinicians in terms of how to treat families of Alzheimer's patients are thereby limited.

Finally, research that focuses only on caregivers ignores the ways in which other family members experience Alzheimer's disease, and how their experience is different from or similar to that of primary caregivers. This is particularly salient for family therapy researchers whose primary goal is study of the family in context; exclusion of particular family members, for whatever reason, means that one piece of the context of families coping with Alzheimer's disease is missing. The potential for propagating a myth that the only painful or legitimate experiences of families dealing with Alzheimer's disease are the experiences of primary caregivers is great. If the experiences of these other non-caregiving family members are not studied, it becomes virtually impossible to compare their experience with that of primary caregivers to assess important areas of similarity and divergence. Identifying ways that caregivers and non-caregivers are alike (experiencing pain, fear, confusion, etc.) could feasibly be an important tool for clinicians in building bridges in families where decisions about care have caused significant tension.

Rationale

Because there is not an extensive body of literature detailing the experience of non-caregivers, and because the aim of this study is to understand the ways in which non-caregivers experience their parent's Alzheimer's disease, the use of a qualitative methodology to explore this phenomenon makes sense. An in-depth qualitative interview will generate rich, detailed descriptions of the experiences of this sample of people, and will begin to highlight how non-caregiver's experiences are similar to or different from the experiences of primary caregivers as described in the available literature. This type of study will provide a basic understanding of this population that could facilitate future studies comparing the experiences of caregivers and non-caregivers.

Theoretical Framework

Three guiding theoretical frameworks will be employed in this study. They are Phenomenology, Family Systems Theory, and Ambiguous Loss. A description of each theory and its usefulness in exploring this topic is listed below.

Phenomenology.

Fundamentally, phenomenology is aimed at discovering the "meaning, structure, and essence of the lived experience" (Patton, 2002, p. 104) of a particular phenomenon for a particular person or group of people. There are several basic tenets of this theory. First, phenomenology assumes that all knowledge is constructed socially and is therefore relative and provisional (Boss, Dahl, & Kaplan, 1996). Second, phenomenology posits that the researcher is an instrument, and cannot be separate from the phenomenon being studied. Patton (2002) explains this when he states that “the only way for us to really know what another person experiences is to experience the phenomenon as directly as possible for ourselves” (p. 106). Because the researcher becomes such an intricate part of the study, phenomenology also assumes that no study is ever totally objective and that there is some level of bias inherent in all research. These biases must be made explicit (Boss et al., 1996). Finally, phenomenology assumes that the experiences of people are important and worthy of study, that the way these experiences are described is significant, and that similar events can have different meanings for different people (Boss et al., 1996).

As this study is exploring the experience of non-caregiving children of Alzheimer’s patients, phenomenology fits well as a guiding theory of this research. Accordingly, the overarching assumption of this study is that understanding the experience of this group of people is important. Also inherent in this design is the expectation that each participant’s experience will be different both from the experiences of other participants as well as the experiences of primary caregivers.

Family Systems Theory.

Family Systems Theory is the second guiding theory of this research. This theory states that the context in which people live molds their experiences and the meanings they attribute to them, and that people cannot be viewed outside of this context (Hecker, Mims, & Boughner, 2003). The first basic tenet of family systems theory is that families as systems are an organized whole, and that individual family members are interdependent (Hecker et al., 2003). Nichols and Schwartz (2004) describe this when they say that:

> The essential properties of an organism, or living system, are properties of the whole, which none of the parts have. They arise from the interactions and relationships among the parts. These properties are destroyed when the system is reduced to isolated elements. The whole is always greater than the sum of its parts. (p. 95)

As this quote suggests, each family system is composed of both individual subsystems, as well as dyadic relationships within the system such as husband-wife or parent-child subsystems (Hecker et al., 2003).

Another tenet of family systems theory is that patterns of interaction exist, and are circular in nature rather than linear (Hecker et al., 2003). In order to secure these patterns, families maintain homeostasis, or “the self-regulation that keeps systems in a state of dynamic balance” (Nichols & Schwartz, 2004, p. 95).

Because Family System’s Theory examines the overall structure of families and their patterns of interaction, as well as the roles that individual family members play in maintaining that structure, it is being employed as a guiding framework of this study. The underlying assumption is that non-caregiving family members still experience Alzheimer’s disease as disruptive of family boundaries, and that the disease will therefore still affect them even if they do not provide intensive care for the patient.

Ambiguous Loss.

The final theoretical orientation of this study is that of ambiguous loss. By looking at Alzheimer's disease as a problem that impacts boundaries in the family system, the theory of ambiguous loss supports the notion that non-caregivers can still experience their loved one's illness as distressing even if they are not actively providing care for that person. This theory was initially developed by Pauline Boss (1991, 1993, 1999, 2004, 2006) during her work with families of soldiers missing in action, and was later expanded to include families of immigrants, families of kidnapped children, victims of terrorist attacks, and families providing care for a loved one with a chronic illness, such as Alzheimer's disease.

The theory of ambiguous loss posits that within the mind of every individual there exists a psychological family, "an active and affective bond that helps people live with loss and trauma in the present" (Boss, 2006, p. 26) by providing them with an internal sense of connection that may or may not mirror their external family structure. If the dissonance between a person's psychological family and his or her physical reality is great, the result is stress, trauma, and weakened resilience. This is especially true when a loved one is physically absent but psychologically present (as with soldiers missing in action, kidnapped children, or victims of terrorist attacks whose bodies are never discovered), or physically present but psychologically absent (as with Alzheimer's disease or other forms of dementia, terminal illness, brain injuries, or alcoholism) (Boss, 2006). Boss et al. (1990) define this confusion over a loved one's presence or absence as boundary ambiguity, or "a state in which family members are uncertain in their perceptions of who is in or out of the family and who is performing what roles and tasks within that system" (p. 247).

Alzheimer's disease is an extreme example of how a family member can be perceived as physically present but psychologically absent (Boss, 1999). This theory posits that boundary ambiguity, confusion, frustration, depression, anxiety, and family conflict can all exist in families who are in a constant state of uncertainty about whether or not family members are present or absent (Dupuis, 2002). Boss (1999) articulates the strain families experiencing ambiguous loss are under when she says that:

> Few people, professionals or family members, can tolerate for long being in a situation that is out of their control. The stress is too much. As the ambiguity persists, conflicts increase, not just among family members, but also between the family and clinicians. (p. 50)

Much of the conflict over the patient's presence or absence centers around the amount of closure a family feels. Because Alzheimer's disease gradually takes away a family's loved one, they experience the loss of the person they formerly knew; however, because the physical body remains, families receive no cultural marker of that loss. Boss (1999) describes this when she writes that "religious rituals for mourning loss are reserved for the clearly dead. There are few ceremonies to comfort us when our loved ones are only partially gone" (p. 49-50).

The progression of Alzheimer's disease as an ambiguous loss involves many ups and downs, and is a gradual cycle of crises and adaptations (i.e., just as families adapt to one change in their loved one, they are faced with another). Boss et al. (1988) describe illness as ranging on a continuum from chronic to acute, with long-term, persistent illnesses being chronic, and short-term illnesses or accidents being acute. Alzheimer's disease is unique, in that it is a chronic illness in which family members also experience acute events, such as the onset of a new symptom or the patient’s loss of a particular ability (Boss et al., 1988). Because the key to ambiguous loss is the extent of boundary ambiguity family members experience, and because inherent in a diagnosis of Alzheimer’s disease is a disruption of family boundaries and relationships, Ambiguous Loss is the final theory guiding this study, and will be helpful in exploring how non-caregivers experience and cope with the ambiguous loss of their parent.

Purpose of the Study

In light of the limited available research on non-caregivers and the need for such research to facilitate comparison between caregivers and non-caregivers in the future, and to identify and provide resources for this under served population, the purpose of this study is to understand how non-caregiving adult children of Alzheimer’s patients experience the loss of their parents to that disease, and to explore how they feel their own experience differs from the experience of primary caregivers.

CHAPTER II: LITERATURE REVIEW

The Growing Problem of Alzheimer's Disease

Alzheimer's disease is defined by Cummings and Cole (2002) as a progressive neurodegenerative disorder that gradually robs the patient of cognitive functioning and eventually causes death" (p. 2335). There has been much research devoted to the physiology of the disease in an attempt to find a cause and subsequent cure; no definitive cause has been found, and there is currently no available cure (Du Mars & Du Mars, 1994). Common symptoms of the disease include extreme memory loss and inability to learn new information, difficulty with self-expression, difficulty understanding others, perseverations, apathy, agitation, loss of inhibitions, and changes in behavior or mood (Long, 1997; Mace & Rabins, 1999). The symptoms of Alzheimer's disease follow a course of gradual and predictable decline, and the entire course of the disease can last up to two decades (Kaplan & Boss, 1999).

Because Alzheimer's disease is an age-related disorder, it will become more and more prevalent as life expectancies for healthy adults continue to increase (Boss et al., 1990; Cummings & Jeste, 1999). Davidhizar (1999) postulated that women who reach the age of fifty without suffering from cancer or heart disease can expect to live nearly ninety-two years. Statistics are similar for men, with projected life expectancies of up to eighty-one years for those men who reach age sixty-five (Davidhizar, 1999). With these extended periods of life expectancy for average adults, the percentage of older people within the United States population is shifting dramatically. According to Teel and Carson (2003), "by the year 2030, approximately 20% of the population will be 65 years and older, with the most dramatic growth expected among the oldest old, the cohort of persons 85 and older" (p. 38-39). Because risk for

Alzheimer’s disease increases with age, the prevalence of the disease will continue to grow as the average life expectancy becomes longer (Cummings & Jeste, 1999). The disease currently affects an estimated four million people, accounts for seventy-five percent of all cases of dementia, and impacts nearly half of those people living in the United States who are eighty-five years of age or older (Cummings & Jeste, 1999; Teel & Carson, 2003). Cummings and Cole (2002) provide the following statistics about the prevalence of the disease and its projected growth:

> The prevalence of AD [Alzheimer’s disease] doubles every 5 years after the age of 60 increasing from a prevalence of 1% among those 60- to 64-years-old to up to 40% of those aged 85 years and older. . . . The number of new cases per year is estimated at 360,000 equating to 980 new cases per day or 40 new cases every hour. The population of patients with AD will nearly quadruple in the next 50 years if the current trend continues. (p. 2335)

As the aforementioned research suggests, Alzheimer’s disease will continue to become more common as the average life expectancy of people living in the United States increases, and will affect the members of the oldest old cohort—and their families—with particular significance (Teel & Carson, 2003).

Effects of Alzheimer’s on the Family

When the increasing prevalence of Alzheimer’s disease is viewed through the lens of the family, exploring this disease in family therapy research becomes even more salient. Consider that for every person suffering from Alzheimer’s disease, there is also an accompanying family comprised of at least one member. Consider also that the majority of Alzheimer's patients are cared for at home by a relative (Levine & Lawlor, 1991). According to Teel and Carson's (2003) assertion that four million people are currently suffering from this disease, that translates to approximately four million families that are presently coping with the Alzheimer's disease of a loved one. Given the fact that the prevalence of this disease is expected to quadruple in the next 50 years (Cummings & Cole, 2002; Teel & Carson, 2003), and that the average Alzheimer's patient can live anywhere from eight to ten years after diagnosis (Small et al., 1997), this disease could well become one of the most pervasive family problems of our time.

There is extensive research on the toll that Alzheimer's disease can take on families. Much of this research is presented in terms of the impact the disease has on the structure of family systems and the delineation of family roles. Fabisewski and Howell (1986) suggest that Alzheimer's disease disrupts established family roles, causes depression and stress, and requires complete reorganization of family boundaries in order to successfully cope with the illness. Research has also focused on how Alzheimer's disease disrupts the organization of the system in that family members must take on roles and complete tasks that once belonged to the patient. This reorganization causes the family to remain in a constant state of flux and adjustment as the Alzheimer's patient's condition worsens and that person becomes progressively less self-sufficient (Bonder, 1987)

At the same time that this reorganization of roles is occurring, however, Globerman (1994) suggests that family structure is at work to keep family members rooted firmly in their family of origin roles in order to manage the crisis of the disease. In an effort to understand how families dealing with Alzheimer's disease deal with the illness and construct their lives around it, Globerman (1994) conducted a cross-sectional exploratory qualitative study of six families (a total of seventeen individuals) in three different caregiving stages (two families currently providing care, two families whose relative was in an institution, and two families whose relative had died). She found that family members frequently returned "to the family of origin into an expected and known role" (Globerman, 1994, p. 221) in order to deal with the crisis of the disease. When this occurred, family members had difficulty changing or negotiating these roles, and had to suspend their own developmental tasks for a time in order to navigate the family emergency. Globerman (1994) stressed that this transition was difficult for both caregivers and non-caregivers.

As family members cope with this transition, feedback within the family system ultimately becomes useless, because just as the family adapts to a change in the Alzheimer's patient, that person is likely to change again; thus, the family is never able to achieve homeostasis (Bonder, 1987). Globerman's (1994) findings support this. She states that "families experience the behavioral and social disturbances which characterize the disease as stressful but also describe confusion, frustration, anger, and distress at not being able to predict the daily course of the disease" (Globerman, 1994, p. 217). The family's sense of unity is disturbed which can impair their use of traditional coping mechanisms (Bonder, 1987).

In her description of Family Systems Theory and how it can be helpful in conceptualizing the family dealing with Alzheimer's disease, Bonder (1987) theorizes that Alzheimer's disease will affect a family's boundaries in unpredictable ways. She asserts that family members who find it impossible to cope with the illness may attempt to cut themselves off from the family; conversely, she contends that family members who choose to stay connected must deal with the intrusion of health care professionals into their private lives. At the same time, the family must deal with changes in its hierarchical structure, both within the family system and also within the larger context of the community (Bonder, 1987). Bonder (1987) describes how friends and neighbors may become uncomfortable around the Alzheimer's patient and avoid contact with the family. She states that "the position of the family relative to other systems becomes unclear resulting in a sense of loss of support" (Bonder, 1987, p. 18).

Research on Caregivers

Though the aforementioned studies have demonstrated that Alzheimer's disease is a *family* stressor, a majority of the research on this disease has focused on primary caregivers. Levine and Lawlor (1991) provide some basic demographic information about caregivers, stating that, "one million demented elderly are cared for at home by a spouse or family member, and 80% of all home care is provided by family members and not by public or private agencies" (p. 385). These authors go on to say that seventy-two percent of caregivers are female (twenty-nine percent are daughters of the patient and twenty-three percent are wives), and that the majority of caregivers spend forty hours per week or more caring for the Alzheimer's patient (Levine & Lawlor, 1991).

Research on primary caregivers has focused substantially on caregivers' experience of burden and the adverse effects they feel as a result of providing care. Baronet (1999) conducted a critical review of the research literature on caregiver burden in mental illness, sampling twenty-eight studies that evaluated caregiver burden using instruments with proven reliability and validity. Her intent was to identify aspects of caregiving that are considered throughout the research literature to be most burdensome, and the studies she reviewed researched several different aspects of "burden" experienced by caregivers of patients with mental illness. Her review of caregiving literature revealed that caregiving activities commonly perceived as burdensome included providing transportation, managing finances, taking on extra domestic responsibilities, providing supervision, providing monetary support, and restriction from pursuing their own goals. Caregivers also experienced the patients' unpredictable behaviors, demands, and excessive dependency as burdensome (Baronet, 1999).

Rabins, Mace, and Lucas (1982) conducted a structured interview of 55 primary caregivers of dementia patients using a 52-question survey that examined to what degree they were experiencing problems associated with caregiving (both behavior problems in the patient as well as a personal experience of burden). Forty-eight of the fifty-five caregivers interviewed indicated that they felt "angry, sad, depressed, or tired most of the time" (Rabins et al., 1982, p. 333). Thirty respondents reported having given up friends, jobs, or hobbies in order to care for the dementia patient, while thirty-one respondents believed other family members were not helping enough or did not approve of the care being provided. Those caregivers who had to assume responsibilities previously held by the patient reported this change in roles as stressful. Some caregivers also reported "feelings of guilt, worry, fear of illness, fear of the patient, and marital stress" (Rabins et al., 1982, p. 334).

Cooper, Katona, Orrell, and Livingston (2006) studied the relationship between anxiety and coping strategies in Alzheimer’s caregivers. They recruited 126 caregivers through local psychiatric care centers, volunteer services, and care institutions. The sample was representative of the larger population in terms of the setting in which care was being provided, gender of the participants, and the severity of the dementia. They administered the anxiety subscale of the Hospital Anxiety and Depression Scale to measure caregiver anxiety, the Brief COPE instrument to measure caregivers’ coping methods, the Social Readjustment Ratings Scale to measure life events, the Zarit Burden Scale to assess the level of caregiver burden, and the Quality of Life-Alzheimer’s disease scale to measure the quality of the caregiver’s relationship with the Alzheimer’s patient. They found that depression and dysfunctional coping strategies independently predicted caregiver anxiety, a relationship that could potentially be two-directional (i.e., poor coping mechanisms lead to caregiver stress and anxiety, and anxious caregivers in turn have difficulty coping and tend to use dysfunctional coping skills). The authors contend that caregivers’ particular coping styles are “the most important predictor” (Cooper et al., 2006, p. 19) of caregiver anxiety.

In a comparison study of forty-nine primary caregiver spouses of Alzheimer’s patients to 52 non-caregiving spouses, Beeson (2003) used the UCLA Loneliness Scale and the Center for Epidemiological Studies Depression Scale to assess loneliness and depression in caregivers and non-caregivers. She also gathered data on gender and spousal relationship (i.e., whether or not participants were husbands or wives), data on relational deprivation, and data on loss of self by asking a series of ten questions. She hypothesized that caregiving spouses would report more loneliness and depression than non-caregivers, and that loneliness would significantly explain caregiver depression (more so than the other variables). A t-test analysis confirmed that Alzheimer's caregivers in this study reported significantly higher levels of depression and loneliness than non-caregivers. Step-wise regression also showed that loneliness accounted for 49 % of the variance in caregiver depression (Beeson, 2003).

Russo, Vitaliano, Brewer, Katon, and Becker (1995) tested a diathesis-stress model of psychopathology by comparing the history and onset of psychiatric disorders in 82 caregivers of Alzheimer's patients with 86 demographically matched controls. They wanted to see whether or not vulnerability or predisposition to mental illness interacted with the stress of caregiving to result in psychiatric disorders in caregivers. Caregivers were recruited through physicians' offices, the University of Washington Alzheimer's Disease registry, the Alzheimer's Disease Association, and community announcements. A psychiatric assessment using the computerized version of the NIMH DIS Version III-R, a diagnostic interview that assesses for both current and lifetime diagnoses, was administered to participants two times, eighteen months apart. Caregiver data from the DIS was compared to the date of the onset of the patients' Alzheimer's symptoms to determine a sequence of disorders, and then the prevalence of psychiatric disorders for participants was divided into five intervals (prior to the onset of the disease, and then various intervals after the onset of the disease). Russo et al. (1995) found that those caregivers who had a history of psychiatric disorders before the onset of the Alzheimer's symptoms were more likely to experience an episode of Major Depression or Generalized Anxiety Disorder after the onset than those caregivers who had no history of mental illness.

In a literature review of available epidemiological data on the occurrence and pervasiveness of emotional disability in caregivers, and in a concurrent review of eleven treatment studies in which blinded intervention was used to address that emotional disability, Rabins (1998) found that Alzheimer's caregivers had higher levels of emotional distress and disorder than non-caregivers. He found that "when a number of studies are examined, one finds that about 30 to 40 % of caregivers are significantly distressed" (Rabins, 1998, p. 27). However, he also states that the majority of caregivers do not require psychiatric treatment to address their emotional distress, and that caregivers who were less successful dealing with stress in general were more likely to have difficulty coping with the stress of caring for an Alzheimer's patient. Rabins (1998) also asserts that "caregiver perception of 'burden' is a stronger correlate of caregiver distress than is the objective severity of the dementia" (p. 27).

This emphasis on caregivers and their experience of burden holds true even in international studies. Sansoni, Vellone, and Piras (2004) employed a descriptive, repeated measures design using three surveys to study the levels of anxiety and depression in thirty-four Italian caregivers for Alzheimer's patients over a total of 816 days. In their literature review they emphasized that anxiety and depression occurred more frequently in Alzheimer's caregivers than in comparison groups from the same demographic cohort, and that these symptoms were compounded by caregivers' own physical illnesses or the increasing behavioral problems demonstrated by the patient as the disease progressed. The levels of depression and anxiety reported by subjects in this study were concurrent with the levels reported in the broad caregiving research. Sansoni et al. (2004) found that the number of hours spent in caregiving were positively correlated with higher levels of anxiety and depression in caregivers, and that most caregivers were physically and mentally exhausted and had no time for self-care.

An additional study by Ory et al. (1999) used data from more than 1,500 caregivers collected from the 1996 National Caregiver Survey to compare the experience of people providing care for a patient with dementia with the experience of people providing care for a patient with a different terminal illness. The survey data was collected from two samples; one was a “fully replicated, stratified, single-stage random digit dialing (RDD) sample of U.S. households with telephones generated in-house by the ICR Survey Research Group, Inc.” (Ory et al., 1999, p. 178), while the second was generated from ICR’s EXCEL Omnibus Service and was comprised of minority participants. The total sample included 1,509 participants; 623 were Caucasian, 306 were African American, 307 were Hispanic, 264 were Asian, and 9 listed themselves as “other.” To be considered a caregiver, participants had to have provided unpaid care in the past 12 months, or be currently providing care for a relative or friend who was 50 years old or older. Participants who indicated that they were caregivers were then asked questions about the health of the patient in order to separate the caregivers into dementia and nondementia groups.

The survey consisted of forty-four questions assessing the amount and type of care provided, the impact of caregiving, and the caregivers’ utilization of services. Ory et al. (1999) found that dementia caregivers spent more time per week providing care than nondementia caregivers, that dementia caregivers assisted the patient with more activities of daily living and instrumental activities of daily living than did nondementia caregivers, and that more dementia caregivers had to either retire or accept a less demanding job in order to fulfill their caregiving responsibilities (Ory et al., 1999). Dementia caregivers in this study were more likely to report experiencing negative effects of caregiving. More dementia caregivers than nondementia caregivers had to give up pleasurable leisure activities, had less time for other family members, and were more prone to experience other family members as "not doing their fair share" (Ory et al., 1999, p. 182). Dementia caregivers also reported an elevated amount of family conflict, higher degrees of emotional and physical stress, and were more likely to report experiencing mental or physical problems that they attributed to caregiving. Overall, this study demonstrated that dementia caregivers were more negatively affected by their caregiving demands than nondementia caregivers (Ory et al., 1999). The authors attribute this to the unique characteristics of dementia and the inherent stress that comes from dealing with the behavioral problems manifested by most patients with dementia.

As the literature demonstrates, primary caregivers have often been the focus of studies because of their heightened experience of burden. However, one finding that is interesting to note, and particularly salient for this study, is Baronet's (1999) literature review of caregivers that found that while living with the patient was associated with a sense of increased burden, it was not associated with worry. She states that "this suggests that caregivers who do not live with their ill relative still worry as much about them" (Baronet, 1999, p. 823). This study is attempting to determine the ways in which non-caregivers are emotionally impacted by their relatives' Alzheimer's disease, despite being free of the constraints and burdens of providing full-time care.

Alzheimer's Disease and Ambiguous Loss

Boss et al. (1988) contend that the boundary ambiguity that ensues when a family member is diagnosed with Alzheimer's disease can lead to stress and family dysfunction. Boss (1999) also asserts that the more boundary ambiguity there is the more symptoms of depression the family will exhibit. According to Boss and Greenberg (1984) and Boss et al. (1988), it is the level of ambiguity family members feel rather than the disease itself that predicts the level of stress a family will experience. Boss (1993) even goes so far as to suggest that focusing on caregivers' experience of burden is unproductive, stating that:

> Caregiver burden may no longer be a fruitful variable on which to focus. More than the degree of burden, it is the *outcome* of burden that indicates trouble. . . . Depression in members of the caregiving family, for example, may be a more important outcome variable than the degree of caregiver burden or degree of stress. (p. 268)

Boss and Couden (2002) contend that it is boundary ambiguity, not experience of burden, which hinders coping and can result in depression, anxiety, hopelessness, conflict, erosion of close relationships, and a loss of mastery (the extent to which individuals feel in control of their situation and choices, rather than ruled by fate, according to Kaplan and Boss, 1999). If this is indeed true, then it makes sense that non-caregivers could potentially experience the same emotional struggles despite not being burdened with the daily responsibilities of care.

Coping with Ambiguous Loss.

Dupuis (2002) conducted a study of thirty-eight adult daughters and twenty-three adult sons, fifty years old or older, who were caring for a parent with dementia who was currently living in a long-term care facility. Her intent was to understand the experience of providing care for an institutionalized parent, to assess whether or not family members in different stages of caregiving described their experiences differently, and to assess for and examine the ambiguity family members experienced in their caregiving roles. She used data from two data collection phases of an on-going study that was looking at the role of the family in institutional care; phase one of this study explored the role of adult daughters while phase two explored the role of adult sons. In order to be included in the study, the adult children caring for an institutionalized parent with dementia also had to be listed as the primary contact on the patients' admittance paperwork, and their level of experience with caring for an institutionalized dementia patient had to vary (i.e., participants were in various stages of the caregiving process). Sample criteria also evolved as the study progressed; for instance, as the researchers learned that adult daughters with both parents living characterized their roles differently than adult daughters with only one living parent, they sought out more adult daughters with both parents living to understand that difference in role definition. Of the entire sample, 31.1 % of the participants were considered to be in the early caregiving phase (having provided care from one to nine months), 27.9 % were in the mid-phase (having provided care from ten months to two years), and 41% were in the later phase (having provided care for over two years) (Dupuis, 2002).

Using a grounded theory approach, Dupuis (2002) conducted in-depth active interviews with each participant. Interviews were transcribed and coded, and member checks were conducted. Data were then analyzed using a modified constant comparative method. The data indicated that for this particular sample, ambiguous loss was a process, and not a singular event. Dupuis (2002) described this progression as encompassing three phases. Anticipatory loss seemed to be experienced more by caregivers in the early phase of the illness, when their parent was still psychologically present, but the caregivers were anticipating what they would feel when that was no longer the case. People in the mid-phase of caregiving seemed to be experiencing progressive loss, which includes the gradual deterioration of their loved one. Finally, Dupuis (2002) describes acknowledged loss, which is typically experienced by caregivers in the later stages of care who have acknowledged the psychological loss of their parent and have arrived at an understanding that their parent no longer exists.

Dupuis (2002) also discovered two primary ways that family members cope with these phases of ambiguous loss. The first was coping through acceptance of the situation. Family members who coped in this way were described as being able to accept their parent’s limited psychological existence in their lives, to reframe that absence in a positive way, and were able to shift their focus to their own lives. Conversely, family members who coped with their loved one’s Alzheimer’s disease by avoidance were less likely to visit the patient at all, were less likely to visit the patient alone, and often cut themselves off totally from their ill parent. Dupuis (2002) states that, “family members who coped through avoidance of the situation expressed much more pain and emotional distress in their roles than those who were able to come to a place of acceptance of the situation” (p. 108).

It therefore seems logical to assume that feelings of ambiguity would have a great deal of influence over how care is provided to the Alzheimer’s patient. Furthermore, it might very well be the case that family members who make a conscious choice not to be the designated caretaker of their ill parent do so because the loss is too painful or ambivalent.

Boundary Ambiguity and Depression.

Several studies have explored the relationship between ambiguous loss in Alzheimer's disease and caregiver depression. Caron, Boss, and Mortimer (1999) conducted a longitudinal study of seventy-two Alzheimer's patients and their caregivers. Of the caregivers interviewed, 86 % were spouses of the patient, 8% were children, 4% were siblings, and 2 % were close friends. These caregivers ranged in age from thirty to eighty-four years old, with a mean age of 63.57. Seventy-nine percent of the caregivers were female. The Alzheimer's patients assessed for this study ranged in age from fifty-three to ninety, with a mean age of 68.26. Seventy-eight percent of the patients were male. Respondents were assessed in face-to-face interviews two times, twelve months apart. Researchers used the Mini-Mental State Exam, the BEHAVE-AD, and the Instrumental Activities of Daily Living scale to assess the Alzheimer's patients; they used the Zung Depression Scale, the Pearlin Mastery Scale, and the Boundary Ambiguity Scale to assess caregivers. The researchers discovered that caregivers' emotional cut off from the patient resulted in increased symptoms in the patient, which in turn lead the caregivers to close out the patient even more (Caron et al., 1999). Another interesting finding was that as caregivers became more depressed, so did the Alzheimer's patient, though the inverse of this relationship was not true (i.e., increased depression in the Alzheimer's patient did not affect caregiver depression) (Caron et al., 1999). This study suggests that how the family chooses to deal with the ambiguity of their loved one's Alzheimer's disease can have tremendous implications, not only for the levels of stress a family experiences, but for the Alzheimer's patient as well.

Other studies have supported the notion that boundary ambiguity influences a sense of mastery, and that mastery is in turn related to the degree of depression experienced by the caregiver. In 1990, Boss et al. conducted a study of seventy dementia patients and their caregivers to examine what impact boundary ambiguity and mastery had on a caregiver's experience of depression. They used the Mini-Mental State Examination, the Instrumental Activities of Daily Living scale, and the BEHAVE-AD scale to asses the severity of the patients' dementia, and they used the Boundary Ambiguity Scale, the Pearlin Mastery Scale, and the Zung Depression Scale to assess boundary ambiguity, mastery, and depression in caregivers. Using stepwise regression and path analytic techniques, they found that both boundary ambiguity and mastery "significantly predicted depression in the caregivers of Alzheimer's disease patients," (Boss et al., 1990, p. 250), with mastery as the stronger predictor, accounting for 10% of the variance. A finding of particular interest was that there was no direct relationship found between the level of the patient's disability and the depressive symptoms the caregiver experienced, suggesting that the caregiver's experience of burden is more related to the ambiguity they experience than to the severity of the patient's illness. Boss (1993) concluded that "it was the caregiver's perception of high boundary ambiguity and her or his subsequent lack of mastery, more than the illness itself, that predicted the caregiver's depression" (p. 262).

Kaplan and Boss (1999) conducted a similar study of eighty-four community-dwelling spouses of Alzheimer's patients who were being cared for in an institution to determine the effects of six independent variables (boundary ambiguity, mastery, couplehood, stress/daily hassles, social support, and poor caregiver health) on caregivers' level of depression. Kaplan and Boss (1999) used the Center for Epidemiological Studies (CES-D) Depression Scale to ascertain levels of depression; they used the Couplehood Scale to determine the extent to which respondents felt they were part of a viable couple; they used the Boundary Ambiguity Scale to assess the level of boundary ambiguity subjects experienced; they used the Pearlin Mastery Scale to determine respondents' sense of mastery; and finally, they used the Coping and Stress Profile to determine respondents' general experience of stress, social support, and overall health. They found that 51% of the variance in depressive symptoms could be accounted for by boundary ambiguity alone, while mastery accounted for 32%. Interestingly enough, these were caregivers who no longer lived with the patient or cared for the patient in their home. The symptoms of depression, according to this study, resulted from an experience of boundary ambiguity in the relationship and continued even after the "burden" of caregiving was removed (Kaplan & Boss, 1999).

If, as these studies suggest, depression in caregivers is related more to a sense of confusion about who is in and who is out of the family system than to the specific daily tasks of caregiving, and if these symptoms of depression are present even when a former caregiver is no longer providing intensive care, it seems logical to assume that the stress inherent in Alzheimer's disease is a relational one. Furthermore, if this is true, then it seems logical to expect that non-caregiving relatives of Alzheimer's patients might experience the same level of boundary ambiguity, and consequently the same sense of loss of mastery and the same symptoms of depression that caregiver's experience.

Studies Extending Beyond the Primary Caregiver.

Boss (1993) herself has acknowledged that a focus only on primary caregivers is biased. She emphasizes that data on ambiguity should be collected systemically, and that research should take into account not only the experiences of primary caregivers, but also the experiences of siblings, spouses, extended family members, and the care recipient. Garwick, Detzner, and Boss (1994) did just that in their study of thirty-eight multigenerational families dealing with the Alzheimer's disease of a relative. These families were selected from a sample of participants who had volunteered to be part of a longitudinal research study. The primary caregiver for the dementia patient was asked to invite whoever he/she perceived to be in the family to attend the interview. Two to three generations of family members participated in each interview, with the number of family members present ranging from three to eleven. Global Deterioration Scores and Mini-Mental State Exam scores for the dementia patients indicated that all patients were either in mild or moderate stages of cognitive decline at the time interviews were carried out. Garwick et al. (1994) conducted qualitative interviews with each of the families in an effort to elicit common themes that families emphasized in their conversations about what it was like to live with Alzheimer's disease. Interviewers asked each family what the chapter headings would be if they were to write a book about the family's life the previous year, and then analyzed the transcribed responses for recurring themes. Four major themes came up for all the families (Garwick et al., 1994).

The first was a sense of uncertainty about the Alzheimer's patient's diagnosis. This was related to the inability to obtain a clear diagnosis from a physician—a common occurrence with

Alzheimer’s disease since it is only officially diagnosable by autopsy (Forsyth & Ritzline, 1998). The second theme was a feeling families described of sensing something was wrong. This generally had to do with the onset of the disease and the symptoms family members noticed before they received a diagnosis. In some cases, however, family members first learned something was wrong when a physician told them, and were in these instances shocked to learn of the diagnosis (Garwick et al., 1994).

The third theme was that of excluding a family member (Garwick et al., 1994). Interestingly enough, this did not always refer to the family’s collective exclusion of the Alzheimer’s patient in the form of emotional closeout. In one case it was the Alzheimer’s patient excluding himself from family activities, and in another case, a mother, the primary caregiver for her husband, put a family ritual on hold by ignoring her son’s birthday in response to her husband’s disease. Another example was that of a caregiving wife not informing her son about changes in his father’s condition, thereby “excluding him from the information chain” (Garwick et al., 1994, p. 336).

The final theme described by these families was the ambiguity they *all* experienced as a result of living with Alzheimer’s disease (Garwick et al., 1994). This ambiguity was most pronounced in terms of changes in family roles and relationships, and not just changes in the relationship family members had with the patient. The authors contend that “changes in spouse/spouse, parent/adult child, and grandparent/grandchild relationships were described by many families” (Garwick et al., 1994, p. 336). The authors saw this emphasis on changing relationships as evidence that Alzheimer’s disease has an intergenerational effect on families, rather than affecting only the primary caregiver. Their conclusions about the implications of all four themes were as follows:

> Our findings suggest the importance of assessing the degree of boundary ambiguity from the perspective of the whole system. . . . In summary, the clinician needs to assess how individual family members, as well as the family as a whole, view the experience of living with Alzheimer's disease. . . . Our findings lend empirical support to the premise that Alzheimer's disease affects the whole family, not just patients and primary caregivers. (Garwick et al., 1994, p. 339)

Despite the clear implications of this study, a focus on primary caregivers is still the norm. This is true even of literature on terminal illness in general. Though attempts were made to find articles that explored the experience of non-caregiving family members dealing with other terminal illnesses, none were found, which suggests that a focus on the primary caregiver extends beyond the field of Alzheimer's research. This study will attempt to bridge that gap by exploring the experience of non-caregivers and looking for the presence of these themes experienced by families in Garwick et al.'s (1994) study.

Research Questions

This study intends to answer the following research questions: (1) How do non-caregiving adult children of Alzheimer's patients experience their parents' Alzheimer's disease? (2) How do non-caregiving adult children of Alzheimer's patients feel their experience differs from the experience of primary caregivers?

CHAPTER III: Methods

Qualitative Study

To explore these research questions, this study employed the use of a semi-structured qualitative interview. Patton (2002) asserts that qualitative methods enable researchers to gather rich, in-depth information by allowing them to pay attention to the surrounding details and fine distinctions of the interviewees' experiences. As information about the details, context, and nuances of being a non-caregiving relative of someone with Alzheimer's disease contribute greatly to understanding the participants' experience, and since the primary purpose of this study was to understand that experience, a qualitative interview facilitated that goal.

Participants

Participants in this study were three adult children of Alzheimer's patients who did not consider themselves the primary caregiver for that parent. Participants were recruited by word of mouth. One participant responded to an advertisement of the thesis criteria on an online database, one participant was identified through a work contact of the researcher, and the final participant was identified by a member of the researcher's church. Two of the subjects were female and one was male. All participants were required to have *at least* one sibling who was providing care in order to ensure that there were options for family care (i.e., only children might not have a choice as to who provides care for an elderly parent, whereas two or more siblings can decide how and by whom care will be provided). In light of this criterion, the first subject had four siblings, and the second and third subject each had two siblings. All three identified a specific sibling as the primary caregiver for their parent.

The term “primary caregiver” has been criticized in some literature for not being clearly defined (Harvey & Burns, 2003). Therefore, for the purposes of this study it was defined as the person primarily responsible for overseeing a majority of activities of daily living (assisting the patient with getting into/out of bed, dressing, getting to and from the toilet, showering, feeding, or diapering) as well as a majority of instrumental activities of daily living (managing finances, shopping, housework, preparing meals, administering medication) for the Alzheimer’s patient (Ory et al., 1999). In the event that oversight of these activities was shared among siblings, participants were accepted if they oversaw only instrumental activities of daily living. This limitation was based on the assumption that some instrumental activities of daily living are less distressing and/or can be performed from a distance, while activities of daily living tend to be more personal, more physical in nature, and require more direct and frequent contact with the Alzheimer’s patient. It was expected that caregiving might not be as straightforward as it is often described to be, and that siblings who were not necessarily the *primary* caregiver might still contribute to care in some ways. It was also thought to be possible, as some researchers have pointed out, that these less burdensome contributions to care might be overlooked, thus creating more stress or guilt for siblings who were not the primary caregiver (Globerman, 1994; Harvey & Burns, 2005). The participants’ self-report was crucial in determining their eligibility for this study: whether or not they viewed themselves as a primary caregiver was a more important distinction than a delineation of the various areas of caregiving to which they did or did not contribute, and for this reason, subjects were first asked whether or not they viewed themselves or another sibling as the primary caregiver.

For the purposes of this study, “adult children” was defined as those offspring (biological or adopted) of the Alzheimer’s patient that were between the ages of thirty and seventy. Though these were somewhat arbitrary age parameters, the intent was to exclude people who might still live with their parents (since some level of care would be inherent in living in the same house with an Alzheimer’s patient), those people who might have only recently left home to attend college or to live on their own (as these people could have potentially been heavily involved in caregiving in the recent past), or those people who are just beginning their own careers and families (whose experiences or reasons for refraining from caregiving would be different from those older individuals whose careers and families are well established).

This age cut-off was also intended to reflect the likely age of people whose parents were old enough to be Alzheimer’s patients. Piercy and Chapman (2001) reported a mean age of fifty-five for adult children and thirty-three for grandchildren of care recipients in their study, while Ory et al. (1999) reported a mean caregiver age of forty-six, and Teel and Carson (2003) reported a mean caregiver age of sixty-two, with ages ranging from forty-five to eighty-three. If the potential to develop Alzheimer’s disease doubles every five years after the age of 65 (Cummings & Jeste, 1999), it makes sense that children of Alzheimer’s patients would be older when their parents required care. The sample was therefore limited to people between the ages of thirty and seventy in the hopes that these cut-off ages sufficiently enclosed the parameters of the people whose parents were in need of care. As was expected, all three participants fell somewhere around the middle of this age range, with two being in their mid-fifties and one being in her mid-sixties.

Participants were excluded from the study if they fell outside of the identified age parameters, if they shared caregiving responsibilities collectively with other siblings or with a parent (i.e., no one sibling could be identified as the primary caregiver), or if the Alzheimer's patient had been placed in a nursing home or was otherwise being cared for by a person who was not the participant's sibling or sibling-in-law.

Procedures

Once potential subjects were identified, participants were contacted by phone to schedule an interview. During this initial phone conversation a screening was conducted to ensure that each participant met the inclusion criteria listed above. Face-to-face interviews were then scheduled. All interviews were conducted in the participants' homes. Before each interview began, participants were offered information about the aims of the study, were warned about potential risks (i.e., strong emotions regarding feelings of grief, loss, etc.) and benefits of the study, and were given information about how the study results would be used. Participants were assured of their confidentiality and their right to choose not to participate at any time. Participants were also given a list of resources at the end of each interview. Interviews lasted between one and one-and-a-half hours. No payment or incentive for participation in the study was offered to participants. In order to ensure the confidentiality of participants, all information about potential subjects has been safeguarded. All names, addresses, phone numbers, etc. of participants were secured in a password-protected computer file kept in a safe location in the researcher's home.

Instruments

Once informed consent was obtained, individual interviews were conducted with each participant. Interviews were semi-structured, and questions focused on understanding the individual experience of each participant as well as the way each participant made meaning out of their loved one's illness. The interview questions were as follows:

1. What has been your experience of your mother/father's Alzheimer's disease?
2. What has the progression of your parent's disease been like for you? Have you or your siblings had to assume responsibility for tasks formerly fulfilled by your parent? If so, how did the family decide who would take on those jobs, and how was the situation discussed with your parent?
3. What were your relationships with other family members like at the time Alzheimer's was diagnosed? What are they like now? What has changed, if anything, in you? In the patient? In your family of origin? In your family of procreation? In anything else?
4. How do you interact with your mother/father now? How do you interact with your other family members? Are you satisfied with your level of involvement with your family?
5. How do you feel your experience has been different from the experience of primary caregivers?

Design and Analysis

Interviews with each participant were audio-recorded. Tapes were then transcribed, and interview transcripts were read through twice before analysis to ensure that there were no errors in transcription. Data analysis occurred after all of the interviews had been completed.

As described by Strauss and Corbin (1990), data were analyzed first by a process of open coding. Each individual interview transcript was broken down into basic themes, phrases, and categories. As analysis progressed with each interview, new themes emerged, previously noted themes recurred, and some themes were found only in one interview and not others. Throughout this process the researcher maintained a process of journaling to record any thoughts or questions that arose during the analysis. These memos and notes were particularly helpful during data analysis, and aided the researcher in making links between the three theories used as a guiding framework. Once open coding was completed, the process of axial coding began. Recurrent codes gleaned from each transcribed interview were reorganized under broad headings with more specific codes in each category until a complete coding scheme had been developed. Throughout this process, coding was supervised by an advisor who offered an additional perspective both by recognizing any codes the researcher had missed, and by confirming the accuracy of codes the researcher found.

CHAPTER IV: RESULTS

Introduction

In this study I explored the experiences of non-caregiving adult children of patients with Alzheimer's disease. I conducted three qualitative interviews. Two participants were female, one was male. All subjects had at least two or more siblings. In all three cases, the mother of the participant was the parent with Alzheimer's disease. Two participants' mothers had already passed away at the time of interview, while one subject's mother was still living. The three experiences varied in interesting and significant ways. Throughout the coding process, I viewed the data through the lens of my three theoretical frameworks (Phenomenology, Family Systems, and Ambiguous Loss). Some interesting patterns and themes emerged from the data, many of them overlapping in ways that I believe are noteworthy. In the following chapter I will present brief summaries of each interview followed by an analysis of my data by theory. This chapter will also delineate some important ideas that surfaced within the context of each guiding framework, as well as ways in which all three of these theories seem to be interrelated.

Interview One: Summary

Betty is a Caucasian woman in her fifties. She is married with two children (both in college now), and she is an attorney. She has three siblings, one older and one younger brother, and one younger sister. She lives in the metro D.C. area, her brothers live in Alabama, and her sister (the primary caregiver for her mother, who has Alzheimer's) lives in a small town outside of Atlanta, Georgia. Her father is in a nursing home in Alabama where her brothers check in on him weekly.

In articulating her experience, Betty began by describing the process by which she and her siblings knew something was wrong with their mom. She described the gradual onset of her mother's symptoms, she explained how she and her siblings noticed those symptoms and took their mother to see a doctor, and she explained how the doctor diagnosed their mother with Alzheimer's. After that, the siblings tried to keep their mother in her home (which was her wish) by bringing in professional caregivers. When this did not work, they ultimately moved their mother to the youngest sister's house, where she has been living now for two years. Betty says that throughout all of this, she and her siblings pulled together, worked cooperatively to decide what was best for their mom, and divided up responsibilities for her care in ways that made the most sense to them based on their family roles, their locations, and their individual talents and skills. Betty reported a belief that she and her siblings are closer as a result of this experience. Of all three interviews, Betty's is the most rich in detail.

Interview Two: Summary

Bob is a Caucasian male in his late fifties living in the metro D.C. area. He is married to Julie and has one grown, married daughter, Samantha. He has two siblings, a brother and sister, who are both single. His sister, Catherine, lived in California with his parents and gradually assumed the role of primary caregiver for his mother (who had Alzheimer's) after the death of his father. His brother, Jack, also lived in the metro D.C. area, but spent more time in California helping with their mother's care as a result of being single and having a more flexible work schedule.

Bob began his interview by describing his experience as "detached." With his family on the opposite coast, and with the demands of a wife, a daughter, and a job, he did not visit often and was admittedly not actively involved in his mother's care. His brother and sister agreed that their mother suffered from Alzheimer's, and sent him a book, "The 36-Hour Day," to help explain her symptoms. Bob maintained that his mother did not have Alzheimer's, but "some form of dementia," though he never clarified what this distinction meant to him or gave any reason for it. There was no active family discussion about how the siblings would approach their mom's care. Bob described no changes in his relationships after the onset of the disease. He also reported that there was no conflict over decisions the siblings made about their mother's care, nor was there any conflict after her death over division of assets or property. Detachment was the word he used most often to describe his experience, and his detachment was evident in his interview, which was the shortest of the three, and the sparsest in detail.

Interview Three: Summary

Claire is a Caucasian female in her mid-sixties. She is single, and lives in the metro D.C. area. She has two older brothers. Joseph is the oldest, and is fourteen years older than Claire. Jim is the middle brother, and he is ten years older than Claire. Both brothers also live in the metro D.C. area. All three siblings have children and grandchildren. Claire's mother moved to the D.C. area in nineteen-eighty-six, and lived with Claire for about a year and a half. When their differences of personality became too difficult to bear, Claire consulted with her siblings and her mother moved in with Jim. Their mother lived with Jim until her death, fourteen years later, in the year two-thousand. Her Alzheimer's disease was not formally diagnosed until approximately three years before her death, though she had begun displaying symptoms around the time of her move to Virginia.

Claire's described her family's experience as much more stressful than either of the other two participants, and she identified that stress as coming from sibling relationships more than anything else. When her mother moved in to live with Jim, Joseph resented that decision (believing, according to Claire, that their mother would have been happiest living with her). Decisions about care were not openly discussed, and there was no family plan for their mother's care. Claire characterized the experience as tense, stressful, and frustrating, and she believes that though she and Jim have become closer, Joseph and his family have become more estranged from them. She lamented the ongoing tension in the family, seven years after her mother's death. The focus in her interview seemed to be less about her mother and the disease, and more about how differences in opinions and personalities led to a disintegration of family relationships.

Phenomenology

Externalization of Symptoms.

An ability to externalize the symptoms of Alzheimer's disease and separate the parent from what was happening to them was one of the first key concepts to emerge from the data. The concept of externalization involves "personifying problems and attributing oppressive intentions to them" (Nichols & Schwartz, 2004). Participants' responses to their parents' symptoms tended to inform the meaning they derived from the experience as a whole; moreover, interpretation of the symptoms also appeared to structure participant's interactions with their parent and siblings. The theme of externalization surfaced in different ways for all three participants, and these variations in their experiences appeared to set the tone for how they coped with the disease, both as individuals and as families.

Externalization was most prominent in the first interview. Throughout our meeting Betty stressed that her mother was smart, and directed her frustration at a disease that robbed her mother of the capacity to learn or continue to care for herself. She emphasized her mother's intelligence and capability, often using the following words to describe her mother: articulate, bright, well-educated, having advanced degrees, etc. Conversely, Betty characterized the disease itself as the problem, saying at one point, "It's really a really mean disease." Her ability to externalize seemed to allow her to maintain an untarnished conceptualization of who her mother was, while simultaneously allowing her to direct her energy toward and attribute any difficulties she experienced to Alzheimer's disease. In doing this, she made a clear distinction between who her mother is and what the disease has done to her, and she did this so often that it seemed like a distinctive part of her experience, as is evident in the following quote from her interview:

> She's still perfectly aware of things, and she's still intelligent, and she's not crazy. She just couldn't remember things. She couldn't remember what happened ten minutes ago . . . and she couldn't remember she had already done something or she'd already said that or she had, you know, said the same thing ten times, or whatever.

Betty's tenacious differentiation between her mother and the disease appeared to be vital to her ability to manage her mother's symptoms and respond with patience and understanding. She seemed to espouse her personal philosophy in one sentence: "This is not her, this is the illness." It is this ability to put Alzheimer's disease in the chair and make it a separate entity that seemed to fuel how Betty and her siblings approached decisions about their mother's care.

In the second interview, the theme of externalization was evident in contrasting ways. Rather than externalizing his mother's symptoms, Bob explained them by blaming them on his mother, minimizing their severity, or laughing about them. All three methods involved a refusal to believe that the behaviors he had witnessed were, in fact, symptoms of Alzheimer's disease. He used phrases such as "she was just leading me on," or "she was basically torturing herself" to describe the forgetfulness or the paranoia he witnessed in her, rather than characterizing those behaviors as common symptoms of a disease. He laughed at other manifestations of the disease, choosing to view them as sources of humor rather than as indicative of a larger problem. The following quote highlights this:

> And she couldn't remember when she'd eaten. It'd be funny, we, we'd laugh about it because we'd sit down to have a meal and then, within ten minutes after having the meal, she'd say "I'm hungry." We'd say "Mom, you just ate. You just had a very good meal." "We did? What did I eat?" And we'd describe it to her. Now whether that's Alzheimer's or whatever, I don't know.

This tendency to blame his mom for her erratic behavior, or otherwise laugh it off or ignore it, seemed to point to either a refusal or an inability to accept a diagnosis of Alzheimer's. Bob's approach seems to establish that buying into the diagnosis is crucial to externalizing the symptoms.

Externalization is largely absent from Claire's interview. She acknowledged her mother's symptoms and drew frequent comparisons between how her mother was before the disease and how she was after the onset of the symptoms, but she did not emphasize the symptoms as being separate from her mother, nor did she blame her mother for her erratic behavior. This family may or may not have externalized their mother's symptoms, but there are no specific examples of it within the text of the interview.

The ability to externalize seems significant in a number of ways. For Betty, it enabled her to adapt, to focus on the disease as the entity that she had to contend with while allowing her to continue to view her mother as a competent, intelligent person. In the second interview, Bob's inability or unwillingness to externalize his mother's symptoms allowed him to question the diagnosis of Alzheimer's disease, which may have possibly allowed him to remain detached (which is the self-proclaimed definitive characteristic of his experience). Given the interesting ways in which the theme of externalization surfaced in these interviews, it appears to be an area worthy of further exploration. What is the relationship between externalization and coping? Does an ability to externalize impact the meaning one attributes to the experience? If it does impact the meaning made of the experience, how does externalization interact with boundary ambiguity? In other words, if you externalize can you more easily accept ambiguous boundaries? Does an inability to externalize keep boundaries firm and thus protect one from ambiguity?

Belief in the Diagnosis of Alzheimer's Disease.

An ability to externalize the patient's symptoms appears to be fundamentally linked to the family's willingness to ascribe those symptoms to a diagnosis of Alzheimer's disease. The symptoms make sense in the context of the disease. This pattern was most evident in a comparison of Betty and Bob's interviews.

Betty seemed to welcome her mother's diagnosis. She said, "My mother's symptoms are absolutely classic Alzheimer's . . . everything that you could read about Alzheimer's is what she's like." Betty was able to rally around this diagnosis because it fit her mother's symptoms and gave her a context in which they made sense. This in turn helped her to externalize those symptoms. This was evident when she said, "we know what's causing all of this. . . . After the first year when we figured out . . . what all the . . . manifestations of the disease are . . . we just learned how to handle it and how to deal with it." Being able to name the disease and understand how if effects people enabled Betty and her siblings to deal with it.

Conversely, the diagnosis of Alzheimer's disease for Bob's mother was never clear, and he openly disputed it. Throughout the interview he dismissed behaviors that could indeed be symptoms of Alzheimer's disease (i.e., his mother forgetting that she had eaten, her expressed paranoia over what her husband might have done with their finances, confusing her son with her brother when they talked on the phone, forgetting to exercise, saying she had done things when she had not, etc.). His siblings—who admittedly were more involved than he was—believed she had Alzheimer's, but he either could not or would not accept that diagnosis. The following quotes illustrate this reluctance:

> Now, the diagnosis of, uh, the Alzheimer's rather than senile dementia came from my brother. And this he made in 2004 . . . when he sent me this book, 'The 36-Hour Day' to explain what was going on.
>
> My mom—it was very funny, because what I saw, when I was out there for visits, and talking to my sister—uh, was not . . . the classic case of Alzheimer's. It was a case, rather, of dementia.

It seems logical that his inability to externalize his mother's symptoms could be linked to this inability to recognize the potential source of them. Moreover, it is intriguing to think about the many reasons why this diagnosis might be difficult to accept. If an admittedly detached son believed in the Alzheimer's diagnosis, would he be compelled to be more involved in his mother's care, and if so, how might that impact his life? Would he be more impacted by ambiguous boundaries if he bought into the diagnosis?

Over the course of a fourteen year illness, the diagnosis of Alzheimer's disease was not officially given to Claire and her family until roughly three years before her mother passed away. She stated that the absence of a diagnosis was frustrating. In this case, then, there was no diagnosis to dispute or rally around. This leads one to wonder if the absence of a diagnosis for so many years had any bearing on the outcome for this family. Is a timely and accurate diagnosis crucial to coping? When talking about her children, Claire intimated that something about receiving the official diagnosis of Alzheimer's disease made the situation seem more difficult:

> They just felt that it was because she was getting older and, you know, that, that, that's what happens when you get old. But then, uh, they just—once we knew that it was Alzheimer's—then they, they knew what was gonna happen, but it still made them, you know, they were just very sad about it.

In this quote it seems as if the difference between Alzheimer's disease and old age was an important distinction for the whole family. Is that because Alzheimer's disease carries certain emotional connotations that old age alone does not?

The contrast these three interviews provide on this one issue is striking. Betty received and accepted the diagnosis, and was able to use it to plan and enable her to externalize her mother's difficult behavior. Bob received an informal diagnosis, but chose not to believe it, because the difference between calling his mother's problem "dementia" or "Alzheimer's" was significant for him in some way. Claire, in a different sense, seems to hone in on that distinction: the discovery that her mother had Alzheimer's—despite more than ten years of symptoms—still had the power to make the entire family sad, because it foreshadowed something worse than regular old age, something worse than senility.

These three different experiences of the diagnosis and its impact on these families seem to illustrate that the experience of Alzheimer's disease is fundamentally different for families than the experience of some other terminal illness, or even other forms of dementia. The importance placed on a diagnosis seems significant in this light, and leads to several questions. How does a conviction in the diagnosis of Alzheimer's disease influence the experience? How do confidence in the diagnosis and an ability to externalize fit together?

Acceptance.

The theme of acceptance surfaced in different ways in all three of the interviews. Betty mentioned it first, and for her family she stated that acceptance allowed them to move toward stability.

> I think we're now at a point now where we're more accepting and kind of over the initial shock and, and, you know, the sadness that went along with all of that. Now we're much more into a more stable situation than we were.

For this family, at least, acceptance was an important step toward stability and enabled the family to cope with the crisis. Conversely, Bob could not even accept the possibility of the diagnosis of Alzheimer's disease (as mentioned above). Though his situation was not unstable, he did not appear to have managed it as well as Betty. Would acceptance have been a more effective coping mechanism than the ones he appears to have employed (detachment, denial, blame)?

While Bob's siblings appeared to manage well without his acceptance of their mother's diagnosis, Claire's interview highlighted acceptance as a family process. She and her middle brother accepted the situation and adapted to change relatively well. She describes Jim as a "happy-go-lucky person . . . comfortable with himself, and his religion" who "takes things as they come. He deals with them, but he doesn't appear to worry a lot about what might have been." However, Joseph's inability to accept their mother's illness and death had far-reaching consequences for the entire family. Claire described this when she said:

> I know that Joseph was just very, very unaccepting of the fact that mother was gone . . . we would try to talk to him about her estate and what was gonna be done with her estate—refuses to this day to deal with it.

For this family, it was not enough that Claire and Jim could accept the changes, because Joseph's inability to do so kept them all stuck.

All three examples raise some questions about acceptance and the role it plays in the experience of Alzheimer's disease for families. How important is acceptance to stability? Is the experience of the disease more chaotic for families who cannot accept the situation they find themselves in? Is acceptance a family process, where even one member's inability to accept the situation influences the experience of all other family members, or is it an individual process? Can acceptance feasibly be considered the same thing as coping well with boundary ambiguity? If so, do externalization and a belief in the diagnosis have to be present in order for acceptance to be attained? If that is the case, is it fair to assume that the meaning you make of the experience will greatly impact whether or not you experience it as an ambiguous loss, and how well you cope?

Resources.

The utilization of resources appeared as an interesting theme in all three interviews. Betty talked about reading books, seeking a doctor's opinion, attending seminars, hiring multiple caregivers to assist them, and she described all of these things as helpful. She even wondered at one point during our interview how people do this without help, as though having help in many different forms was a key to her family's ability to manage the crisis. While resources were accessed in Bob's family (his brother read books on Alzheimer's disease, his sister hired a live-in caregiver to help her), he did not use them. His detachment seemed to protect him from needing resources, even though his family seemed to rely on them.

Claire's mother was diagnosed so late in the disease that it seemed to inhibit the family's access to resources, though she does mention utilizing adult day-care centers. In this family, however, resources became a source of contention rather than support. Claire described Joseph's reaction when their mother had to spend a weekend at an assisted living facility while Jim and his wife went out of town:

> Then there come a time when I was supposed to keep her for a week or so, but I just couldn't, and we had to find a place to put her. And it, that caused such hard feelings between my oldest brother and the rest of us.

It is interesting to note that something that was instrumental for one family could be a source of conflict for another, but the conflict for this family seems mitigated by Joseph's rigid expectations. This seems to imply that successful coping is a process of whole families, not individuals.

Among the participants that utilized resources, one found them to be indispensable, and the other experienced them as divisive. This raises questions about the context in which resources can be helpful. Does access to various resources aid coping, or are they only effective in the context of a shared family philosophy about how to manage the disease? What relationship exists between seeking help and managing the experience well? When families either do not have access to various resources or do not take advantage of the resources available to them, how is their experience different? What happens when people can't afford certain resources (i.e., extra caregivers, adult day-care, medical expenses, etc.)?

Detail.

What is the relationship between the meaning you make of the experience and your ability to discuss it? Betty's interview was richer and more detailed than the other two. She spoke freely about her experience and provided in-depth answers to the questions. Her open and informative matter was noticeably different from Bob and Claire's demeanor during their interviews. Though willing to discuss their experiences, their answers were much more succinct and much less detailed. It seems noteworthy that the participant whose family appeared to have coped most successfully with Alzheimer's disease was the participant who seemed most able to talk freely about that experience. What is it about her experience that enabled her to share it so openly? What is it about the experiences of the other two that kept their answers brief and perfunctory? Was Betty able to discuss her experience so openly because she was managing it so successfully? Does the absence of rich detail in Claire and Bob's interviews signify that they were not managing their experiences as well?

Focus.

In each interview, the aspect of the experience that the participant focused on the most was different. The differences appear to suggest that what you focus on—how you characterize the disease and its subsequent difficulties—greatly influences how you make meaning of the experience. Betty cited most of her difficulties as coming from Alzheimer's disease, having to manage difficult symptoms her mother exhibited. Bob cited his difficulties—which were few—as coming from his mother's behavior (she's lying, she's torturing herself, leading me on, etc.—blame).   Claire specified that her difficulties came from her tense relationships with her mother and with Joseph (specifically difficulties arising from Joseph's controlling nature). This raises an interesting question about the importance of perspective in families coping with Alzheimer's disease. What is it about individuals and families that dictates their focus? Is it tied to family of origin roles, personality, circumstances, or something else? Since the focus of each participant appears to be related to how they made meaning of the disease and how well they coped, determining how people arrive at their particular perspectives might be an important area for future study.

Worry.

Children that buy into the diagnosis of Alzheimer's disease and externalize their parent's symptoms must consequently believe their parent to be in danger if the parent is living alone. It would be interesting to explore in more detail whether or not this sense of worry engenders feelings of helplessness in families who are coping with Alzheimer's disease, particularly from a distance. It would also be interesting to speculate about whether or not a sense of worry motivates children to be more actively involved in the caregiving process.   In Bob and Betty's interviews, worry surfaced in interesting ways, and was often mitigated by trust in the caregiver. Betty described worrying about her mother when she was living alone and was far away. In fact, she described this feeling as the worst part of the experience:

> I think that was really and truly the very worst part, was when, you know, when she was living by herself and wouldn't let anybody take care of her. . . . I would lay here and just worry about her terribly at night. You know, is something happening to her?

When her mother went to live with Betty's younger sister, she talked about being able to "rest easy" knowing her mother was well cared for. It raises an interesting question: was worry a motivating factor for the children in this family? Since none of them lived near their mother at the onset of her symptoms, did their worry about what might happen to her contribute to their ability to work cooperatively together to ensure she received proper care?

In a similar way, though Bob never expressed worry about his mother, he raved about the woman his family hired to help his sister provide care. Bob even expressed shock when his mother died of congestive heart failure. He believed she had been so well cared for that her death seemed inconceivable. It is interesting to speculate about whether his total trust in the caregivers kept his anxiety at bay, or if his detachment from the situation and his doubt of the Alzheimer's diagnosis shielded him from anxiety in the first place. If worry about a parent engenders helplessness, is it possible that Bob's inability to externalize or accept the diagnosis protected him from feeling powerless?

Distance and Involvement.

An intriguing and complex issue raised by these three interviews is that of geographic distance and its impact on relationships. These three families had three very different experiences of distance, particularly as it related to involvement in the patient's care. Betty found the distance from her family difficult, but managed to remain involved with her family members. She was power of attorney for her mother, she visited her parents and siblings frequently, and she took an active role in caring for her mother even though it was not the primary one. She overcame the distance and built relationships with her siblings that were emotionally closer than they previously were.

Bob stated his position as one of detachment at the beginning of his interview, and he reiterated that position throughout. He cited his geographic distance from his family as a primary reason for this detachment, saying, “I, being twenty-five-hundred-and something miles away, was rather detached from the entire situation.” He even acknowledges that his detachment would have been impossible had he lived nearer his family when he says:

> Would it have been different if all three of us were located near my mom and dad? And, what would the impact have been on Julie and Samantha also? It would have been different from the standpoint of the demands made on us, on a personal level, to assist in the . . . caregiving. It had to be, would have had to have been different. We could not have been detached, as it were. We would have been involved.

It is interesting to note that while Bob’s distance from his mother lets him off the hook, so to speak, Betty’s distance from her family (which is also considerable) has no such function.

Conversely, Claire’s physical proximity to her family did not seem to enhance their relationships or diminish the tension. She cited family conflict repeatedly, between she and her mother (“It didn’t work out, us living together,” and “she was mad when she left and she didn’t talk to me for several months”), but particularly between she and Joseph, or between Joseph and the rest of the family. Though the three siblings live in the same town, Claire and Jim's relationship with Joseph is so estranged that she said, "I honestly do not know when the last time I saw him was. . . . I would say eight or nine months."

Clearly, distance from or proximity to the patient alone does not dictate the roles people will take on. How are some people able to overcome the obstacle of distance, while others make it their main reason for lack of involvement? These will be important questions to explore in the future, because these three interviews seem to suggest that distance and proximity are not necessarily good barometers of intimacy or involvement in caregiving.

Communication: Having a Plan.

The process of communication that siblings engage in to establish their caregiving plan appears to be related to how they make meaning of and cope with the disease. Bob's detachment was prevalent during his descriptions of how he and his siblings planned for their mother's care, but both Claire and Betty agreed that having a plan was essential. Despite their agreement, however, this preference was manifested differently in their experiences. For example, Betty, in the context of seeking information and accessing resources, said:

> It helped me to be able to, you know, sort of chart a path for us and to talk about "Well, here's what we need to start doing so that we're at a certain place at a certain time," and you know, to help plan.

For Betty's family, planning involved a lot of communication, a process of gathering information, an assessment of family of origin roles and relationships, and a division of responsibility. Having a plan, in turn, enabled them to manage the disease successfully.

Conversely, Claire recalls that there was little to no communication and no plan with regard to who took on what jobs. This is evident when she discusses how Joseph came to be in charge of their mother's finances:

> Joseph, being the oldest, he had already assumed the role of her financial person. . . . He just did it, I don't know whether her, there was a will, but, uh, but it was never very clear. . . .He still manages her money. . . . That's just the way it was. . . . Joseph had always been in charge of her money, and that—from what Jim and I understand—was the way she wanted it.

In this example, it was unclear to Jim and Claire exactly how or why Joseph absorbed this role, but an inability or an unwillingness to discuss it left this family stuck. Seven years after their mother's death, Joseph "still manages" their mother's finances and her estate has not been settled. In a similar process, Claire could not recall how she and her siblings came to make important decisions about her mother's care. When asked about the family's decision to bring her mother to Virginia, she said:

> I don't know about that. It was just decided and she agreed. . . . I'm not sure how that discussion came about or who discussed it, but it was decided that she was going to come to Virginia, and she did.

Claire's absence from this discussion is striking, considering that she was the one that her mother was initially going to live with upon moving. Her omission from these conversations (or perhaps, the absence of any discussion at all) seems to exist within a family context in which everyone had a different idea of how things "ought" to be. These perceptions were never discussed or challenged, and conflict inevitably arose when necessary changes meant that Joseph's rigid expectations went unmet. Claire seemed to convey the powerlessness engendered by the absence of communication when she said, "No matter what I would have ever done with . . . mother . . . from Joseph's perspective would not have been enough, because she should have been living here." At the end of her interview, she openly lamented not having a plan, saying that the absence of a strategy led to family "dissension" and "guilt." When asked if having a plan would have changed her family's experience, she stated:

> Oh, I think so, I think so. If there had been some clear delineations of who should do what . . . and that just didn't happen with us, and there was just always tension, especially with Joseph. . . . And you can always be able to be flexible with your plan, but at least have some kind of plan.

However, in another interesting contrast, Bob's detachment from his family's planning elicited no conflict. He left the planning to Catherine and Jack, he agreed to whatever they decided, but he appeared to be uninvolved in the actual planning. There was no communication among the siblings, but also no disagreement. When asked about whether or not he and his siblings discussed their mother's care, he said:

> No, there was no discussion whatsoever about it. Catherine just took on a, the roles. She assumed it naturally, became the caregiver . . . and there was no problem with that whatsoever, and, uh, no argument with it whatsoever. . . . My sister, brother, and I saw eye to eye right from the beginning. . . . There was never any discussion of it, to be honest with you. It was just a common agreement.

These three experiences again raise some interesting questions about the importance of communicating about and planning for a parent's care by highlighting the complexity involved. Betty's family's abundant communication and tireless planning contributed to their success, while the absence of those things in Claire's family led to confusion and difficulty. Bob's family managed to tread some intriguing middle ground, where a lack of communication and an avoidance of conflict were possible within the context of some shared family understanding, some unspoken agreement about how things ought to be done to which all three siblings ascribed. Three such different outcomes lead one to wonder how family of origin roles combine with family history and individual personalities to inform how families create a plan, or if a plan is even necessary.

Experience of Burden.

As one might have predicted, the non-caregivers interviewed in this study did not discuss burden as a part of their experience; in fact, when asked about the primary difference between their experiences and that of primary caregivers, all three participants made some allusion to being free from the daily burden of care. The following quotes from each interview illustrate this common theme.

Of his experience, Bob says "I was nowhere near as personally, totally involved as my sister," and discusses the absence of burden in his experience when he says "suffice it to say that I had nowhere near the experiences, the ups and downs, uh, daily, nightly, that my sister and brother did."

In comparing her experience with that of her brother Jim, Claire went a step beyond Bob and made an additional distinction. For her, she describes her *emotional* experience as being just as valid as that of her siblings, caregivers or otherwise, and distinguishes between her experience and that of caregivers by discussing their different physical experiences of the disease. She honed in on this experience of burden as well, particularly the idea of "daily ups and downs" mentioned by Bob, saying:

> We probably all had the same emotional experience or something close to that, because of what was happening to mother. The, the physical experience had to have been much harder for Jim and Susan than for me, because I was outside of it. I mean, I wasn't there on a day to day basis to deal with mother. . . . Emotionally, maybe the same, but physically certainly not the same, because they have the day to day, uh, ups and downs, and certainly in the last years, more downs than ups.

Betty also talked extensively about the difference of the day to day experience, or the burden of care, as being the primary distinction between her experience and that of her younger sister. She said:

> Well, I think it's obvious that I can get away and go do things and that I can have a social life and I can, you know, go on vacations. I can do whatever I want to do and my sister really can't. . . . and then not being able to let your guard down. You know, when my mother was here, just not being able to go take a nap, or, you know, just having to watch her all the time. And I could not go anywhere without her, I couldn't do anything without her. And, and three weeks it wasn't that big a deal, but if I had to live that way all the time I think it'd be extremely stressful, you know?

These siblings, though not faced with the experience of caregiver burden, still acknowledge the role it plays within their collective family experience. They see it as the primary distinction between their experiences and those of their caregiving siblings. This would seem to suggest that research that explores caregiver burden is important and valid, not detracting from the experience of whole families, but rather, providing important information about the extra strain faced by caregivers. However, it is important to emphasize Claire's point: the emotional experience of this disease is, in her view, not necessarily related to the experience of burden. It is a separate experience, and one that impacts all family members equally.

Family Systems

Sibling Relationships.

The impact of the disease on sibling relationships is varied. All three interviewees experienced different outcomes in terms of the effects of the disease on their relationships with their siblings. It is interesting to note that pre-diagnosis relationships do not necessarily predict post-diagnosis relationships. Relationships can improve, worsen, or remain the same, but which course they take seems to be determined by the meaning the family makes of the experience and whether or not they are able to pull together to manage it. This suggests that something about how family members make meaning of the experience and cope with the disease influences how they feel about one another, regardless of what their relationships were like before the crisis.

Betty stated that the experience of her mother's Alzheimer's disease strengthened her bonds with her siblings. She talked about working together cooperatively to manage the disease, making decisions as a sibling group, and dividing up responsibilities based on their individual skill sets, geographic location, and relationship to their mother. Her final assessment of their current relationships was a positive one:

> Before my mother's Alzheimer's . . . we got along well, but we generally tended to . . . see or talk to each other at family gatherings . . . We were living our own lives, everybody was doing their own thing. . . . Whereas after the diagnosis, you

> know, we were talking to each other a lot on the phone . . . and spent a lot more time, um, discussing what was going on and coordinating with each other. And you know, I mean, we still do. Um, we have to. . . . I just think we're just more, um, more involved with each other now. . . . I think it did bring us a lot closer together emotionally. . . . From the standpoint of the relationship with my siblings, it's been a positive.

In contrast, Bob's relationships with his siblings remained unchanged. At the end of their experience, he could identify no enhanced closeness or increased estrangement. At one point, he even described his relationship with his siblings as "Just there." Speaking of his relationships with Catherine and Jack, he said they were:

> Same as normal. I mean nothing changed with that. Nothing at all. . . . We haven't been especially close, but on the other hand, we haven't been especially distant . . . and nothing changed.

In Claire's family, the experience of the disease had a negative impact on Claire and Jim's relationships with Joseph. She reported that she and Jim "get along," but that she and Joseph "talk," and the distinction is a subtle but important one. Whatever the difference between "getting along" and just "talking" meant for Claire, it was enough of a difference for her to acknowledge that her relationship with Joseph is not the same as it was before their mother's illness. Of her interactions with Joseph, she said that "he tells me what he wants me to know, and what he don't want me to know he don't." However, Jim and Claire's relationship with each other remained close. She talked about this contrast in her relationships with Jim and Joseph when she stated that:

> Jim and I are much closer than I guess we've ever been . . . and Joseph, sometimes I don't talk to him for six months or so. He calls when he says "Claire, I've changed the flowers on mother's grave," or "Claire, it's your time to change the flowers on mother's grave," or, you know, something like that. But, then, just for any kind of a relationship, we really just don't have much of one, other than he's my brother and if he ever asked me to do something I would certainly do what I could.

Something about the experience of their mother's illness altered these siblings' relationships. The relationships are so severely changed that Claire's sense of "family" is greatly diminished. She emphasized this by saying:

> There's not much of a family there, a relationship, you know, other than the fact that we're family, and if somebody—anybody—needed anything we would be there for each other. But, our day to day contact, or, you know, that kind of relationship that brothers and sisters usually have is just no . . . Joseph and I and Jim and Joseph just, just did not have that.

It seems important to note here that neither Claire nor Joseph was the primary caregiver, and that conflicts over their mother's care left their relationship damaged despite the fact that neither was primarily responsible for it. If the same conflicts over care exist in other families, regardless of which family member holds the title of "primary caregiver," it could be an important finding: that the conflicts that arise in families dealing with Alzheimer's disease are not always necessarily conflicts between the primary caregiver and other siblings. It speaks to the influential role that rigid expectations play in the caregiving process, and highlights the need to target whole families.

Shared Family Philosophy.

An interesting concept brought out by all three interviews was the idea of a shared family philosophy, and the role of that philosophy in determining how families manage the crisis of the disease. It seems like a shared philosophy about how the family will approach care is important. The philosophy does not necessarily have to reflect a consensus about the diagnosis, although that helps, but it does seem necessary that everyone agree about how the parent will be taken care of.

Betty's family reached a consensus about the symptoms their mother was exhibiting. They all bought into the diagnosis of Alzheimer's disease, and they were able to "work cooperatively" together to decide how to manage it. Betty highlighted this need for a shared family philosophy when she said, "If you've got a family you have to pull together for something like this, it's more than one person can deal with."

Bob did not agree with his siblings about the root cause of their mother's behavior, but he was still able to ascribe to a shared family philosophy that dictated how their mother should be cared for. He and Catherine and Jack were able to navigate decisions about their mother's care without incident. It would appear that theirs was a philosophy centered on how to care for parents rather than how to manage Alzheimer's disease, and their philosophy worked. Bob said:

> So it was never any of this argument that I think typically ensues among siblings with regard to disposition of funds. It was always directed toward what's good for Mom and Dad. . . . The feeling amongst the three of us was straight and normal, that Mom deserved the best care we could get for her and whatever

needed to be done would be done.

The key to this particular family philosophy seems to be doing what is best for a parent. It is a simple directive, but it enabled Bob and his siblings to avoid conflict.

On the other end of the spectrum, Claire's story seems to illustrate what can go wrong when siblings cannot organize around a shared family philosophy. Joseph's rigid expectations about how the disease should have been managed seem indicative of a personal philosophy that was incongruent with that of his siblings. Claire highlighted this by saying that Joseph "always tries to put guilt on you anyway . . . she was gonna live with me, and that's the way it was supposed to be, and it just didn't work out that way." When that philosophy was challenged, the result was family tension and conflict. Claire stated that the decision to move her mother from her own home to Jim's "especially did not go over well with Joseph . . . because he knew that mother would prefer to either live with me or with him."

The idea that successful outcomes could depend, at least in part, upon a shared family philosophy at the onset of care leads to several questions. Does a shared family philosophy enable families to cope successfully with the disease? If so, is it influenced by each individual's ability to externalize and accept the diagnosis? If this is true, then is it also true that people who cannot externalize and/or who dispute a diagnosis of Alzheimer's disease will have more difficulty reaching a family consensus about how to care for their parent? What is the interplay between externalization, belief in the diagnosis, reaching a family consensus, and being flexible or accepting? How important is a shared family philosophy to the outcome of the experience?

Parental Relationships.

As mentioned before, while no discernable predictions can be made about post-illness sibling relationships based on what those relationships were like pre-diagnosis, the reverse seems to be true—for these participants, at least—when it comes to their relationship with their parent. Betty, for example, directly attributed part of the pain of the experience to the nature of her relationship with her parents before their illnesses when she said “Because we were real close to our parents, I mean it was, it was very stressful and very painful.” Her assessment of the family’s experience seemed to imply that having a close relationship with her mother before the diagnosis of Alzheimer’s disease made the experience of the disease more distressing.

Conversely, Claire described her relationship with her mother as having been historically tense. When she decided she could not continue to live with her mother, she explained that “we just could not seem to get along. And, and that had been a—a lifelong problem.” Here, the pre-existing conflict in Claire’s relationship with her mother was exacerbated by the disease. When her mother moved out of her home and went to live with Jim, Claire reported that “she was mad when she left and she didn’t talk to me for several months.”

It is intriguing, and perhaps significant, that Bob does not comment on his relationship with his mother before or after her diagnosis. He describes his position throughout her illness as one of detachment, and it begs the question: was his relationship with his mother always detached, and is that what enabled him to remain detached during her illness? Or, if he had experienced a close relationship with his mother before her diagnosis, could his detachment during her illness have protected him from the type of pain Betty experienced? In either case, the influence of pre-diagnosis relationships with the patient on the experience for children is an idea worthy of further exploration. If you are not close to your parent, is the experience more or less painful, or the same? What is the relationship (if one exists) between parent-child closeness and the child’s experience of the disease?

Family of Origin Roles.

This study yielded interesting examples of the complex ways in which family of origin roles operate when families attempt to manage the crisis of Alzheimer’s disease. For these families, their roles appeared to exist on a continuum that ranged from utilizing their family of origin roles as helpful tools that enabled them to organize around and manage the disease successfully, all the way to using those roles as weapons designed to keep family members in unbending positions that ultimately impeded the family’s ability to deal productively with the crisis of the disease. It is interesting to theorize about a possible formula that might explain how these roles operate. For instance, would it be true to state that neutral to positive pre-diagnosis relationships combine with functional family roles to lead to successful coping, or conversely, that neutral to poor pre-diagnosis relationships combine with dysfunctional family of origin roles and result in poor management of the crisis?

Betty’s family served as an example of the former. She described a process by which her mother in some ways dictated the roles her children could assume in her care based on the relationships she had with them before the diagnosis. She was “emotionally closer” to her youngest daughter, therefore it made sense for that daughter to be the primary caregiver. Betty was an attorney, and her parents had relied on her for financial help in the past. Consequently, she was the child her mother trusted most to advise her in legal and financial matters, and she became power of attorney for her parents. In these examples it appears that the children returned to known and accepted family of origin roles in order to manage the crisis of the disease. The roles were functional, appropriate, and helped the family organize and manage the crisis successfully. These roles enabled all family members to assume responsibility for certain aspects of their mother's care that were directly related to either their own capabilities, their relationship with her, or a combination of both of those things. Betty said that she and her siblings "divide[d] up the workload among us," and "work[ed] together cooperatively."

Alternately, Bob identified his primary role as with his family of procreation—his wife, Julie, and his daughter, Samantha—rather than with his nuclear family. He even connected more emotionally to the experience of providing care for his mother-in-law before her death than he did to the experience of his own mother's illness. In this way, it appeared that his roles as father, husband, breadwinner, etc., trumped any roles he might have fulfilled as son or sibling. His identification with this husband/father role gave him an "out," so to speak. He could detach from his nuclear family and use his roles in his family of procreation as appropriate justification for that. Bob spoke of his own detachment and alluded to the idea that his brother and sister being single somehow made them more suited to be primary caregivers when he said:

> But I have to say that, being here, and being involved in a lot of working activities and things like that, I was mostly detached and most of the . . . care for my mom fell on my sister. . . . My brother was out there quite frequently. . . . Neither of them are married, so they had no ties.

When he did discuss his role in terms of the tasks he absorbed to contribute to his mother's care, he seemed to view those responsibilities as a way to "pitch in." He did odd jobs around the house, changed light bulbs, installed doorbells, etc. This type of role allowed him to be useful without incurring any emotional strain (like being the power of attorney, like having your parent stay with you occasionally). Bob's experience elicits questions about the significance of what a person perceives as their primary role and whether or not that was at play here, or if his detachment was simply a function of the distance between him and his mother.

In contrast, Claire's family presented an example of family of origin roles as rigid, restrictive, and damaging. Claire was expected to take care of her mother, though it is unclear why (because she is a woman, because she is the youngest—she identified no clear reason other than her mother's preference, despite their historically tenuous relationship, and Joseph's belief that she should). When that arrangement failed and Jim assumed the role of primary caregiver (an arrangement that, according to Claire, was better for all involved), Joseph could not handle the change, and clung instead to rigid ideas about how things should have been. Claire assumed a more supportive role, helping Jim and his wife as needed, but her abdication of a known and expected role engendered Joseph's lasting resentment.

Furthermore, Joseph was identified as being just like his mother: extremely controlling. Claire calls him "the number one son," which seems to indicate some perceived preference for him by their mother. She painted a picture of Joseph as wanting to dictate how care should be managed ("she was gonna live with me, and that's the way it was supposed to be"), but as incapable of communicating with his siblings. She claimed that:

> You could never get an answer from him . . . it's always been that way with Joseph. You can never get an answer from Joseph about anything . . . nothing. If you ask him . . . if this piece of paper is white, he would take a week to answer you. . . . Very frustrating to try to deal with him. . . . And every situation, it was always, "I'll get back to you."

If homeostasis was at work in Joseph's desire for things to play out the way he thought they ought to, it was also at work in Jim and Claire's response to him. Claire confessed that she and Jim did not question Joseph's decisions for fear of reprisals. Interestingly, she cited the reason for this as a desire to preserve the family, but she later admitted that she and Jim only maintain the pretense of a relationship with Joseph. All of these examples seemed to indicate an interesting family pattern where relationships are structured according to doing what is expected, and questioning is forbidden. The covert family rule might say "Our roles are rigid and our relationships cannot withstand conflict, challenges, or disagreement. Change is unacceptable." Additionally, it seems as though age and gender stereotypes are at work here, though not explicitly stated. Joseph was in charge of their mother's finances, but the only justification given for that was that he was the "oldest." There is a rigidly held expectation that the youngest—the only female—should care for their mother. It would be interesting to know if other families experience conflict around roles because of age or gender stereotypes.

Another interesting point to make here is that Claire said her mother would have preferred to live either with her or Joseph, but Joseph's wife prohibited her living with him. Just as in Betty's family, Claire's mother (consciously or not) seems to have directed the roles her children could take on, but with results that were much less successful. Perhaps the key is flexibility. When things did not work out the way this family expected, change was met with anger, resistance, even cut-off. So do roles that are directed by the patient or each child's relationship with them only work within the context of flexibility?

All three of these experiences produced some intriguing observations that lead to some important questions. Clearly, family of origin roles are at work and can impact the experience of the disease in a variety of ways, both positive and negative. It is important to note that roles and relationships became barriers in Claire's experience, while Betty's family was able to utilize their roles to enhance their experience. Does family coping go awry when expectations of others and the roles they are expected to fulfill go unmet? It would be interesting to explore how flexibility and adaptation to change fit in with family of origin roles, especially since an inability to modify rigid expectations appears to have stunted Claire's family's efforts to cope.

Change and Flexibility.

Alzheimer's disease, particularly when viewed as an ambiguous loss, presents a huge challenge to families in terms of adapting to change. The disease is ever worsening, gradually presenting each family with new obstacles to be overcome, continually blurring their established family boundaries, and perceptibly altering relationships—for better or for worse—as families reorganize to manage the changes they encounter. In the face of such drastic change, it seems evident that families with a greater capacity for flexibility would be better suited to deal productively with the crisis of the disease. As referenced above, a striking contrast between family flexibility versus family rigidity was most prominent in Betty and Claire's interviews.

Betty conveyed the shock of the onset of the disease by abundant use of the word "sudden." All of the changes in her mother were described as happening "suddenly." It gives one the sense that Alzheimer's disease catches people off guard, happens unexpectedly, and disrupts life in unpredictable ways. She described so much of her family's process as one of flexibility. They had to know when to talk to mom openly and when not to, they had to know when to let her dictate how things would go and when to pull rank, they had to know when to be honest with her but also when to lie to protect her, and they each had to be willing to do things differently, oftentimes, things that went "against their grain." In the following quote she illustrates how flexibility enabled her and her siblings to take care of their mom by giving themselves permission to do things differently:

> There's no more rational conversations. There are no more, you know, trying to reason with her. It's just a waste of your breath. And so we did some of that, we tried to do it, and we finally just quit and started doing what we had to do. And if that meant lying to her, it meant lying to her. . . . We just did a lot of that kind of stuff, and it was just the sort of stuff that we would never have done. We would never have lied to our parents before, you know? But you just do what you have to do at that point. . . . It goes against your grain when you're, when you're the kind of person who believes it's wrong to flat out lie to somebody, you know? But that's what, you just, you have to rationalize it in your own mind that this is the way you get things done or you protect her. And that was a lot of what we did, was to protect her.

All of this suggests an adaptability that aided Betty and her siblings. It also seems that their ability to be flexible is connected to externalization. Characterizing their mother's behavior as a "symptom" of the disease allowed them to justify modifying their approach because that was what the disease merited. In a sense, an ability to externalize gave this family permission to "go against their grain" because that was the only way to productively manage their mother's symptoms. If this is true for other families as well, then an ability to externalize is tied once again to an ability to cope. What significance does that hold for people who cannot externalize?

In contrast to the flexibility demonstrated by Betty and her family, control emerged as a prevalent theme in Claire's interview. It seems to have made this family incapable of flexibility.

Even when Jim and Claire were able to be flexible within their roles, Joseph maintained rigid expectations and saw their flexibility as an abdication of responsibility. This led to intense family conflict and cut-off. Claire's description of her mother and brother's controlling natures seemed to suggest that flexibility might be connected to family of origin roles. She highlighted the contrast of flexibility versus resistance to change in her family when she said:

> Jim and I seem to be somewhat alike, you know? We, you know, we, things happen, but you have to go on living, and you go on and you do what you have to do. . . . And Joseph doesn't seem to be able to do that . . . I guess within his own self he just doesn't seem to be able to move on . . . Joseph is just so much like mother. He has to control everything.

It is interesting that control surfaced so repeatedly as a theme in Claire's interview, given that a rigid sense of personal control seems at odds with a disease notorious for stripping people of their self-command. Joseph's focus on the behavior of others—the one thing that he could never hope to control—seems futile, ineffective, and exhausting, but it raises an important question about the protective nature of rigid personal ideals. Did Joseph's unyielding expectations protect him? Did they allow him to view his siblings as the problem instead of Alzheimer's disease? The knowledge that Alzheimer's disease robs people of their personal control leads one to wonder if Joseph's stringency was a response to that, an attempt to control something since the disease itself cannot be restrained by any person.

These interviews seem to represent two opposite ends of the spectrum. They raise some important questions about the role of flexibility in managing this disease. Does family coping depend on how well family members—both as individuals and as a whole—adapt to change already? Is externalization an important component of being able to adapt to change? Does an inability to externalize translate into an inability to be flexible, to adapt to the changes of the disease?

Intergenerational Transmission.

In each family interviewed, the way the adults in the family experienced and coped with the disease seemed to directly influence how their children and grandchildren experienced and coped with the disease. In each family the consequences were different, but they all experienced some form of this transmission. If this holds true for other families coping with Alzheimer's disease, this is a finding that could have particularly salient implications for family therapists.

In Betty's family the siblings divided responsibilities and enjoyed close, meaningful relationships with one another. The grandchildren were also described by Betty as being helpful. She discussed her relationships with her nieces, mentioning "family jokes" they had shared. She commented on the way her children helped her when her mother came to visit. She reported that her sister's children also helped their mother with their grandmother. Throughout her interview it was evident that in Betty's family, the successful management of the disease by the children had filtered down to other family members.

Just as the cooperation among Betty and her siblings was transmitted to her children, nieces, and nephews, so was Bob's detachment transmitted to his daughter. Though she was the only grandchild on his side of the family, she had a limited relationship with her paternal grandparents. Bob acknowledged that she did not take their loss as hard as she took the loss of her maternal grandparents (and interestingly enough, he too seemed more able to connect emotionally to the loss of his wife's parents than to his own). His detachment seems to have contributed to her detachment.

In Claire's family, tension was transmitted down to children and grandchildren. Just as Jim and Joseph lived in the same town but went months without seeing each other, so did their sons (who live in the same North Carolina city). Claire described how her kids questioned the way things were handled when she said, "There's been a lot of stress, and, you know, they—my kids, Jim's kids have all wondered why there has never been a settlement of her estate." She also reported a time when her children picked up on her tension, and it created in them resentment toward Joseph, saying "they could just hear it in my voice. And they had some resentment towards Joseph because of the—they felt that he had, that he caused a lot of the stress." Joseph did not attend the wedding of his great niece. This particular absence on his part led Claire to mourn the loss of her sense of family, saying "I wish we could be more like a family unit, but it just is not going to happen."

Roles versus Self-Care.

The rigid expectations of Joseph, and the backlash experienced by Claire and the rest of the family when those expectations went unmet, leads to some serious questions about the interplay of family of origin roles with a basic need for self-care. In Claire's family in particular, these two elements seem to be at odds. She attempted to fill her known role. She tried to live with her mother for a year and half, but of that arrangement she said:

> Mother was such a controlling person. And I guess I must have a little bit of that control myself, because, you know . . . I was a grown woman. I had had three children. I had grandchildren. And I didn't have to have someone to tell me when to vacuum my floors or when to do this, or when to do whatever I was

> gonna do. So, it just got so bad till we didn't talk for days at a time. It was just, it was a very bad living experience.

When Claire could no longer live with their mother, she admitted that the arrangement they had was not working. Claire was engaging in basic self-care by acknowledging that this situation was more than she could handle. However, this acknowledgement was met with resentment. Joseph's inability to reconcile his own idea of how things should have been with Claire's needs resulted in family tension and cut-off.

If this same type of pattern exists in other families, it has the potential to create a no-win situation for all involved. What happens when a person's self-care conflicts with what's expected of them, or with their ability to provide care to the patient? Claire knew her own limitations—that taking care of her mother even for a week or two was more that she could handle—and yet acknowledging that created "hard feelings" between her and Joseph. He expected her to do it anyway. What happens when your knowledge of yourself and your own limitations is in direct conflict with a known and expected role?

Environment and Roles.

The role of the community in the caregiving process was an interesting theme that emerged particularly through Betty's interview. In the case of this family, Betty lived in a large, urban, densely populated community. She was able to make a great deal of money and had access to a variety of resources, but could not network comfortably enough to be able to establish an adequate support system that would have enabled her to be the primary caregiver. Conversely, her younger sister lived in a small town with a broad support network and access to known people that she trusted who helped her provide care. She did not have the same easy access to resources that Betty did (i.e., Alzheimer's association seminars, adult day-care centers), but she did have the support of a community (i.e., she attends church with the family doctor, and the women that help her care for her mother baby-sat her children).

This difference in environment and the concept that each sibling's location might make them better suited for certain tasks than others brings up an interesting question: How—if at all—does environment impact the roles assumed during care and the family's ability to cope with the experience? Is location—not just of the patient, but of all family members—critical in determining how families cope with the disease or divide up responsibility? How would this family's experience have been different if Betty had become the primary caregiver? What is the role of "community" in the caregiving process, and should it be explored more fully?

Necessity of Family Involvement.

In reading through Betty's interview, it becomes increasingly clear that outside caregivers were insufficient. Despite their training, creativity, sweetness, willingness to help, or the endorsements they received from her children, all the caregivers brought in to help Betty's mother were not successful. She was too difficult for them to handle. Betty referenced this several times in her interview, mentioning how her mother would lock caregivers out of the house or demand that they leave. One caregiver, as she describes below, only stayed a few days:

> So finally we tried a second caregiver and she lasted about three days. She called me and said "You can come get your mother, I am not staying here another day," because mother was so rude.

Only when Betty's younger sister volunteered to be the primary caregiver was the family able to describe their mother's care as manageable:

> So now she's been up there again with my sister since, uh, March, I think of last year, of 06, almost a year now. And she does well there, she's very happy there. . . . My mother is very good natured at my sister's house. She is cheerful, she wants to do things around the house, she gets along well with everybody there, and my sister has enjoyed having her there.

For Betty's mother, only her children could provide care in a way that she would accept. This behavior is striking, because it essentially implies that Betty and her siblings had no choice, other than "who" became the caregiver (or, to assign a professional caregiver in the knowledge that their mother would fight that decision and possibly suffer). It leads one to wonder if this occurs in other families. Are their other children who are—for lack of a better word—forced into providing care because they are the only person the parent will accept? This family managed that well, but what happens when children who are "forced" to absorb this role do not manage it well, or resent it? Claire's family provides a good example of what happens when the patient's chosen caregiver cannot manage that responsibility (hurt feelings, anger, cut-off, lasting family tension). What if there is no good solution (i.e., the patient does not cope well or is difficult to manage regardless of who is providing care)? Taking all of this into consideration seems to underscore the complexity involved in making decisions about care. This is not a simple process—something can go wrong at every stage.

Control versus Resignation.

In Claire's interview an interesting dichotomy of control and resignation, power and powerlessness, emerged. It was subtle, but it seems significant. For example, Claire commented that she could never have lived up to Joseph's standards because he expected her to be the primary caregiver. She follows that remark up by saying “that’s just all there was to it.” It occurred again when she referenced the family’s confusion over Joseph’s failure to settle their mother’s estate, but their reluctance to do anything about it, saying, “We always knew that if we ever challenged Joseph, in court or anything, that that would probably be the end of any kind of a relationship.” This same pattern was evident again when she said, “I wish we could be more like a family unit, but it just is not going to happen.” It seems that there is some sort of established pattern in this family by which Joseph draws a line in the sand, and the other family members resent it, but do not challenge it.

Claire’s is the only interview where control came up, but it is also the interview where the family appeared to have the most difficulty coping. Violation of personal control surfaced repeatedly: Alzheimer’s disease robbed Claire’s mother of her personal control, for which she is renowned; Joseph’s sense of control was violated when things did not proceed as he expected, even if the changes he objected to were better; Claire’s sense of control was violated by living briefly with her mother and being told what to do. These examples raise numerous questions about how decisions about care or the experience of the disease as a whole are influenced by patterns of power and control in families.

Ambiguous Loss

Time.

In these three interviews, ambiguous loss or the experience of boundary ambiguity seemed to be mitigated by the variable of time. The gradual onset of Alzheimer’s disease and the progressive worsening of symptoms, the advancement through the different stages of the disease, the way the disease intensifies over time, and anticipation that the disease will continue to worsen all seem to be steps in a process whose trajectory is set and predictable, but whose end is not in sight. Betty mentioned that her adjustment to the disease required time, and she commented on the unpredictable ways in which things can change when she said:

> It goes over such a long period of time. If it were just a one year thing you could handle it, but when you're talking about something that can go as long as ten, fifteen years . . . it's just a long term commitment.

This quote seems to imply that Betty understands that her family is coping well for the time being, but they have only been at this a few years. This acknowledgement of the time commitment her family is facing seems to carry with it an understanding of the uncertainty of their position. Will their successful coping continue, or will their experience look different ten years from now?

In a similar way, Bob also dealt with the disease over a short period of time. His mother ultimately died from congestive heart failure and not from the deterioration of Alzheimer's disease. Would he have been able to sustain his detachment over time? If his mother's symptoms had worsened, if he could no longer question her diagnosis, would his experience have changed, and if so, in what ways?

Claire's family dealt with this disease for fourteen years, a period which she describes as "such a long period of time." Seven years after their mother's death, this family still cannot manage to settle her estate. Claire believes her older brother cannot accept that their mother is gone, despite a twenty-one year period of time that has lapsed since the onset of her mother's symptoms until now.

The different stages each of these families were at in the disease in terms of time spent dealing with ambiguity leads one to wonder how the variable of time factors back into the experience and the meaning people make of the disease, as well as the sustainability of their relationships. If ambiguous loss occurs over time, then it is completely feasible that a family's experience and relationships early on in the process might not mirror their experience or their relationships with one another later.

Role Reversal.

All three participants spoke about the difficulty of watching a parent become like a child, having to redefine their position within the family system, and having to readjust the boundaries that determine how each person functions within the system. Betty talked about this as part of the collective experience, implying that primary caregivers are not the only ones who experience a parent-child role reversal:

> It's like having a five or six year old child to take care of. She doesn't dress—she would wear the same clothes for weeks at a time if you didn't make her change clothes. She doesn't bathe. She doesn't brush her teeth. . . . Someone has to watch her all the time, you can't leave her alone, not five minutes.

Conversely, Bob talks about a parent-child role reversal as the distinction between his experience and his sister's, having not experienced it directly (presumably because of his distance and detachment). When articulating what he believed to be the basic difference between the experience of primary and non-caregivers, he said:

> I think the major difference was that it, you, you reverted to—from a mother-child relationship to a child-mother relationship. . . .Child raising mother.

This leads one to wonder if the fact that he did not experience this directly, and cited it as the main difference between his experience and a primary caregiver's, made it easier for him to doubt the diagnosis of Alzheimer's disease. If this is true, it might be possible that his inability to externalize his mother's symptoms is a function of not directly experiencing the boundary ambiguity of a parent-child role reversal.

Claire specified that the role reversal was one of the things that changed over time, saying, "You're reversed. They, they're children again . . . and the farther it goes, they're back into infancy." So then, even the role reversal can gradually be expected to worsen, with the children of the Alzheimer's patient gradually assuming more and more responsibility as their parent's condition continues to deteriorate. For Claire, she said that watching this happen helped her to realize the importance of having a support system in place.

Resources and Coping with Boundary Ambiguity.

Betty is the only subject who spoke extensively about accessing resources. She is also the only participant who discussed the experience of boundary ambiguity in detail. This leads one to wonder how gathering information, accessing resources, and seeking help are related to experiencing boundary ambiguity. Is there something about seeking information and help that enables people to recognize and cope with boundary ambiguity? The following quote seems to illustrate this idea:

> The one thing that's been helpful to me really was to be able to go to conferences or go to classes or go to seminars or whatever, and hear, you know, um, how to do things. . . . It helped me to be able to, you know, sort of chart a path for us. . . . You need classes in this. It's, it's such a different disease, and if you don't, if you don't understand it, you don't understand what's going on, it can really, um, uh, it

> can be really hard because, you know, the, the person changes totally.

Detachment and Ambiguous Loss.

In Bob's interview there is a seeming lack of expressed ambiguous loss, which leads one to wonder if his acknowledged detachment served to protect him from experiencing boundary ambiguity. Are detachment and ambiguous loss related? Did being detached help Bob maintain a fixed idea of his mother's presence in the family system? Is detachment a way of coping with boundary ambiguity? Or, does detachment prevent you from noticing or experiencing ambiguous loss? Perhaps Bob's tendency to blame his mother for her symptoms, rather than externalizing them, was an alternative to dealing with boundary ambiguity.

Acknowledgement of Boundary Ambiguity.

Of the three interviews, Betty seemed to be coping most successfully with the disease, but she is also the participant that acknowledged and openly discussed a sense of ambiguous loss or boundary ambiguity. Claire acknowledged boundary ambiguity once in her interview, when she said:

> It's like the last two or three years it's just that mother was already gone . . . Her body was still here . . . but her mind was just no longer here. You could talk to her but nothing registered. So it was just, it was just a horrible experience . . . to see her go like that.

While this signifies that Claire experienced her mother's illness as an ambiguous loss, this was the only instance during the interview in which she openly acknowledged that ambiguity. Bob made no references to ambiguous loss of any kind. In contrast, examples of and references to boundary ambiguity were abundant in Betty's interview.

Betty talked about changes in her mother ("this was a complete change of personality for her"). She described the ambiguity of providing care for a person who is not totally incompetent, but also not totally self-sufficient (i.e., confusion over presence or absence in the family system). The following quote illustrates this:

> The worst thing that we went through was that my mother wouldn't move out of the house. . . . the first two years or so she wasn't incompetent, she wasn't completely unable to care for herself, she could still do some things. . . . Mother wasn't paying her bills, and I would try to, for example, change the address on the bills, and she wasn't stupid. People with Alzheimer's are not idiots, they're not stupid. . . . They are real smart, my mother is extremely smart and very resourceful. And I would change the address so the bills would come here and she would go behind me and change it back.

Betty talked about the family's loss of traditions:

> And that's the hard part, I think now, for us, is we had these family traditions. And you think that's gonna go on forever and it's not, there's just an end to something. And that's the hard, you know, I think that's one of those things that you feel a sense of loss, because something you've been doing for all your life, you know, going to your mother's house at Christmas or the holidays or whatever, is over. You don't do that anymore.

Betty also discussed the loss of the relationship with her mother, focusing in on how the ambiguity of that loss is specific to Alzheimer's disease and distinguishes it from other illnesses that require long-term care. The following quote represents this struggle:

> It’s not like a, a cancer where you can still have a conversation. And I guess the hardest thing for all of us now is there are just times when you want to pick up the phone and call your mom and talk to her and have a conversation about what’s going on. . . .And you really can’t. . . . You want to talk to ‘em when you have problems, but you also want ‘em to be proud of you and to know that something good has happened. And so, if you want to tell ‘em about some accomplishment or something, something good about the family, or whatever, you can tell ‘em, but by and large they’re not gonna remember any of that. . . . You feel, even at my age, you feel almost like an orphan, you know? I don’t have parents to go to if I have a problem, whereas I always did before. If I, anything in my life that I had a problem with I could go and tell my mother about it or my dad about it or, you know, ask for their advice, and that’s all, that’s all gone, you know? And you, you think it’s not gonna affect you when you’re an older person, but it does, you know, it does, it really does. . . . you miss ‘em. You do miss ‘em, even if they’re older.

Perhaps the entire experience of ambiguous loss can be summed up by one sentence from Betty’s interview: “They’re both still alive, but I feel like they’re not. . . . like they’re gone.” Betty went on to predict the course of the disease, anticipating and acknowledging that these difficulties will only continue to worsen (“at any time something can happen that would just . . . change the whole situation”).

Betty’s ability to talk openly about her experience and her numerous references to ambiguity—especially when compared with the absence of references to ambiguous loss in the other two interviews—prompts questions about the relationship between acknowledgement and acceptance of boundary ambiguity and the meaning people make of the experience. Do externalization and acceptance of the diagnosis help a person live with ambiguity? Is living well with ambiguity a result of how families have first interpreted and dealt with the experience?

Betty's experience—particularly when compared with Claire's—also seems to suggest that coping with ambiguity needs to be a process that the family system undertakes as a whole. Claire and Jim seemed able to adjust to changes in their mother, but when Joseph could not, he disrupted the coping process not just for himself, but for the entire family (even children and grandchildren). Basically, these interviews lead one to believe that coping with ambiguous loss is intricately linked to how families make meaning of the disease, and how they manage it not only as individuals, but also as a system. If that is indeed the case, then a lot more study could be done here.

CHAPTER V: DISCUSSION

Introduction

The original intent of this study was to explore the experiences of children of patients with Alzheimer's disease who were not the primary caregiver for their parent, in the hopes of opening these under-researched experiences up to further study. The results, explored in the previous chapter in great detail, were varied and interesting and raised numerous questions about the complex ways in which whole families—not just primary caregivers—manage the crisis of a parent's Alzheimer's disease. The following chapter will summarize the important findings and compare them to existing literature on families dealing with Alzheimer's disease. It will also explore the clinical implications and limitations of this study, and offer suggestions for future research.

Summary of Findings

Essentially, this study accomplished what it set out to: it explored the experiences of a population that has been, up until this point, very under-researched. Beyond this primary aim, however, the findings proved that this experience is complex, not just for primary caregivers, but for whole families. Perhaps the most important overarching theme of this study is the discovery that none of these particular theories alone can fully describe the experience. In terms of this research, the experience of the participants is best understood in the ways in which these theories overlap—the ways in which phenomenology, family systems theory, and ambiguous loss combine to more fully and sufficiently explain the experience than any of those theories could account for it alone. There are numerous examples of this interplay of different theoretical concepts throughout this study.

For instance, the findings on externalization and confidence in the diagnosis do not stand on their own for these participants; rather, an ability to rally around a diagnosis and externalize the symptoms of the disease seem to be tied to each other (i.e., belief in the diagnosis is essential to externalization), but also appear to be intricately tied to how one derives meaning from the total experience, how one interacts with other family members (not just the patient), whether one experiences boundary ambiguity, and how well one copes with the crisis. Likewise, an ability to adapt to change with flexibility informs how one experiences the disease, but it also relates back to patterns of interaction and roles within the family of origin. Again, in a similar way, family of origin roles can help families organize constructively to manage the disease, or they can restrict a family's ability to cope; in this instance, whether or not family roles are helpful or hurtful is largely tied to the ability of all family members to accept and make meaning of the situation they are faced with, acknowledge the inherent boundary ambiguity of the disease, and to communicate and plan for it accordingly.

Coping with the disease appears to be a collective experience, where each person's ability to contribute to a successful outcome for the entire family is tied to the way in which they make meaning of the disease. These results demonstrate that when siblings as individuals cope well, the collective experience tends to be more positive (as in Betty's family) than when individuals within sibling groups cannot adjust (as in Claire's family, where Joseph's inability to accept changes in his mother impacted the entire family's ability to manage the crisis). This also highlights the error of a focus on primary caregivers. Nowhere is this more evident than in the outcome for Claire and her family. Neither she nor Joseph were the primary caregiver, but theirs is the relationship that is most damaged at the end of the experience (whereas Claire's relationship to Jim, the primary caregiver, is intact and even emotionally closer than before). Clearly there is more at stake for families dealing with Alzheimer's disease than the relationship of the primary caregiver with other siblings. There is something about the experience of Alzheimer's disease and what is required of whole families to cope with it that has the power to disrupt all kinds of relationships, even to sever bonds between people whose role in the caregiving process is secondary or limited at best. Further study is required to determine exactly how and why this happens, but here again, these results seem tied to other important factors: family roles, resilience in the face of ambiguity, acceptance, communication, and flexibility.

Similarly, the experience of ambiguous loss is not one that can stand alone. It is mitigated by the variable of time and flexibility, so that a family's response to the crisis has to be viewed over the entire course of the disease. It encompasses not just how they deal with specific instances of change and disruption, but how they continuously adapt and manage an ever-changing disease, where the next hurdle is sure to be greater than the ones dealt with previously. The interpretation of the experience as an ambiguous loss also appears to be tied to the ways in which individuals derive meaning from their experience, which in turn seems to be influenced by family history and family roles.

The ways in which these three theories appear to overlap is complex; one could list examples for pages and potentially not exhaust the material. However, for the purposes of this discussion, the important thing to note is not only that the experiences of non-caregivers are rich and detailed and worthy of exploration, but also that their experiences (much like the experiences of primary caregivers) need to be examined within the larger context of the whole family.

Links to Previous Research

Beyond the aim to understand the experience of non-caregivers, a secondary goal of this study was to see how those experiences compared with current available literature detailing the experiences of primary caregivers. In comparing the results of this study with the studies referenced earlier in the literature review, some interesting similarities and differences became evident.

Experience of Burden.

As described earlier, a majority of the studies that have explored the experience of Alzheimer's disease for primary caregivers focus on the experience of burden for those caregivers. Baronet (1999) explains that the term burden was established because it denoted that "the behavior of the ill individual required that caregivers and other family members place their own needs and wishes after those of the patient" (p. 819). All three of the participants in this study seemed to validate the pre-existing body of literature focusing on caregiver's experience of burden. Each of them identified the experience of burden, the day-to-day challenges of providing care, and the necessary curtailment of caregiver activities as the principal difference between themselves and their caregiving siblings. In this way, the interviews highlight what is possibly the major difference between caregivers and non-caregivers, but also serve to differentiate important areas of future study. If experience of burden is the defining characteristic of caregivers, then it ought to be studied; however, the emotional experience and the impact of Alzheimer's disease on the family exist independently of burden, and are also worthy of study.

Distance.

In her article “Caregiving from a Distance,” Davidhizar (1999) discusses the challenges faced by children of aging and ailing parents who must contend with geographic distance in order to provide care for their parent. In her article, she briefly explores the growing nature of this problem and offers some practical solutions for children faced with the prospect of providing long-distance care for their parents.

The findings of this study lend credence to Davidhizar’s (1999) contention that long-distance caregiving is complex and difficult, but they also raise some interesting questions about the relationship of physical distance and emotional distance. Betty and her siblings were able to navigate geographic distance productively, while Bob’s primary reason for his detachment was the distance between he and his mother. Conversely, Claire’s family had the most difficulty navigating their mother’s care despite the fact that all three siblings lived in the same area. These vastly different examples of the interplay between physical and emotional distance are incredibly interesting, and they raise several important questions. Clearly, geographic distance or proximity is one of many factors influencing decisions about care. Distance does not necessarily preclude involvement in the caregiving process, as Davidhizar (1999) stresses and as Betty’s example shows, but nor does physical proximity necessarily ensure a less stressful experience. Distance—at least as it appears in the experiences of these participants—seems to be connected to relationships and intimacy. This connection might merit further study.

Family Roles.

Globerman (1994) stressed in her research that the families she studied returned to a family of origin role in order to manage the crisis of Alzheimer’s disease. Her results were mirrored in the participants of this study in interesting ways. Betty, for example, described a process by which she and her siblings divided up responsibilities for their mother's care based largely on their relationships with their mother and their family of origin roles. This much corresponds to Globerman's (1994) findings. The interesting divergence is that the participants in Globerman's (1994) study experienced this return to known and safe roles as a loss of self, meaning that they suspended their own developmental tasks for the purpose of managing the crisis of the disease. Betty does not seem to view this as part of her experience; rather, she experiences her family of origin role as a helpful way to divide up tasks, utilizing it as a tool. Though she acknowledges that her experience of her mother's Alzheimer's disease is painful, she never hints that she has somehow put her own life on hold in order to manage it.

Claire's experience seems to fit more with Globerman's (1994) findings. She undertook to return to an expected role—that of primary caregiver—and certainly did experience a loss of self. Once again, though, her experience differs from that of Globerman's (1994) subjects in that she did not maintain that role indefinitely. Her decision to give that responsibility over to Jim—who was, by all accounts, better suited for it—was seen as an unacceptable abdication of responsibility by Joseph (emphasizing the engrained nature of these roles and the expectations that enforce them), and led to irreparable family conflict. In spite of this, Claire refused to experience a loss of self in order to fulfill a role. This response is interesting when viewed in the context of Globerman's (1994) findings, because it illuminates the no-win situation Claire faced: maintain the role, and experience a further loss of self, or abandon the role, and endure family conflict. Though Claire escaped the loss of self, she did not escape the loss of an important relationship, and this presents an interesting dilemma for all families: how to free themselves from unhelpful roles without the loss of connection.

Bob's experience also ties in with Globerman's (1994) findings, but in contrasting ways. In the results section it was noted that Bob's primary experience was one of detachment, and that when it came to family of origin roles, he identified more strongly with his role as father and husband in his family of procreation than he did with his roles as son and brother in his family of origin. Initially, this seemed like a function of his detachment. However, Globerman (1994) encountered an interesting pattern in her own study that might more reasonably account for Bob's detachment. She says:

> In this study a pattern emerged that identified family members who described less pulls to the family of origin and less experience with the suspension of their developmental tasks. These individuals appear to be relatives who do not abandon their own developmental tasks and those in their created families or relationships when they return to the family of origin. These data suggest that this pattern exists with relatives who are the "baby" in the family, the "spoiled one," the "pampered one," the "sheltered one," or the "entitled one." For various reasons, in the family of origin when growing up they were allowed to "do their own thing." They were left alone to get on with their own developmental tasks. When the AD crisis occurred and they returned to the family of origin, they returned "in role," into those old patterns where they were entitled to be different or do their own thing. In these role-relationships they seem to be autonomous, and do not abandon their own developmental tasks. (Globerman, 1994, p. 225)

As family roles were not the sole focus of this study, Bob cannot definitively be said to embody this pattern. However, it is interesting to theorize about whether his detachment is fueled by an adherence to the kind of "entitled" role that Globerman (1994) mentions above, or if his detachment from the caregiving process is indicative of some other cause or pattern. All three of these interviews support and diverge from Globerman's (1994) study in ways that suggest, once again, that the ways in which family of origin roles operate in families facing the crisis of Alzheimer's disease are complex, and merit a great deal of further study.

Family Conflict and Cut-off.

Ideas abound about the function of cut-off in families dealing with Alzheimer's disease. For instance, Bonder (1987) posits that family members who are unable to deal with the illness may leave the family system instead. Boss and Couden (2002) take this a step further by hypothesizing that conflict in families can arise from the stress of having to navigate ambiguous family boundaries. The end result here is cut-off as well, but the cut-off from the family is a result of the individual's inability to cope with ambiguity. None of the participants interviewed for this study can be said to have fully cut-off from their families, but their stories do provide some interesting examples of the many forms cut-off can take. Bob, for example, would not describe himself as "cut-off" from his family, preferring instead to articulate that his primary feeling was one of "detachment." In light of the available literature, one might wonder what the distinction between the two is. Is detachment one step away from cut-off, or is it an entirely different phenomenon? Could detachment too, like cut-off, represent an inability to cope well with ambiguity?

Similarly, Claire's older brother Joseph, though he still interacts with his siblings in a sporadic and superficial way, could probably be safely conceptualized as having "cut-off" from his siblings. If this is true, both Bonder (1987) and Boss and Couden's (2002) hypotheses could apply to him: it could be true that he left the system because he was unable to deal with his mother's illness, or it could also be true that he was rendered incapable of dealing with his mother's Alzheimer's disease because he could not cope with ambiguity. In either scenario, the different possible explanations for all of these behaviors point to the need for further study about how family roles, family boundaries, and ambiguity interact in families dealing with Alzheimer's disease.

Additionally, in their comparison of dementia and non-dementia caregivers, Ory et al. (1999) found that dementia caregivers experienced more family conflict than non-dementia caregivers. Where conflict was present in this study, whether or not the conflict was fueled because the family was dealing with dementia was not as clear. Perhaps the more important underlying question is not whether family conflict exists, but why it arises. While Claire's family certainly did experience conflict, it is impossible to determine conclusively from these data whether that conflict was a result of their having to provide care for a loved one with dementia, if it was significant of deeper problems within the family system, if it was a response to the ambiguity of the disease, or if it was a combination of all three of those things. Bob and Betty reported no significant conflict, which leads one to wonder if their families simply dealt with the crisis of the illness in more productive ways, or if caregivers and non-caregivers reports about conflict within their families vary greatly. Perhaps, as Ory et al. (1999) suggest, the propensity for family conflict is greater when dealing with a disease as stressful as Alzheimer's disease; and perhaps the contribution of this research is to suggest that the pre-existing propensity for conflict is mitigated in complex ways by roles, boundaries, patterns, and coping styles within the family system, as well as by the ability of individuals and entire systems to live with ambiguity. Dementia alone cannot be its own recipe for family conflict; the job of researchers is to discover what ingredients contribute to successful management of the disease, and what ingredients promote conflict and cut-off.

In this vein, Lieberman and Fisher (1999) identified that families that employed "positive conflict resolution methods" (p. 164) and left decision making up to one family member, with input from others, were better able to provide help to the Alzheimer's patient than families whose conflict resolution and decision making styles were more disorganized. Betty's family seems to be an example of this. Though she reported no conflict among her and her siblings, their general approach to caregiving was one of cooperation. It seems more likely that they have successfully resolved conflicts along the way than that they have not encountered any conflicts at all. Moreover, when it came to decision making, Betty described herself as acting like the "chairman of a committee." Her job was to provide her siblings with information and lead the discussion. The example of Betty and of her family's adherence to the skills espoused by Lieberman and Fisher (1999) leads to two interesting points of consideration. First, of all three participants, Betty's family seems to have managed the crisis of Alzheimer's disease most successfully. This supports the findings of Lieberman and Fisher (1999), and sets the stage for future research to be done in the areas of conflict resolution and decision making in families dealing with Alzheimer's disease. Secondly, it is interesting to note that, though not the primary caregiver, Betty assumed the role of primary decision maker in this family, and according to Lieberman and Fisher (1999), having someone in this role enables families to provide better care for their loved one. This underscores again that managing Alzheimer's disease is a family task, and highlights the important ways in which non-caregivers can contribute meaningfully to the family caregiving process.

Coping With Ambiguity Through Acceptance Versus Avoidance.

In her study, Dupuis (2002) found that caregivers employed two different methods of coping with ambiguity: coping through acceptance, and coping through avoidance. She defines coping through acceptance as follows:

> They accepted the fact that their parents no longer existed in their lives, at least psychologically, or no longer existed as they once had, and reframed the situation in more positive ways. (Dupuis, 2002, p. 107)

Speaking of coping through avoidance, she says that the family members who employed this technique sought to “protect themselves from the loss by avoiding the situation altogether” (Dupuis, 2002, p. 108). In her research, family members that coped through avoidance expressed more emotional anguish than those who coped through acceptance (Dupuis, 2002).

In this study, Betty stands out as an example of coping through acceptance, even saying (as discussed in the results section) that an ability to accept her mother’s illness led to a feeling of increased stability for the entire family. Examples of coping through avoidance, however, are less clear. While Bob was certainly detached during his mother’s illness, he did not express any emotional distress nor did he seem to have any difficulty moving on from the experience. Perhaps Claire’s brother Joseph is a better example of coping through avoidance; seven years after his mother’s death, Claire reports that Joseph still cannot seem to grasp the fact that their mother is gone. She even uses the word acceptance, mentioning several times that Joseph could never “accept” their mother’s illness or death. If Joseph is indeed an example of coping with ambiguous loss through avoidance, then the illustration of Claire's family raises an important question: what happens in families where the siblings cope in different ways? Was Claire and Jim's ability to cope through acceptance in direct conflict with Joseph's avoidance, and if so, did that contribute substantially to their current estrangement?

Stages of Ambiguous Loss.

Another interesting idea raised by Dupuis (2002) and supported by this study was the idea of certain stages of ambiguous loss. She mentions three specific stages: anticipatory loss, where the Alzheimer's patient is in the early stages of the disease and the family members are anticipating a time when the patient's psychological absence will be more pronounced; progressive loss, where the Alzheimer's patient is in the middle stages of the disease and family members have already experienced some level of deterioration; and finally, acknowledged loss, where the Alzheimer's patient is in the final stages of the disease and the family members have acknowledged the complete psychological absence of their loved one (Dupuis, 2002).

In this study, Betty seemed to be an example of a person in the stage of anticipatory loss. Her numerous references to her mother's intelligence and resourcefulness, aside from aiding externalization, also seem to suggest that Betty's mother is still psychologically present in some sense, even if not fully. But at several times during the interview, Betty alluded to a time when her mother's psychological absence would become more pronounced. The following quote illustrates this sense of anticipatory loss:

> And so, trying to predict, you know, what's gonna happen or can my sister continue to take care of her for any particular given time in the future . . . Right now things are OK. I mean this is really, this year has been kind of a lull in the

> storm, so to speak . . . but at any time something can happen that would just, you know, change the whole situation so we have to do something different . . . and I don't know what we're gonna do yet.

In contrast, Claire was able to recall the final years of her mother's Alzheimer's disease and describe the sense of acknowledged loss she felt even years before her mother's death. She said:

> The last two or three years it's just that mother was already gone. . . . Her body was still here, but her mind was just no longer here. . . . You could talk to her, but nothing registered.

Though not all three stages of ambiguous loss were present in these data, the presence of at least two seems significant. It also seems significant to note that these stages are experienced not just by the primary caregivers that Dupuis (2002) interviewed, but by non-caregivers as well. If these stages of ambiguous loss could be expanded and extrapolated to include whole families, then the ideas presented by Dupuis (2002) could become an important way for family therapists to conceptualize where families are in the process of coping with the loss and enable them to provide interventions tailored to each specific stage.

Reciprocal Coping.

In the study conducted by Caron et al. (1999), one of the more interesting findings was that depression in caregivers led to increased symptoms of depression in the Alzheimer's patients. Though these data showed no evidence of that particular phenomenon, Caron et al.'s (1999) discovery does lead to some interesting questions. Could the reverse be true? As an example, consider the successful management of the disease by Betty's family. Her mother did not function as well under the care of professional caregivers as she did with her youngest daughter. Is it possible that Betty and her siblings' ability to cope well influenced their mother's behavior? What if she does relatively well because the rest of the family does well? And then, what if in turn, the rest of the family does well because the patient appears to be doing well? If the family's ability to manage the crisis well forms some sort of feedback loop to the patient's behavior, with each influencing the other reciprocally, then maybe the experience of the disease for individual family members is contingent on the collective response (i.e., how the entire family system makes meaning, interacts with the patient, with one another, etc.). This definitely merits further study.

Mastery.

Both Boss et al. (1990) and Kaplan and Boss (1999) have conducted studies that explored how a sense of mastery contributed to a sense of depression in caregivers and influenced the ability of caregivers to cope with ambiguous loss. If mastery is the extent to which individuals feel as though they are in control of their lives and decisions, then perhaps the prevalent theme of control that emerged in Claire's interview should be viewed through this lens. Did Joseph's rigid expectations and controlling nature reflect some perceived loss of mastery? Was the experience of his mother's Alzheimer's disease such an ambiguous loss for him that he felt out of control, and was therefore compelled to respond to his family in ways intended to restore some sense of personal mastery? Since Joseph himself was not a participant in this study, it is difficult to speculate much about his experience. However, if the examples of his control that Claire experienced were really an attempt to regain some sense of mastery, then the possibility that non-caregivers could feel just as out of control when faced with Alzheimer's disease as some caregivers do could be an important finding.

Study Limitations

There are a number of factors that limit the findings of this study. The first was undoubtedly the difficulty encountered in recruiting participants. Recruitment for this study was challenging, and despite multiple attempts to recruit participants, only three willing subjects who met all the study criteria were found. The study criteria were akin to a double-edged sword: they were narrow out of necessity, because this study required a very specific group of people, but their narrowness made it a challenge to find people that met all of them. I encountered a lot of difficulty.

Some caregivers responded who were willing to be interviewed (a clear violation of study criteria, as *non*-caregivers were specifically requested), but insisted that their non-caregiving siblings would never consent, and therefore refused to pass along my information. There were two primary caregiver respondents who were not even children of the Alzheimer's patient, but daughters-in-law. Some non-caregivers responded to the initial inquiries with emails that seemed a bit defensive, as if they were anticipating judgment rather than curiosity about their experience; the subjects who responded in this way never replied to any subsequent attempts to contact them. Some people in a unique position to help recruit participants—adult day care centers, local chapters of the Alzheimer's Association, geriatric psychiatrists, adult respite care nurses, etc.—either refused to help or never responded to inquiries. Other people (friends, family, and colleagues) were willing to help, and passed on names and contact information of possible subjects; however, upon contacting these people, few actually met the study criteria. This seems representative of the inherent difficulty of recruiting through word of mouth; people may helpfully pass the study information along to subjects who, for one reason or another, are unsuitable participants. Then the challenge becomes not only seeking out a population that is difficult to access, but also sifting through and contacting respondents who cannot participate. Given these difficulties, it should be evident that the recruitment process was tumultuous, full of expectation and subsequent disappointment. It prolonged the study, and at times led to significant discouragement. One challenge for future researchers studying this population will be devising creative ways to locate and persuade non-caregivers to be interviewed.

However, I would be remiss if I failed to acknowledge the hidden benefits of this limitation. Because of the difficulty finding subjects, my interviews tended to be widely spaced, giving me significant amounts of time to process the data after it was collected. The participants who responded and met all of the criteria were able to give rich and detailed interviews that generated quite a bit of useful data. Furthermore, because there were only three subjects, I was able to take my time with data analysis. Ultimately, though the recruitment difficulties were certainly discouraging, I think this ability to "percolate" on the data aided my analysis.

The second limitation is one of diversity. All three respondents were middle-to-upper class Caucasian adults with similar socioeconomic status and levels of education. Only one subject was male. Because of the similarity of the participants in these crucial areas, speculations about the ways in which wealth, ethnicity, education, and gender influence the experience of Alzheimer's disease cannot be made.

A final limitation was the stage at which all three participants were in dealing with the disease. Ideally, it would have been nice to have had a broader sample here in order to represent people in all different stages of coping with Alzheimer's disease. For Betty, she and her family were in a relatively early stage of managing the disease, while Bob and Claire's mothers had both passed away. It is possible that people whose parent has already died talk about their experience differently than people who are still in the midst of managing the crisis of the disease. If, for example, two people in each of Dupuis's (2002) three stages of ambiguous loss could have been interviewed, then perhaps a more nuanced perspective could have been obtained. What differences and similarities exist between non-caregivers in the anticipatory, progressive, and acknowledged loss stages and people whose parent has already died? These data cannot speak to this particular situation, and future research aimed at understanding the experiences of non-caregivers in various stages of the disease is warranted.

Clinical Relevance

The findings of this study have important implications for clinicians working with families dealing with Alzheimer's disease. In describing a therapist's theoretical approach, the word "eclectic" is often eschewed as a cop-out, a way in which therapists water down certain theories and use only bits and pieces of each, oftentimes with less efficacy than a single, unadulterated theory might provide. In light of this criticism, it may seem odd for any research to advocate an eclectic approach; however, this sort of approach seems to be merited based on these data. These three interviews demonstrated that the theories of phenomenology, family systems theory, and ambiguous loss interacted in complex ways to account for the experiences of these subjects. Moreover, the interplay of these theories seemed to more fully represent the experiences of the subjects than any of the theories alone would have. For this reason it could be important for therapists working with families dealing with Alzheimer's disease to enter the therapy room with all three of these theories in mind. What is the experience of this disease like for the family, and how are they making meaning of it? How do family history, family patterns, flexibility or resistance to change, and family of origin roles influence their experience? Is the family experiencing this as an ambiguous loss, and if so, how is each family member coping with the ambiguity? At the very least, these theories can inform the kinds of questions the therapist asks and can aid in clinical assessment and treatment planning.

Second, it will be important for clinicians to expand the focus of clinical attention. Inviting whole families to participate in counseling could be an important way to promote family resilience and to manage conflicts early on, and could possibly be the key to helping families cope well with the disease. Considering the numerous and complex ways in which this disease impacts entire family systems, therapists should make it a point to ask questions designed to illuminate not only how their particular client may be coping with the disease, but also how that client's relationships with his or her parent, siblings, spouse, and children are impacted. This means assessing the system as a whole, but also dyadic relationships within the system: parent-child, sibling-sibling, grandparent-grandchild, spouse-spouse, spouse-in-law, aunt/uncle-niece/nephew, cousin-cousin, etc. It will be important for therapists to note that, when dealing with Alzheimer's disease, tension is not limited to caregiver-non-caregiver relationships, but can be present—and devastating—in any number of configurations. It will also be important for therapists to pay attention to the ways in which family conflict is transmitted to younger generations of the system.

Third, in addition to general assessment of the system and its various relationships, it will also be important for clinicians to make a distinction between the physical experience of the disease and the emotional experience of the disease. In his interview, Bob seemed surprised that someone was soliciting his perspective, as though he had relatively little to offer. In a similar way, some clients may be inclined to minimize their own experience of the disease by focusing on what they do not do, or may ascribe to a belief that their experience is less important because they are not the primary caregiver. In situations such as this, clinicians need to emphasize that experience of burden is not the only emotional difficulty inherent in coping with this disease. Clinicians may need to give their clients permission to talk about the emotional and relational aspects of this disease. As in Bob's case, therapists may find that some of their clients can identify no particular difficulty, but it will still be important to ask the questions. Whether clients deny the presence of pain or speak openly about the difficulty of their experience, either outcome will be clinically illuminating.

Finally, these data suggest that there are several factors that influence how family members cope with Alzheimer's disease, and clinicians can better serve the families they work with if they pay particular attention to some of these things. As is evident in the examples of Betty and Claire's families, family communication and planning is paramount. Clinicians are uniquely positioned to help the families they work with engage in appropriate and effective communication and to connect them with resources that will help them plan for the care of their loved one. Clinicians can provide education about Alzheimer's disease as an ambiguous loss, and explore with clients any ambiguity they might be experiencing. Clinicians can explore family history and family of origin roles with their clients, and process the ways—both helpful and unhelpful—that those roles may resurface as they manage the disease. Clinicians can work with their clients to be more flexible and to adapt productively to all the change inherent in

Alzheimer's disease. Lastly, clinicians are uniquely placed to work with families over time and to help them cope with each successive hurdle of the disease.

Suggested Future Research

Despite the limitations of this research, these data have established that the experience of non-caregivers is rich and varied and worthy of further study. One such area that merits additional exploration is the role of externalization and a belief in the diagnosis, and how they interact to influence the experience of the disease. Are they related to successful coping? Do they promote successful management of ambiguous boundaries?

The relationship between emotional distance or closeness, and geographic distance or closeness is also worth exploring. Does distance inform relationships, or do relationships inform distance? What is the relationship between geographic distance and coping? The relationship between family coping and individual coping seems important as well. Is coping a reciprocal family process? Do positive outcomes for the system as a whole hinge in part on the ability of each individual family member to manage their own experience productively? If whole families cope well with the disease, does that in turn influence the patient's behavior?

Another area where further study is necessary is in the interaction of family relationships with the meaning each family member makes of the disease. Sibling relationships varied greatly in this study—some improved, some worsened, some stayed the same—and the changes in those relationships seemed related to how each person interpreted the experience. More research is needed to determine if the two are, in fact, related, and if so, what that means for families, researchers, and therapists.

Additionally, the nature of conflict in families coping with Alzheimer's disease is an interesting area for future research. Not all conflicts occur between the primary caregiver and non-caregiving siblings. Claire and Joseph's relationship is a prime example of this. If this holds true for other families as well, it speaks to the need to promote healthy conflict resolution and decision management in whole families.

Longitudinal research could also be an important advancement. This study provided snapshots of people in very different stages of this disease: one woman at the onset of the disease, organizing and planning for the future, and two participants whose parent had already passed away. The experiences at either end of the spectrum were informative and illuminating, and it leads one to wonder what the experience looks like as it evolves. If there is rich data at either end of the experience, then it can be inferred that there is also rich data in the middle stages. To this end, longitudinal research that follows non-caregivers or whole families throughout the course of the disease could provide important information about how the experience changes over time and how families adapt as it does.

Finally, there is great opportunity for additional study when it comes to family of origin roles and the way they influence the experience. How does a return to known roles enhance coping? How might it impede successful management of the crisis? What is the interplay between flexibility, adaptation to change, and utilization of family of origin roles? Do other families experience the same intergenerational transmission when it comes to their ability to cope with the disease and with other family members?

When this research was begun, the intent of the study was twofold: to ascertain the experiences of an under-researched population and to pave the way for future research. As these data prove, non-caregivers' experiences of a parent's Alzheimer's disease are meaningful, legitimate, important, and worthy of exploration. The experience of Alzheimer's disease has implications for whole families, caregivers and non-caregivers alike. Now that a glimpse into the experiences of non-caregivers has been provided, it will be important for future researchers to expand their focus. These data ultimately underscore the need for further research that focuses on non-caregivers as well as whole families, and emphasize that Alzheimer's disease is first and foremost a relational disorder, with potential consequences for entire families, not just primary caregivers.

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APPENDIX A

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY

Informed Consent for Participants In Research Projects Involving Human Subjects

Title of Project: A Qualitative Study of Non-Caregiving Adult Children's Experiences of a Parent's Alzheimer's Disease

Investigator(s): Erin L. Peirce

I. Purpose of this Research/Project

The aim of this study is to understand what non-caregiving adult children experience when their parent has Alzheimer's disease. The goal of the study is to hear your experience. Another goal is to see how your experience is like or unlike that of primary caregivers. A final goal is to prompt future studies on this topic.

II. Procedures

- You will be asked to take part in an interview that will last about 60-90 minutes. This interview can take place in your home, or at some other location agreed upon by the two of us.
- You will be asked to describe your experience of your parent's Alzheimer's disease. You will be asked what effect the disease has had on you. You will be asked about how your family has managed roles and tasks. You will be asked about changes in your relationship with your parent. You will also be asked about changes in your relationships with other family members. You will be asked how you believe your experience is different from the experience of primary caregivers. Interviews will be audio-taped.

III. Risks

For this study you will talk about a disease that most people feel is stressful. You will explain how that disease has affected your relationships. Talking about these things might make you sad. On the other hand, being able to discuss your experience might be helpful. At the end of your interview I will provide a list of mental health agencies you can contact if you want to talk to someone. Please note that you are responsible for any costs associated with follow up care. I will also provide a list of numbers you can call for more information about Alzheimer's disease.

IV. Benefits

There are not many studies that explore how Alzheimer's disease affects individuals who do not take care of the patient. Because this disease changes the way family members interact, it makes sense that it would affect whole families and not just primary caregivers. It is important to study the experience of all family members so that professionals can support whole families. The results of this study may prompt more research on the effects of Alzheimer's disease on families.

V. Extent of Anonymity and Confidentiality

All interview responses will be confidential. I will assign numbers to the interviews and will use those numbers in place of names to transcribe the interview sessions. Names will be kept separate from the interview transcripts and will be under lock and key. All results will be reported in a way that will protect your identity. Only those people directly involved in the study will have access to the study information. Audiotapes will be destroyed at the end of the study.

All study information will be kept confidential except in cases where elder abuse is suspected or if participants lead the facilitator to believe that they may be a threat to themselves or to someone else. If elder abuse or threats are suspected, the researcher is required by law to inform the appropriate authorities.

VI. Compensation

You will not be compensated for your participation in this study.

VII. Freedom to Withdraw

Participation in this study is completely voluntary. Whether or not you participate is solely up to you. Participation will not be allowed without signed informed consent. You may withdraw from the study at any time without penalty. You may refuse to answer any questions without consequence.

VIII. Subject's Responsibilities

I voluntarily agree to participate in this study. I have the following responsibilities:

- I will be asked to take part in an interview that will last about 60-90 minutes.
- I will describe my experience of my parent’s Alzheimer’s disease. I will be asked what effects the disease has had on me. I will be asked about how my family has managed roles and tasks. I will be asked about changes in my relationship with my parent. I will be asked about changes in my relationships with other family members. I will be asked how I believe my experience is different from the experience of primary caregivers. My interview will be audio-taped.

X. Subject's Permission

I have read the Consent Form and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent:

____ Date__________
Subject signature

Should I have any pertinent questions about this research or its conduct, and research subjects' rights, and whom to contact in the event of a research-related injury to the subject, I may contact:

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