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Experiences of Elderly Recipients of Care: A Feminist Case Study Analysis of Mother-Daughter Dyads

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Whitney A. Brosi

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Barbara D. Am
Major Professor's Signature

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EXPERIENCES OF ELDERLY RECIPIENTS OF CARE: A FEMINIST CASE STUDY ANALYSIS OF MOTHER-DAUGHTER DYADS

By

Whitney A. Brosi

A DISSERTATION

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Abstract

EXPERIENCES OF ELDERLY RECIPIENTS OF CARE: A FEMINIST CASE STUDY ANALYSIS OF MOTHER-DAUGHTER DYADS

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The purpose of this study was to examine intergenerational elder care dyads with a particular focus on recipients of care. Family ecology theory, feminist theory, and contextual theory guided this qualitative study and case study design. Ten mother-daughter dyads participated in 30 individual, semi-structured interviews. Each dyad is reviewed individually and the collective results are discussed through emergent themes which reflect the theoretical framework. Emergent themes include immediacy of care, fear of nursing homes, expectations for family care, gender socialization, contentment with caregiver role, and shift in decision making process. Implications for future research, gerontology, family science, and marriage and family therapy are discussed.

This work is dedicated to and in loving memory of three family members

I lost during the course of this project

Jason
'my big brother and two-step partner'

Grandpa
'my role model, friend, and cribbage partner'

&

Edith
'my adopted grandma'

The most important things I know about family care, I learned from the three of you.

I miss each of you very, very much.

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List of Tables

List of Figures

Table of Contents

Chapter Four

Chapter Five

CHAPTER ONE: INTRODUCTION

Background of the Problem

As adults age and baby boomers move into retirement, the needs of Americans and their families are changing. Men and women are living longer, and while this provides new opportunities for cross-generation relationships, it also spawns questions about care in late life (Moody, 2000). When late life needs exceed the capabilities of individuals to remain independent, how do families adapt? The declining incidence of multigeneration, co-resident homes has led some to conclude that the commitment to provide care to other generations is decreasing (Piercy & Chapman, 2001; Pyke & Bengtson, 1996). However, Goldscheider & Lawton (1998) conclude that such a decrease is a result of greater affluence rather than a decline in level of commitment. It is also important to note that when family members provide care, it is significantly more likely to be a female family member. In fact, nearly half of all women between the ages of 45 and 55 will provide some level of care to an elderly parent (Cicerelli, 2000).

Much of what we know about care systems relates to caregivers and specifically the negative outcomes of caregiving (Berg-Weger, Rubio, & Tebb, 2001; Cox & Munk, 1996; Dilworth-Anderson, Williams, & Cooper, 1999; Noonan, Tennstedt, & Rebelsky, 1996; Sherrell, Buckwalter, & Morhardt, 2001). This literature provides an important contribution to understanding both the caregiving experience and outcomes of caregiving. It informs the understanding of caregivers and their reactions to caregiving. Although this literature is substantial, it is heavily focused on caregivers, leaving other members of the caregiving system virtually unexamined.

In addition to research focused on caregivers, there is a smaller body of literature that examines intergenerational dynamics as a part of the caregiving process (Bleiszner, Usita, & Mancini 1996; Lieberman & Fisher, 1999; Litvin, 1992). These studies often include two or three generations, although rarely including the elderly recipient of care. When recipients of care are included, it is commonly for the purpose of measuring congruence of caregiving expectations. Therefore, examinations of recipients are still in the context of caregivers' experiences, and recipients of care are rarely the primary focus of research.

Although the intergenerational research acknowledges the recipient, research rarely has focused on the recipient of care and his/her experience with caregiving. Brubaker, Gorman, and Hiestand (1990) reported that "scant attention has been directed toward the perceptions of elderly recipients of family care" (p. 267). Although this statement was published more than 13 years ago, Horton & Arber (2004) postulate that the literature still has little to offer scholars relative to understanding of the eldest generation in the caregiving system.

Purpose Statement

The goal of this study was to explore the experiences of elderly recipients of care, in the context of informal care dyads. This study aimed to understand the experiences of recipients of care relative to family caregiving from both a current and historical perspective. This study examined the recipient of care's experiences as the primary source of data. Each recipient's adult child, who was providing some assistance to his/her parent, also was interviewed. Informed by Ecological Theory (Family Ecology Theory and the Human Ecology Model), Feminist Theory, and Contextual Theory this project gave voice to a key member of the caregiving system, the recipient of care. This research reviewed the role of the recipient of family care over time, including changes in power and involvement. Not only was this research important from an individual and developmental perspective, it examined care relationships between recipients and their adult children.

Definitions and Assumptions

Two components are necessary to understand the framework from which this study was conceptualized – definitions and assumptions. For the purpose of this study, the following definitions were used.

<u>Recipient of care (RoC)</u>: an unmarried adult, who was at least 70 years of age, and was receiving some assistance from an adult child.

<u>Primary Caregiver</u>: the one person most responsible for providing care to the older adult on a regular basis (Stephens, Franks, & Townsend, 1994)

<u>Caregiving system</u>: at least two generations that were actively involved in family care at the time of the study (at least one caregiver and RoC).

<u>History of care</u>: the description of family care traditions across time, as perceived by the recipient.

<u>Decision making</u>: a process by which a person or persons (a family) considers all known options and makes the best choice (Griffore & Phenice, 2001; Paolucci, Hall, & Axinn, 1977).

<u>Values</u>: a group of beliefs that a person/family considers to be important and central to the decision making process (Bubolz & Sontag, 1993).

Ecological Factors: any variable at all levels of influence (e.g. micro or macro) that shapes the way a family makes decisions and organizes itself in relation to one another and outside systems. Examples of ecological factors specifically related to elder care include gender socialization, living conditions, or sibling position.

Gender: the categorization of an individual as either male or female, which is central to the socialization of individuals in society.

In addition to the definitions provided above, the proposed study was rooted in the following assumptions:

1 – The family caregiving system includes individuals across multiple generations

2 – Caregiving is a normative family task that creates transitions, and consequently stress, for all members

3 – Younger generations are more overtly involved with care decisions than elderly recipients of care

4 – Elderly recipients of care are the least commonly studied members of the caregiving system because of pervasive stereotypes about age, involvement, and care in later life

5 – Family members make decisions based on what they find most valuable, and this changes over time with various roles and experiences.

6 – Collaboration between family members, including the recipient of care, is the ideal framework for which family care decisions are made.

Research Questions

Using the definitions and assumptions provided above, as well as the theories outlined later in this paper, the following research questions guided this study:

1 - How did ACCs and RoCs describe the current care arrangement?

2 - What ecological factors contributed to family care? What messages (values) existed about care?

3 - How did the family make decisions about family care and what role did the RoC play in this process?

4 - How did elderly recipients of care describe the history of care in their families and what role did they play in care over time (as a child, young adult, older adult)?

5 - How did RoCs compare their care experience to experiences of their siblings, friends, and other RoCs in their family?

6 - Were RoCs and ACCs reports/perceptions congruent (current care system members, history of care, messages about care)?

Theoretical Framework

Three theoretical frameworks informed this qualitative study – Ecological Perspectives, Feminist Theory, and Contextual Theory. Family Ecology Theory served as the foundational theory and was used to view the caregiving system relative to values, decision-making, resources, and boundaries (Bubolz & Sontag, 1993; Griffore & Phenice, 2001; Hook & Paolucci, 1970; Paolucci, Hall, & Axinn, 1977). Related concepts from Bronfenbrenner's Human Ecological Model were used, including macro and micro influences, the ecological transition, and the chronosystem (Bronfenbrenner, 1997 & 1999). Feminist Theory was used to examine concepts of power and gender as they relate to aging families and specifically caregiving families (McGoldrick, 1998; McGoldrick, Anderson, & Walsh, 1989). Contextual Theory offered a clinical review of potential intergenerational outcomes, such as ledgers, entitlement, and loyalties (Boszormenyi-

Nagy, I., Grunebaum, J., & Ulrich, D., 1991). Each of these theories informed the grounded theory approach to this qualitative study.

Family Ecology Theory

With historical roots in general systems, human systems, and human ecology, family ecology emerged to examine the family as a "life support system" to developing individuals (Hook & Paolucci, 1970, p. 315). This specific perspective, with the family as the central support system of the individual, allows scientists to closely examine the complexity of interactions that occur within the family (Bubolz & Sontag, 1993). It also allows an examination of interactions between families and other systems. For this reason, family ecology is widely used among scientists who study both individuals and families (1993).

According to Kantor & Lehr (1975) the family is comprised of three subsystems – "the family-unit subsystem, the interpersonal subsystem, and the personal subsystem" (p. 23). Although these three subsystems are the primary components, the interface between each subsystem and environment is critical to understanding families and relationships (1975). In the spirit of the philosophy that interactions between individuals and environments are central to understanding families, Paolucci, Hall, & Axinn (1977) identified family members as one of three essential components of the family ecosystem, including external environments and human interactions. The following section identifies key concepts within family ecology and is meant to highlight central components as well as identify a system of concepts that interact with one another. No one concept stands alone, just as no one family member is isolated from his/her family or other contexts.

Environments

Environments are external forces that influence a system's, in this case the family system, operation and organization (Paolucci, 1977). An infinite number of environments exist when considering familial interaction with other systems. Although it is impossible to identify all potential environments, Hook and Paolucci (1970) identified a "total environment" comprised of three human systems – "the biophysical, the psychosocial, and the technological" (p. 317). The psychosocial environment is particularly important when considering human and familial interaction (Hook & Paolucci, 1970). In regard to the recipient of care, the psychosocial environment is paramount to the caregiving system. Given that elder care is commonly identified as a normative family task, the family is a central environment to consider for the recipient of care (Cicerelli, 2000; Sherrell, Buckwalter, & Morhardt, 2001). Although the family is the primary context used for this study, all environments are important to consider when understanding the context of familial interaction.

Paolucci, Hall, and Axinn (1977) identified four key components of Family Ecology Theory – boundaries, decision making, resources, and values. These four components are central to family processes and family caregiving and comprise the foundational framework for this study.

Boundaries

Boundaries are regulating forces between systems that determine if a system is open or closed, with families generally characterized as semi-open systems (Griffore & Phenice, 2001; Paolucci, Hall, & Axinn, 1977). Boundaries are established and negotiated between systems and members to determine what enters and exits (2001).

They can be physical, functional, or analytical, and although not all boundaries can be seen, they are agreed upon and understood by system participants (2001). Boundaries vary on a continuum, ranging from rigid to diffuse (Minuchin & Fishman, 1981). Rigid boundaries significantly limit the exchange between systems, whereas diffuse boundaries rarely limit what is exchanged between systems (1981). It is not important to identify all of the different variations of boundaries, but rather the ways in which boundaries are negotiated within the family as well as between the family and other systems (Griffore & Phenice, 2001).

Decision Making

Paolucci, Hall, & Axinn (1977) describe decision-making as a process that humans learn over time, based on environments and interactions with other systems. It is a "transacting process" that is based on communication, interactions, perceptions, decisions, (re)actions, and problem solving skills (Bubolz & Sontag, 1993; Griffore & Phenice, 2001; Paolucci, Hall, & Axinn, 1977, p. 2). Once a family determines what it needs, options are evaluated. Often families are not fully aware of what options are available to them and therefore cannot fully consider each of them (Bubolz & Sontag, 1993). Generally, there are three aspects to decision making in families: ranking – the classification of options based on preference; elimination – based on various factors, the list is reduced; closure – when one option is selected, without conflict (Griffore & Phenice, 2001). Family negotiation or decision-making is a constant and dynamic process that occurs on both conscious and unconscious levels (Griffore & Phenice, 2001; Paolucci, Hall, & Axinn, 1977). Decision-making related to caregiving requires consideration of multiple generations and countless variables. Although it is most common to find literature on caregivers, elderly recipients of care are key members of the caregiving system. Although we know little about how recipients of care participate in decision-making, as members of the system it can be assumed that they have some role in decisions relative to their care.

Resources

Resource exchange is a central component of family ecology. Individuals transfer energy and resources among themselves and across systems. Since each relationship in an open system is reciprocal, the exchange of information is ongoing, and the system is dynamic in nature (Bristor, 1995). Resources can be classified into two forms, human and non-human (Paolucci, Hall, & Axinn, 1977). Non-human resources can typically be thought of as tangible, material items – money, dwellings, and objects. A number of factors, including the economy, society, and context, determine the value of resources. In caregiving systems, it is important to understand how value is determined, as individual members will likely have varying formulas for determining value. For example, caregivers and recipients of care may disagree on the value of the recipient of care staying in his/her home. The caregiver may consider it too expensive and have health and safety concerns. The recipient of care may see more value in staying in his/her home for comfort or other personal reasons. Although these variables are less tangible than money, they are considerable resources.

Values

Values are learned from environments and interactions and, like other ecological components, influence current and future interactions. Each family member holds values that may be widely accepted by the family, but also may vary from person to person, based on experiences. Values reflect what individuals determine to be right or moral and are influenced by society, culture, religion, and other environments (Bubolz & Sontag, 1993). In relation to the caregiving system, values are significant and develop long before caregiving begins. Through behaviors and words, families transmit messages regarding what is important to other family members. Much like boundaries, values may be unspoken but fully understood and agreed upon among system members. As caregiving is being viewed as a normative family task, it is a common societal value that younger generations will care for aging family members (Cicerelli, 2000; Sherrell, Buckwalter, & Morhardt, 2001). Within families, who specifically provides that care is often determined by values from the family (e.g. assumptions based on gender, employment status) and smaller systems of influence (e.g. community, ethnic group, religious affiliation). Again, although research addresses the complexity of values relative to caregiving, more research is needed to understand the role of the recipient of care in the process.

As a result of extensive research on caregivers, much is known about employment, child rearing, financial, and marital considerations related to caregiving. However, little is know about how the recipient of care participates in this process. Obtaining the recipient of care's perspective about how the caregiving system is formed and what it looks like is a significant and still missing piece. Using Family Ecological Theory to examine the caregiving system from this unique perspective expands our knowledge about the recipient of care's role in caregiving. Also it will guide the understanding of caregiving as a multigenerational process that occurs over time through value transmission and decision-making.

Bronfenbrenner's Ecological Model

One specific application of Human Ecological Theory has gained significant exposure in the social sciences – Bronfenbrenner's Ecological Model (1979). This model emphasizes four primary levels of influence on individuals and family systems – micro, exo, meso, and macro systems (1979, 1999). A central assumption of this model is that individuals hold roles within various systems. Not only do roles determine individuals' positions and purposes in the family and corresponding systems, they also determine and necessitate shifts across the ecological system (Bronfenbrenner, 1999; Griffore & Phenice, 2001).

The microsystem includes immediate systems that "are experienced by the developing person", such as the family (Bronfenbrenner, 1979, p. 22). Knowing that family may encompass a variety of immediate and extended family members, it is important to note that the microsystem will vary for each family (Berry, 1995; Bronfenbrenner, 1979; 1999). The mesosystem is the interface where two or more microsystems meet. Each microsystem includes the developing individual and creates a need to better understand how these two systems interact (Berry, 1995; Bronfenbrenner, 1979). In the caregiving system, with a focus on the recipient of care, the mesosystem would include systems that directly interact with the care recipient. Examples may include the health care providers, nursing home staff, friends, and extended family members. The exosystem expands to include systems that affect the developing person, however he/she does not directly interact with these systems. In respect to the recipient of care, this might include the adult child's workplace or a grandchild's school system. Neither of these systems directly interacts with the recipient of care, but may indirectly influence him/her. The macrosystem is the broadest of the four levels in Bronfenbrenner's model in that it encompasses many intangible but powerful forces. For example, the macrosystem includes societal rules and expectations that are transferred across generations. This level also includes societal systems such as the government and federal policies (Berry, 1995; Bronfenbrenner, 1979). This level also includes the concept of uniformity across society, encompassing the consistent societal rules that govern social and political systems (1979).

The final component of this multilevel ecological model is the chronosystem. The chronosystem refers to time, not simply to the passage of time in history but rather a complex process with many dimensions. When considering individuals' development, the chronosystem relates to their physical, psychological, and social development across the lifespan. In addition, the chronosystem allows family scientists to consider the developmental process of the family over time. This level also includes the concept of time in history, attending to the unique influences of context related to various cohorts and generations.

A related concept described by Bronfenbrenner (1999) is the ecological transition, which refers to the inevitable shift of a person's position in the ecological environment as a result of changing roles and/or settings over time. Time and role transitions are critical variables when studying families across the lifespan. As individuals pass through various life stages, they learn how families makes decisions and what role they play in such decisions. A caregiving example may be an individual's role transition from being a caregiver to becoming a recipient of care.

Clinical Perspectives

In addition to Family Ecology Theory and Bronfenbrenner's Model, several clinical paradigms guide caregiving research and knowledge. Two perspectives that relate specifically to the aging family and caregiving include Feminism and Contextualism (Boszormenyi-Nagy, Grunebaum, & Ulrich, 1991; McGoldrick, 1998; McGoldrick, Anderson, & Walsh, 1989). The feminist perspective is often associated exclusively with gender. However, Feminism informs the clinician's and researcher's understanding of power and related processes in families, not just gender dynamics. These concepts can be applied to all systems in which individuals have varying degrees of power and influence, including the aging person. Contextualism aids the clinician's understanding of multiple generations over time, including the concepts of loyalty and entitlement. Clinicians who are informed by the contextual perspective focus on an individual's perception of equity and ledgers (that individuals are indebted to others emotionally) (Boszormenyi-Nagy, Grunebaum, & Ulrich, 1991; Goldenthal, 1993; Hargrave & Anderson, 1992). This perception over time is a result of many factors, and the outcome is entitlement (constructive or destructive) and an unbalanced ledger (Goldenthal, 1993).

Feminist Theory

Feminism considers the influence of gender, a socially constructed concept, on relationships. Feminism specifically considers how women have been and continue to be oppressed, while trying to find ways to empower them beyond oppression. It also views society as a place with inherent hierarchy and purports that women are limited by such a structure (Imber-Black, 1989). Gender is the primary focus in that Feminist Theory purports that men, specifically white men, have the most significant amount of social, professional, and overall societal power (McIntosh, 1998).

Families and the Social Construction of Gender

A primary assumption of Feminist Theory is that men and women are socialized in different ways. From birth, different expectations are placed upon boys and girls. Although much of this happens in the context of families, these gendered expectations are present in all social systems. Therefore, even the most gender conscious family could not protect a family member from imbedded gender expectations.

A common expectation of women in families is that they will assume some level of care for aging family members (Brewer, 2001; Cicerelli, 2000; Ray, 1996). Whether through the types of chores a female child is asked to do or through watching other women in the family, females are socialized to attend to relationships. In adulthood, this often translates into the expectation that caregiving is a woman's role. Even in dual income families, women are primarily responsible for household and child care tasks (Lee, 1992; McGoldrick, 1989). Since women are socialized to be the primary caregiver to family members, it is no surprise that women make up more than 80% of all caregivers to elderly family members (Brewer, 2001; Ray, 1996). It is also common that even when sons are available, daughters-in-law provide care to their mothers-in-law (Coward, Horne, & Dwyer, 1992; McGoldrick, 1989). Although it is important to note the significant gender discrepancy in caregiving, it is also important to examine the relationships in which such decisions are made.

Feminism and Aging

"The study of aging, by sheer force of demography, is necessarily a women's issue", given the proportion of women who outlive their male counterparts (Ray, 1996, p. 674). Furthermore, "Gerontology and feminism share common goals: development of social consciousness about the inequities confronting older people and women" (Blieszner, Usita, & Mancini, 1996, p. 5). This statement supports Goldner's (1989) assertion that in order to study family relationships, one must consider both age and gender. This does not mean simply including gender and age on a demographic survey, but rather appreciating how a person's gender and age influence their experience in the world.

Since Feminist Theory considers individuals and groups with decreased power, it also relates to the position of the elderly in our society. Falicov (1998) alludes to this dynamic in aging families in the discussion of sibling position and gender. "A son or daughter may gain ascendancy, obligations, privilege, and access to adult information by being the oldest, parentified, or favorite....The child may be in an apprenticeship role to take future care of...the aging parent or the surviving parent" (1998, p. 40). Although subtle, the author seems to assert that aging parents are those who receive care from adult children, rather than being partners in caregiving systems.

Given the perspective of Feminist Theory on issues of gender and age, it is clear that this theory relates to family caregiving. Family caregiving involves multiple generations and is based upon messages passed from one generation to the next. Messages of oppression and gendered expectations are played out in families as well as larger systems and influence family caregiving. Concepts related to aging, kinship, and filial responsibility also are present in caregiving systems.

Contextualism

"Contextual therapy is intergenerational, integrative, multilateral, and oriented toward resources and the future" (Goldenthal, 1992, p. 2). In its application, contextualism attempts to understand at least three generations of families with a balance of attention to each. There are four primary dimensions of contextualism: 1 – existential facts (family history), 2 – psychology (the individual as a system), 3 – family processes and power, 4 – relational balance or fairness (Boszormenyi-Nagy, Grunebaum, & Ulrich, 1991). Each is important to understanding the multigenerational family, its history, participants, and processes.

The primary concepts are related to the family's history and include loyalty, entitlement, ledger, and parentification (Boszormenyi-Nagy, Grunebaum, & Ulrich, 1991; Goldenthal, 1993; Hargrave & Anderson, 1992). The Contextual concept of loyalty has its origins in family care and other family contributions. Nagy (1991) asserts that each developmental stage requires adjustments to loyalty and alters the distribution of responsibility. Nagy (1991) applies the concept of loyalty to clinical populations in his descriptions of split loyalty, which occurs when an individual experiences a conflict as a result of two competing bids for his/her loyalty (Goldethal, 1992). In the case of a caregiving adult child, split loyalties may occur when he/she feels loyalty to care for divorced parents. The concept of entitlement is commonly applied to clinical samples through the term, "destructive entitlement" (Nagy, 1991). This results when an individual perceives that he/she has been wronged and responds with a lack of concern for others

(Goldenthal, 1992). In caregiving families, this may result when an adult child believes that he/she did not get basic needs met by a parent and consequently ignores his/her parent's or sibling's need for help. When a person demonstrates destructive entitlement, Nagy (1991) asserts that he/she has an imbalanced ledger (that personal debts outweigh personal assets). Contextualism is rooted in the idea that imbalanced ledgers are a result of experiences with the family of origin. Manifestations of an imbalanced ledger related to family care might include an adult child's resentment that his/her parent took care of a grandparent rather than him/her as a child.

Contextualism, as a clinical perspective, is rooted in the idea that individuals come from families in which they were not given what they needed or were expected to play a role that was inappropriate for their age/stage in life. This situation manifests itself into entitlement (e.g. he/she owes me this) later in life, which results in that person expecting the debt to be paid by someone other than the person who owes it. Furthermore, loyalties established in the family of origin often remain strong over time. This may or may not be a function of a healthy or unhealthy relationship. However, Contextual Theory would assert that such loyalties lead to unhealthy functions beyond childhood. In caregiving systems specifically, loyalties to one parent over the other may complicate this role. Furthermore, if various siblings have loyalties to a parent, this also may complicate intergenerational caregiving.

Summary

Each of the described theories offers a unique lens through which to study families. Although independently valuable, the integration of these three perspectives informs this study. Specifically, Family Ecology serves as the foundational theory on which the primary concepts of this study rest. Understanding families' experiences with caregiving over time is the central goal of this research. Family Ecology Theory offers the ability to look at the family system, examining resources, boundaries, values, and decision-making processes. Although this is central to the research question, many layers of society and culture influence families. The Human Ecological Model allows researchers to review the layers of influence, looking at micro and macro variables. This perspective intersects well with feminist theory because of common gendered and age related expectations imbedded in society and in caregiving families. The human ecological model also allows families to be reviewed over time, looking at the important role transitions that occur between generations. Feminism offers a framework for studying gender and age related power dynamics and multiple levels (e.g. familial and societal). Furthermore, Feminism is a natural partner with gerontology, qualitative research, and marriage and family therapy – making it a crucial component of this study. Finally, contextualism offers a review of outcomes commonly seen in intergenerational patterns, which are frequently played out in caregiving families. Contextualism and Feminism offer a framework through which to review implications for marriage and family therapy training and clinical work.

The contribution of each of these models results in an ecological framework for studying caregiving, while considering the importance of family, context, intergenerational transmission of values, and an understanding of the influence of gender and age expectations. This model also integrates process and outcome components, addressing the dynamic nature of families (see Figure 1.1)

Figure 1.1: Theoretical Map

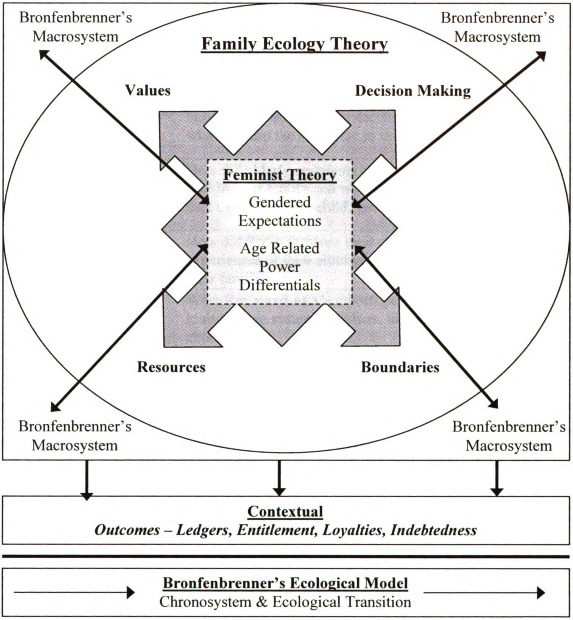


Table 1.1: Guiding Theories and Related Research Questions

Theories &/or Perspectives	**Research Questions**
HE, FET	° How did ACCs and RoCs describe the current care arrangement?
FET, HE	° What ecological factors contributed to family care? What messages (values) existed about care?
FET, Fem	° How did the family make decisions about family care and what role did the RoC play in this process?
FET, HE, Fem	° How did elderly recipients of care describe the history of care in their family and what role has he/she played in care over time (as a child, young adult, older adult)?
FET, HE, CT	° How did RoCs compare their care experience to experiences of their siblings, friends, and other RoCs in their family?
FEC, CT, HE, Fem	° Were RoCs and ACCs reports/perceptions congruent (current care system members, history of care, messages about care)?

HE – **Human Ecology Model** (Bronfenbrenner, 1979, 1999; Griffore & Phenice, 2001)
FET – **Family Ecology Theory** (Bubolz & Sontag, 1993; Griffore & Phenice, 2001; Hook & Paolucci, 1970; Paolucci, 1997)
Fem – **Feminism** (McGoldrick, 1998; McGoldrick, Anderson, & Walsh, 1989)
CT – **Contextualism** (Boszormenyi-Nagy, Grunebaum, & Ulrich, 1991; Goldenthal, 1993; Hargrave & Anderson, 1992)

CHAPTER TWO: REVIEW OF LITERATURE

As individuals live longer than ever before, families and cross-generation relationships are changing. One area that has received significant academic and media attention is elder care by family members. In the past decade, significant information has been produced documenting the caregiving experience of many baby boomers. Experiences of caregivers have been the primary focus of the academic literature, including the effects on and outcomes for caregivers (Berg-Weger & Tebb, 2004; Bleiszner, Usita, & Mancini, 1996; Cox & Munk, 1996; Dilworth-Anderson, Williams, & Cooper, 1999; Dilworth-Anderson, Williams, & Gibson, 2002; Fingerman, 1996; Ho, Weitzman, Cui, & Levkoff, 2000). A smaller proportion of the literature examines cross-generation relationships, including spouses, adult children of caregivers, and elderly recipients of care (Bleiszner, Usita, & Mancini, 1996; Fingerman, 1996 Lieberman & Fisher, 1999; Litvin, 1992; Sorensen & Zarit, 1996). The following section summarizes key components of the extensive caregiving literature and documents the lack of research on elderly recipients of care (Horton & Arber, 2004).

Stress & Burden Perspective

The findings on caregiver stress are extensive and complex, and studies rarely differentiate between co-resident and non-resident caregivers (Cox & Munk, 1996; Dilworth-Anderson, Williams, & Gibson, 2002). Furthermore, studies often fail to identify the differences between spouse caregivers and adult child caregivers. Finally, operational definitions of caregiving vary from study to study, making the collective knowledge difficult to interpret (Berg-Weger & Tebb, 2004).

The caregiving experience is related to a variety of stress reactions, including role strain, financial strain, and emotional/social stress (Cox & Munk, 1996; Dilworth-Anderson, Williams, & Cooper, 1999; Dilworth-Anderson, Williams, & Gibson, 2002; Ho, Weitzman, Cui, & Levkoff, 2000). Caregivers experience a higher rate of depression, anxiety, financial strain, and physical health changes than their non-caregiving counterparts. Increased anxiety and depression among caregivers may indicate that socialization and caregiving expectations contribute to negative consequences of caregiving. The balance between social and familial expectations and other commitments perpetuates this strain (Franks, Pierce, & Dwyer, 2003; Stephens, Franks, & Townsend, 1994).

Another common strain is the financial responsibility that often accompanies caregiving. Caregivers may find themselves providing for multiple generations (children and parents) while earning less as a result of their caregiving role (Calasanti, 1999). Although Calasanti (1999) describes caregiving strains, she also emphasizes that women may benefit socially from caregiving. Benefits of the caregiving role may include strong social networks and life skills that benefit women into late life.

Finally, mixed results are reported regarding needs of the recipient of care and the well-being of the caregiver. Whitlatch, Schur, Noelker, Ejaz, & Looman (2001) found that caregiver wellness and mental health is directly correlated with the needs of the recipient of care, implying that increased care leads to greater caregiver stress. Franks, Pierce, & Dwyer (2003) assert that the recipients' level of need is correlated with the size of the care network. Finch & Mason (1993) discuss the concept of anticipatory negotiation, a process that occurs before action is needed, as a way to prepare both parties for the care arrangement. A benefit of this type of negotiation is the role that both parties have in the plan, giving the future recipient of care a role in the arrangements and consequently attending to their perception of self worth (1993). This may eliminate unnecessary care tasks and caregiver stress about whether or not a recipient is getting what he/she needs and therefore attending to one aspect of caregiver stress. Morgan and Kunkel (1998) note that more research is needed to understand caregiver stress in the context of specific relationships.

Intergenerational Relationships & Care

Caregiver Selection

Research has been conducted that examines caregiver selection or assignment, indicating that many caregivers may be unaware of the *process* by which they became caregivers (Cicerelli, 2000; Piercy & Chapman, 2001; Sorensen & Zarit, 1996; Ungerson, 1987). Furthermore, family scholars may be unclear about the projection of family care and therefore less prepared to assist families with the transition to caregiving. Like the Sorensen and Zarit (1996) study, Keith (1995) reported that much is known about the types of responsibilities involved in caregiving, but research has not successfully identified how caregivers come to take such a role, or how such tasks are allocated.

In a study of 19 caregivers, Ungerson (1987) identified some parts of the caregiver selection process. Overwhelmingly, the participants in this study reported being selected as caregivers based on the "dominant, normative, and gendered rules of kinship" (p. 61). Many of the respondents reported that they were the obvious choice but were unable to explain or identify why. It also was noted that participants' family members believed that the selected caregiver would have the lowest level of life disruption if he/she assumed the role of caregiver (1987).

Piercy & Chapman (2001) examined familial negotiation and found four primary factors related to adoption of caregiving role. The first factor was 'family expectations' indicating that respondents recognized that, earlier in life, they were slated for such a role. Some identified birth order ("I'm the oldest"), while others were unable to identify the source of such expectations. The second factor was 'family rules' which refer to the ongoing guidelines that keep a family running smoothly. Each person seemed to speak knowingly about such rules but did not explain why he/she adhered to such rules while others did not. The third and fourth factors were 'role modeling' and 'role making'. In these two factors, caregivers described the unspoken process by which they learned about caregiving (2001). Although they examined the family legacy aspect of caregiving, Piercy & Chapman (2001) stated that, "we know little about how adult children adopt caregiver roles" (p. 386).

Finally, Cicerelli (2000) examined the trajectory of adult caregivers. Although the research did not result in a specific model of caregiving, there was one primary finding. The major predictor of caregiving was the adult child's perception that the parent was experiencing increased need of care. As adult children perceived greater need by the parent, the caregiver increased his or her efforts. However, the perceived need was not necessarily related to the actual need of the parent.

Collaboration Surrounding Care

The idea that one caregiver provides care has been challenged by the assertion that families collaborate in care of older family members (Cicerelli, 1992). Ingersoll-

Dayton, et al (2003) specifically addressed the issue of sibling collaboration in caring for older parents. This study used qualitative methods and a series of focus groups with siblings who care for their aging parents in various ways. With a focus on collaboration, the authors note two primary approaches employed by siblings – taking turns or deciding by task or by area of expertise. The authors purport that research on sibling collaboration demonstrates that an exclusive caregiver can be identified in less than 10% of cases (2003; Cicerelli, 1992). However, the literature consistently documents the presence of a primary caregiver, with 79% of families identifying one adult child in this lead role (Ingersoll-Dayton, et al, 2003).

The concept of equitable contributions is central to caregiving work, especially when siblings are collaborating in the care of an aging parent. Ingersoll-Dayton, Neal, Ha, & Hammer (2003) assert that the balance of expected care and perceived support of siblings is central to feelings of distress. Specifically, the authors state that, "when people feel that they are giving more than others in a transaction, they will become resentful or angry…when individuals feel that they are giving less than others, they will feel guilty" (2004, p. 202).

Multiple Generations

A limited number of studies have examined the intergenerational dynamics of caregiving, including both the caregiver and the recipient of care (Bleiszner, Usita, & Mancini 1996; Lieberman & Fisher, 1999; Litvin, 1992). Each of these studies takes a different approach, with some using a strengths-based, normative approach and others using a stress and burden perspective.

Fingerman (1996) reports that the relationship between adult children and parents is often romanticized, assuming that the adolescent-parent relationship is more likely than other family relationships to have conflict or tension. Based on this assumption, Fingerman (1996) asserts that a gap exists in the caregiving literature regarding the relationship difficulties that can arise between adult children and recipients of care, specifically related to females. Although the literature documents the stress experiences of caregivers, this study examines the sources of tension between mothers and daughters rather than outcomes for one person. Bleiszner, Usita & Mancini (1996) challenge the idea that caregiving mother/daughter relationships are plagued with conflict, offering an alternate perspective in the caregiving literature. The findings of Bleiszner's, et al (1996) study support Brubaker, Gorman, & Hiestand's (1990) assertion that conflicted relationships may be a result of established dynamics rather than outcomes of caregiving.

Litvin (1992) examined the adult child caregiver and aging parent relationship using the social breakdown perspective. With this perspective, aging is seen as a time of extensive loss or decline, creating stress for both the recipient of care and the caregiver. In this quantitative study, findings revealed several predictors of negative outlook by recipients of care – perception of poor health status, lowered involvement with family and friends, and perceived change in relationship with caregiver(s) (1992). Although this study reiterates several well-documented findings in the caregiving literature it is unique in that it emphasizes the inclusion of recipients in research.

Fisher and Lieberman (1996) and Lieberman and Fisher (1999) included both adult children and recipients of care in their studies of family conflict resolution. Although the recipient of care was included in the analysis, he/she did not respond to any of the measures directly. The recipients were included in the analysis based on medical professionals' evaluations of their functioning. Recipients of care had experienced dementia, a stroke, or had been diagnosed with Alzheimer's disease and therefore were not directly included in the study. Family conflict resolution was measured based on the adult child and spouses' perceptions of conflict resolution. Although it is important to study families experiencing certain conditions, such as dementia or Alzheimer's disease, Berg-Weger & Tebb (2004) postulate that it is important to expand participation to families providing care for conditions other than dementia.

Sorensen and Zarit (1996) included three generations of females (mothers, daughters and granddaughters) in their examination of caregiving anticipation and preparation. Unlike the Fisher and Lieberman (1996) study, the eldest generation in this study was not significantly dependent on others for care. The primary finding of this study documents that older female participants (potential recipients) actively anticipate what will happen to them if they become unable to manage personal or household tasks. Although a significant majority of daughters and granddaughters in this study also reported anticipation, the families reported little planning for such events (1996). These findings support the idea that decisions are anticipated throughout various points in the life cycle and supports Berg-Weger & Tebb's (2004) assertion that there is a need to explore transitions in and out of the caregiving role and "to better understand the process of caregiving" (p. 13).

Reciprocity

"In family roles, older Americans are widely perceived as care recipients, rather than caregivers" (Treas & Mazumdar, 2004, p. 107). However, the concept of reciprocity has been used in the caregiving literature to address either past or current contributions of older adults.

Three forms of reciprocity have been discussed in relation to the care of older family members – immediate, hypothetical, and deferred (Lewinter, 2003). Immediate reciprocity refers to a current exchange; hypothetical reciprocity refers to the belief that the recipient would do the same for the caregiver, and deferred reciprocity refers to the idea that the caregiver is paying back a previous favor or debt (Lewinter, 2003). Immediate reciprocity was most frequently described as an expression of gratitude by the recipient, followed by the enjoyment in taking care of someone with whom the caretaker has a positive relationship. In this study of 107 caregivers to the elderly, a large proportion noted the importance of gratitude and appreciation in their motivation for continued care of their parent.

Role Reversal

Kruypers & Bengtson (1990) summarized three primary macro assumptions that influence the aging family system. The first is that as families age, level of familial (family of origin) involvement will and should decrease. The second assumption states that loyalties in families will shift over time and that investments in younger generations should be primary. Finally, Kruypers & Bengtson (1990) postulate that the widely accepted belief that care should extend from older to younger generations, perpetuates the idea that care of older generations is a dysfunctional family pattern.

Seltzer (1990) purports that the caregiver role places the recipient of care into a child-like position, reversing the structural positions of the adult child and parent. In their 2004 research, Horton & Arber found that "carers were often concerned about the reversal of roles and that a primary concern was to protect the parent's identity and the parent-child relationship" (p. 77). However, some research has documented the caregiving role as a normative family task rather than a source of non-normative dynamics (Sherrell, Buckwalter, & Morhardt, 2001). This assertion challenges the widely held assumption addressed by Krypers and Bengtson (1990) and acknowledges that structural changes in aging families are appropriate.

Despite opinions about the appropriateness of caregiving positions, scholars agree that parent-child relations change in the context of elder care. Not only does the recipient's relationship with his/her caregiver change, it may also challenge his/her position with others in the family. Furthermore, it is likely that many recipients also have been caregivers at one time. In cases where the now recipient has been a caregiver, added transitions are required. "Caregiving has typically been viewed as a specific activity, rather than as a social status that individuals move into and out of at various points in the life course" (Pillemer, Suitor, & Wethington, 2003, p. 24). Redefining caregiving, as a dynamic process, will offer a more accurate view of care activities and will acknowledge the transitions in and out of care roles (Berg-Weger & Tebb, 2004; Pillemer, Suitor, & Wethington, 2003).

Recipient of Care

Brubaker, Gorman, and Hiestand (1990) specifically addressed recipients of care in their chapter on stress in the caregiving system. In their review of literature and conceptualization, the authors addressed personal, situational, and social support variables that influence the recipient of care. A primary conclusion was that the recipient of care's perception of control and power in the caregiving system was most significant in determining his/her stress level. This was applied specifically to the need to better understand how caregivers, specifically adult children, collaborate with their parents relative to caregiving. Brubaker, Gorman, and Hiestand (1990) assert that the greater the level of control recipients of care perceive in the caregiving system, the less stressful their experiences will be. Much of this work relied on the literature that examines the relationship between caregivers and recipients of care. However, this chapter was unique in that it highlighted the experience of the recipient of care rather than the caregiver.

Clinical Perspectives

Gender & the Feminist Perspective

A portion of literature has been committed to viewing family care from a feminist perspective (Brewer, 2001; Goldner, 1992; Ingersoll-Dayton, Starrels, & Dowler, 1996; Neal, Ingersoll-Dayton, & Starrels, 1997; Ray, 1996). This work uses the feminist paradigm as a way to study families with aging members, looking specifically at the concept of gender. As stated in the clinical perspective discussion of feminism, factors other than gender, such as age, are relevant in feminist applications of family care. The following section summarizes work that highlights feminist concepts and introduces the idea that feminist literature can expand to include age as a primary consideration of power, specifically in relation to the recipient of care.

In their study grounded in the feminist framework, Allen and Walker (1992) interviewed elderly mothers and caregiving daughters. The authors aimed "to address two underlying assumptions in the intergenerational caregiving literature: that elderly family members are passive, dependent recipients of care and that outcomes of caregiving for the caregiver are overwhelmingly negative" (1992, p. 198). Findings included a number of positive outcomes of caregiving for both the caregiver and care recipient, including companionship, mutual concern, and appreciation. Allen and Walker (1992) concluded that mothers play an "active role" in the caregiving system and that interactions between mothers and caregiving daughters result in "mutually beneficial activities" (p. 210).

Brewer (2001) utilizes the feminist perspective to discuss the various aspects of socialization as it relates to family care. Her work supports the importance of using feminism to view caregiving systems, given the gendered norms that guide caregiving research and elder care in our society. Brewer (2001) argues that two primary perspectives inform feminist research on caregiving - the burden perspective and the positive view. She asserts that the reality of caregiving likely lies somewhere between the burden perspective and the idea that caregivers find it "meaningful and fulfilling" (p. 227).

Ingersoll-Dayton, Starrels, & Dowler (1996) make a contribution to caregiving work by asserting that there are many gender related variables of the burden perspective as well as viewing "aging parents as potential resources" (p. 483). The authors found a discrepancy in the amount of support provided to daughters versus daughters-in-law, concluding that caregiving daughters-in-law are the most vulnerable of caregivers in the adult child system. This study also documented that elderly mothers receive and provide more assistance than their male counterparts. This finding may relate to the average lifespan of women and men but warrants further examination (1996).

Harris (1998) addresses gender through a neglected topic in the caregiving literature, the role of men. She acknowledges the role of the recipient of care in the selection process by proposing, "that mothers do not select sons as primary caregivers because of their concern for modesty" (p. 343). The sons who participated in this qualitative study echoed experiences similar to female caregivers- duty, acceptance, and work flexibility. This study is applicable to feminist concepts because of the use of gender, as well as its acknowledgement that caregiving may have positive outcomes. Related to males as caregivers, Morgan and Kunkel (1998) state that although mother-daughter dyads are most often researched, "the relationship most likely to experience conflict is that between a father and son, with cross gender dyads (mother/son, father/daughter) falling in between" (p. 235).

Neal, Ingersoll-Dayton, & Starrels (1997) aim to understand how gender intersects with relationship type and care tasks among employed caregivers. They surveyed more than 2,000 men and women who reported providing care for a variety of individuals. The primary finding of this study was that commonly held beliefs about the types of care tasks performed did not differ by gender. These findings did support the thesis that female caregivers experience greater stress than their male counterparts. Despite availability of resources, relationship to care recipient, and other personal characteristics, stress was still higher among female caregivers. These findings, coupled with the fact that female caregivers commonly have fewer resources, emphasizes the variance in caregiving between men and women (1997).

Summary

The literature provides extensive information about family care and specifically caregivers. Information on the stress and burden model, intergenerational care, caregiver selection, reciprocity, and the recipient of care have been highlighted for this study as they summarize key aspects of the research, while also documenting the gaps in the literature. These segments support the concept that family caregiving is a multigenerational process that develops over time. However, "research on the family rarely focuses on dyads, but instead usually describes relationships only through the eyes of one of the participants, with most gerontological contributions taking the adult child's rather than the older person's perspective" (Horton & Arber, 2004, p. 76).

Given what is known about adult child caregivers, more literature on aging parents as recipients of care is needed. Like Horton & Arber's (2004) work, the literature provides several clear calls to family scientists to expand the caregiving literature with respect to the recipient of care. Litvin (1992) states that we "must take into account the differences in the meaning of the caregiving experience for each member of the dyad" (p. 75). In response to a literature heavily focused on caregivers, Keith (1995) asserts that "single-source data collection will not reveal the diverse meanings of the caregiving experience for various family members" (p. 180). Finally, Brubaker, Gorman, and Hiestand (1990) state that "scant attention has been directed toward the perceptions of elderly recipients of family care" (p. 267).

Through research on the caregiving process, scholars are beginning to learn more about how family members come to assume care of an aging parent. However, much more is needed to better understand this process within families. Pyke (1999) clearly stated the neglect of this role in caregiving research and offered an example by which the field of family science has studied relevant dynamics,

> Research on family power has been devoted primarily to dynamics between husbands and wives, leaving power in other family relationships sorely understudied....Meanwhile, other family relationships, such as those between

> aging parents and adult children , have been glorified as harmonious due to norms of attachment and filial obligation. Scholars have been reluctant to recognize power dynamics as an important feature of relationships between aging parents and adult children. As a result, we know little about variations in power dynamics in aging families and what, if any, relationship exists between those dynamics and caregiving strategies. (p. 661 - 662).

Although Pyke (1999) clearly identifies power as an important variable, general transitions and dynamics between aging parents and adult children also are acknowledged. This clearly documents the need for further research on cross-generation caregiving and transitions in power and other dynamics over time.

CHAPTER THREE: METHODOLOGY

This study aimed to understand the experiences of elderly recipients of care, and their caregiving adult children, from both a current and historical perspective. This research examined the role of the recipient of family care over time, including reported changes in power and involvement. Furthermore, it used the recipient of care as the primary source of information while also recognizing the adult child caregiver as another valuable voice in the family care system. This study employed qualitative methods, specifically the multiple case study approach, with elder care dyads (recipients of care and caregiving adult children) as the unit of analysis.

Qualitative Methods

Qualitative methodology was selected for this research because the researcher believed it was the best method for researching this population (elderly recipients of care) about experiences with family care. This was based on two assumptions; that personal contact with the researcher (rather than alternate forms of data collection) increases the participant's comfort and that interviews enrich data obtained from elderly recipients of care (Yin, 1989). The case study approach was selected not only to understand how participating families differ from one another but also to glean the experiences of recipients of care and their history of family care, focusing on unique aspects of each family.

This qualitative, case study approach offered a unique opportunity to hear from recipients of care in order to better understand their current and past experiences. Cases in this qualitative study were care dyads (an elderly recipient of care and an adult child who provided some level of care) who participated in individual, semi-structured interviews. Gillham (2000) states that qualitative research, specifically the semi-structured interview is the "most important form of interviewing in case study research" (p. 65). Yin (1989) reports that the case study approach is meant to address specific types of questions – questions asked of the specific case or of the interviewee such as 'why' or 'how'. Berg-Weger, Rubio, & Tebb (2001) address the value of using such methods with aging families, stating that, "using qualitative methods to study gerontological experiences allows the valuable contributions of the respondents to be highlighted" (p. 264).

The Case Study Design

There are various forms of case study design which differ based on the questions and planned analysis. Case study analysis is done either within cases or between cases. Single case studies use within case analyses of a detailed, often multi-form data source. For those more familiar with quantitative research, a single case study is "akin to a single experiment" (Yin, 1989, p. 53). In multicase research, one can use various cases in one of two ways, as a way to find similar results or to examine contradictory findings that can be explained by a solid theoretical foundation (1989). It is important to note that just as the single case study mirrors a single experiment, the multicase study is comparable to the way researchers approach multiple experiments (1989). When experiments yield variable findings, such discrepancies can be discussed from a theoretical framework.

An important part of the research process entails the investigator's selection of a design (Merriam, 2001). In this study, the case study design was selected for several reasons. First, qualitative methods were used in this project, and the case study design is a logical partner with qualitative research, given they both address how and why questions

(Merriam, 2001; Yin, 1989). Secondly, the case study approach allows the researcher to identify a unit that has discernable boundaries and to study interactional patterns within that unit (Yin, 1989). Once the unit is identified, the case study approach allows the researcher to intensely study the case(s). The purpose of this study was to better understand the experiences of ten specific dyads relative to the guiding theoretical framework, therefore the interpretive case study approach was used. The intent of the interpretive case study is to obtain a "rich description....used to develop conceptual categories or to illustrate, support, or challenge theoretical assumptions held prior to data gathering" (Merriam, 2001, p. 38). Hearing the care experiences of both caregiving children and recipients is an important component of gerontological research. When compared with prior research and theoretical assumptions, the case study data has the potential to offer knowledge that can inform future research (Merriam, 2001).

This study used the multicase design, looking not only within cases but also comparing each family/dyad to others. Case study researchers (Gillham, 2000; Yin, 1989) recommend that research be grounded in a sound theoretical perspective, which is also necessary for the interpretive case study. In an effort to review these data with the three theoretical perspectives that informed this study, both within and cross case analyses were used. Variability between cases was expected as contextual factors varied from case to case. With the use of Family Ecological Theory and the Human Ecological model, these differences are addressed.

Research Questions

The following research questions guided this qualitative study; 1 - How did ACCs and RoCs describe the current care arrangement? 2 - What ecological factors contributed to family care? What messages (values) existed about care? 3 - How did the family make decisions about family care and what role did the RoC play in this process? 4 - How did elderly recipients of care describe the history of care in their family and what role have they played in care over time (as a child, young adult, older adult)? 5 - How did RoCs compare their care experience to experiences of their siblings, friends, and other RoCs in their family? 6 - Were RoC's and ACC's reports/perceptions congruent (e.g. regarding current care system members, history of care, messages about care)?

Feminism as Used in Qualitative Research

The process of qualitative research complements and is informed by the feminist perspective (Myers-Avis & Turner, 1996). It is important to note that feminist research is not a method but rather a way of conceptualizing research defined by a particular worldview (Allen & Walker, 1992; Myers-Avis & Turner, 1996). Feminist research calls for attention to specific aspects of the content and process of research. The feminist researcher attends to power between him/herself and the participants and power in society, attends to history and context, emphasizes social justice, and critiques the self as a part of the research (1996; Rosenblatt & Fischer, 1993).

Through this project, the researcher employed the feminist perspective not only to understand aging families but also to inform the research process. The feminist perspective required the researcher's use of reflexivity or acknowledgement of self in the research process (Allen & Walker, 1992; Merriam, 2001; Myers-Avis & Turner, 1996). Finally, the feminist perspective informed the critical approach of this study with respect to commonly accepted assumptions about care. In line with feminist concepts, this research was meant to challenge society's approach to family care and the role of oppressed individuals in the caregiving system (Myers-Avis & Turner, 1996).

In addition to using Feminism as the guiding paradigm, this study included components of three qualitative methodologies – ethnography, phenomenology, and grounded theory. It was ethnographic in that it was inductive, it reflected and was "shaped by theoretical presuppositions and principles that guide the process of data collection and analysis" (Newfield, Sells, Smith, Newfield, & Newfield, 1996). The ethnographic researcher is interested in learning how theory and participants' experiences reciprocally inform one another. Like ethnographic research, phenomenological methods help researchers understand how individuals make meaning of a phenomenon they are experiencing. Phenomenology is based on the assumption that individuals have their own reality, eliminating an absolute truth (Boss, Dahl, & Kaplan, 1996). Furthermore, this approach to qualitative research is characterized by "meaning questions" from which the researcher seeks to understand how the participant makes meaning of the phenomenon and his/her experience (1996, p. 91).

Finally, grounded theory, specifically substantive rather than formal grounded theory, guided this research (Glasser and Strauss, 1967). Grounded theory research is described as substantive when a specific group is studied. When similar concepts are applied to multiple groups, the classification of formal is more appropriate. For example, in this study, concepts of power and role changes were applied to the experiences of recipients of care. If findings from this study were discovered in additional studies on other family members, then formal grounded theory would be the appropriate classification (Gilgun, 1992).

It is important to note that in addition to shaping the details of this project, they also guided the overall approach/philosophy of this study. Two of the components (ethnography and phenomenology) guided the overall framework of the study, that theory and experiences reciprocally inform one another, that reality is socially constructed, and that individuals make various meaning of their experiences. Furthermore, ethnography and grounded theory guided the proposed methods of this study and were characterized by use of theory and reciprocal coding and analysis process.

Sample

The sample was purposive in that elder care dyads were the focus, placing an emphasis on widowed mothers and biological daughters. This study focused on family dyads that included one recipient of care and an adult child caregiver. Recipients of care were age 70 or older, either single, divorced, or widowed, and had been receiving assistance from an adult child for at least 11 months at the time of the interview. Assistance may have included, but was not limited to, housekeeping, transportation, meal preparation, financial support, assistance with medical management, or personal care.

It is important to note that the focus of this study was on recipients of care and their adult children rather than spousal caregivers or in-laws. This decision was made based on the differences in power and position of adult children, compared to spouses, in the caregiving system (Fisher & Lieberman, 1996). Had caregivers, beyond adult children, been included in this study, it may have diluted the findings given the variability between roles such as adult child and spouse.

IRB Procedures

The procedures for this project were reviewed by Michigan State University's Committee for Research Involving Human Subjects (UCRIHS). Full approval was received from UCRIHS, and a reliance agreement was provided to Ingham Regional Medical Center, identifying Michigan State University as the primary institution responsible for the credibility of research for this project. Following final approval, two revisions were submitted to UCRIHS for the purposes of adding recruitment sites.

Recruitment

Recruitment was conducted at several sites throughout the Lansing, MI metropolitan area. The sites included two medical practices, an adult day center, a university family resource center, and four assisted living facilities. Recruitment consisted of participating professionals (director, physicians) identifying and individually informing qualified families about the study. Approved study information sheets were distributed to these families, and they were given the researcher's contact information (see Appendix A). Fifteen families from the adult day center were informed about the study, two inquired about the project and both completed interviews. Twelve families from the two medical practices were given study information sheets, three inquired, with two qualifying and completing interviews. The university resource center director sent the study information sheet to 104 members of the family caregiver electronic listserve. Seven families contacted through the resource center inquired about the project but only two meet the inclusion criteria and completed the interviews. Finally, four assisted living centers distributed approximately 25 study information sheets. Five families from two assisted living centers inquired about the project and the four that met the inclusion criteria, completed interviews.

Individuals who received the study information sheet and were interested in participation contacted the researcher to schedule an interview. Initial interviews were scheduled with adult child caregivers at a site of their choice (their home, office or the researcher's office). Following the caregiver interview, interviews were scheduled with the parent at the site of his/her choice (home, an adult day center, or the researcher's office). Individuals who chose to participate in the study completed two written consent forms, a general and a direct quote consent form (see Appendix B & Appendix C). The general consent form described the research project, including potential risks and/or rewards. The direct quote consent form was used to describe the use of verbatim interview segments and to allow the researcher to use direct quotes while maintaining confidentiality. At the end of each interview, participants were given a $10 gift certificate for a local retail store ($30 total per family).

Interview Context

The three locations used for interviews, other than participants' homes, were handicap/wheelchair accessible private offices with comfortable seating. The medical office included a suite with casual furniture (a couch and two chairs). The second office was housed within the adult day care center administration suite and included office furniture, a large table, and several chairs. Finally, several recipient interviews were conducted in a meeting room of one of the retirement centers. This attractive room had a dining room table and chairs and was referred to as the "Rose Room".

Although each space was adequate, there were considerations with each location. The medical office provided confidentiality for participants in that the reason for the participant's visit was unknown to anyone other than the researcher. However, there is a hierarchy associated with the medical profession that may have influenced the participant's comfort level and/or responses. Although the confidentiality agreement was reviewed with each participant, an individual may have assumed that his/her physician has access to the data. Since some participants shared the same physician with family members, this may have caused resistance to sharing caregiving experiences. The available office space at the adult day care center made participation convenient and accessible. However, this site did not provide the comfort one might experience at home or in a non-office setting. Furthermore, individuals attending center activities were able to observe the participant's absence and may have inquired about the purpose of the interview.

Data Collection

The data collection for this study included four stages, spanning from the initial recruitment contact to the second part of the RoC interview (see Appendix D). Recruitment included contact between professionals from the sites described above and family members who met the criteria for the study. In cases in which the adult child caregiver was present (i.e. the ACC attended the doctor's appointment with the RoC or is at the Day Care Center at the time of initial contact) both individuals were informed about the study and given a study information sheet.

In stage two, initial contact was made by a participant to inquire about the study. The study was described, including both the RoC's and the ACC's role (e.g. interviews), and the caregiver interview was scheduled. By the end of stage two, the researcher had contacted both the ACC and RoC to schedule interviews.

Stage three consisted of a consultation interview with the adult child caregiver. The purpose of this meeting was two fold, for the researcher to learn more about the adult child's role in the current caregiving system, including how he/she believes that role was assumed, and to answer questions about the study (see Appendix E). This time also offered the adult child the opportunity to ask questions about the recipient interview. Although confidentiality was protected (interview content was not shared), this opportunity offered the caregiver the chance to give her input. For example, one adult child caregiver reported that her mother takes frequent restroom breaks but may forget to do so during a lengthy interview. Therefore the researcher built a 5-minute break into that interview.

The fourth stage of the study included a two-part interview with the RoC. The time between the two parts of the RoC interview ranged from five to eleven days. This interval allowed the RoC time to reflect on the initial interview and considered physical limitations (e.g. sitting too long). Furthermore, the recipient interview was done in two parts to separate questions about the current and past care systems.

After each interview, the researcher completed field notes and family care system ecomaps. These data sources were used to supplement the interview data and serve as a form of triangulation. The ecomaps were especially important in examining the current care system and measuring issues of congruence.

Part one of the interview focused on the current caregiving system, including key members, roles, and perceptions of decisions relative to care. This interview also included questions the RoC was asked to reflect on his/her experience in comparison to others (e.g. siblings, friends) (see Appendix F and Appendix G). Following the first recipient interview, a caregiving ecomap was constructed to illustrate the current caregiving system. Relevant information from the caregiver consultation interview also was included on the ecomap, which aided in measuring congruence.

Initial plans included use of a family genogram and caregiving timeline, to be utilized much like the caregiving ecomap. However, it was determined that these tools were redundant, not useful to the data analysis, and were consequently removed from the data analysis process.

Data Analysis

All interviews were audiotaped and transcribed verbatim. Once transcripts were complete, the simultaneous process of coding and analysis began using the constant comparative method described by Glasser and Strauss (1967). Data were entered into a qualitative data analysis program (e.g. MaxQDA). MaxQDA was used by the researcher to organize and code the interview transcripts. A second coder and peer consultant reviewed transcripts in paper form, coding the hard copies. These comments were integrated into the final coding scheme by the researcher, and the final analysis was completed.

The constant comparative method developed as an integration of two previous forms of qualitative analysis – testing hypotheses by coding and then analyzing data or reviewing data as a way to discover emerging theory. The constant comparative method integrates both of these approaches using the "explicit coding procedure of the first approach and the style of theory development of the second" (Glasser & Strauss, 1967, p. 102).

The constant comparative method is a four-step process beginning with "comparing incidents applicable to each category" (Glasser & Strauss, 1967, p. 105). Each portion of the data is coded into already existing themes or is marked with a newly identified theme. The coding is always done using a frame of comparison with other codes in the same category, developing a type of continuum within that category / theme. In the second phase, Glasser and Strauss (1967) describe a reciprocal process by which the data are delineated into categories but also integrate across categories to support greater findings. In step three, the findings are classified into two primary categories – themes and theory. As the analyst continues to review the data, redundancies will likely emerge. The researcher eliminates redundant patterns in an effort to make the findings more concise and relevant to a larger theory. In the fourth and final stage, the researcher articulates his or her contribution to existing theory (1967).

The data analysis process followed this method, beginning with codes, moving to themes, identifying key findings, and finally linking data to existing theory. Later in this document, links to previous theory are documented and discussed.

Data and Coding Triangulation

Data credibility is fundamental to all research – quantitative and qualitative. In qualitative research, there are various ways to enhance the credibility of research – including data triangulation, peer examination, and the acknowledgement of the researcher's biases (Merriam, 2001). Merriam (2001) defines data triangulation as "using multiple investigators, multiple sources of data, or multiple methods to confirm the emerging findings" (p. 204). Data triangulation was addressed through multiple forms of data: the caregiver consultation interview, the two part semi-structured interview, field notes, and a caregiving ecomap. Field notes were constructed after each interview documenting the researcher's general impressions. Two caregiving ecomaps were constructed for each family to document the caregiving system. The two ecomaps were synthesized into one family ecomap that aided in the individual and cross-case analysis and the descriptions of care systems. The various forms of data served to verify and ensure data accuracy. A second form of triangulation, use of multiple investigators and peer examination, was utilized. In order to add credibility to the coding process, two coders were used and both coded the data independently. Although coding was completed independently, the coding consultant was given the theoretical map before reviewing transcripts. Therefore, both coders were working from a similar theoretical map and framework. It is important to also note that the coding consultant has experience with qualitative research, works with the elderly and underserved populations, and has a similar academic background as the researcher. The second coder and researcher met twice to discuss coding and to process the data in general. Correspondence regarding changes in the coding schemes also was done via e-mail and phone conversations. Although coding schemes were highly congruent, some discrepancies arose. In the case of coding the current care tasks, the coders had differing opinions about how to categorize these tasks. When these discrepancies occurred, the researcher and coder discussed their operationalization of a particular code and in most cases agreed on a category that encompassed both interpretations. It is important to note that overall the coding schemes were closely aligned and therefore minimal differences existed.

Since each person brought her own individual experiences and perspective to the coding process, having multiple coders highlighted similarities in the data that were guided by theory.

Trustworthiness

Although the concept of validity relates to qualitative research, the term trustworthiness is instead used to refer to a sound methodology that gains what the researcher purports to have studied. In order to establish trustworthiness in this study, several approaches were taken from conceptualization to data collection and coding. Three primary, well-established theories informed this study and resulting research questions. Furthermore, the multiple sources of data documentation served to verify the interview information (caregiving ecomap and timeline). Using multiple independent coders ensured that data were accurate and addressed the concept of credibility (the qualitative equivalent to reliability).

The Role of the Researcher

As a part of the qualitative research process, it is important to acknowledge the experiences, strengths, and biases the researcher brings to the study, as these factors influence his/her perspective (Merriam, 2001). Boss, Dahl, & Kaplan (1996) concur, asserting that, "social inquiry is influenced by the investigator's beliefs about how the world works. Subjectivity (rather than objectivity) is therefore recognized as a "researcher's reality" (p. 85).

As with most research, this is part of a process that began many years ago. Although I did not know it at the time, my future research plan began in my grandpa's living room approximately 11 years ago. He was 86, living independently, and chose to talk to his 18 year old granddaughter about his desires for late life care – should the time come. Several years later, I realized the uniqueness of this conversation, learning that he had not had this talk with either of his daughters (at least not that anyone could remember). I found myself in a difficult position. I knew what my grandpa had articulated to me but saw that it was not being implemented. Although my grandpa was cognitively very aware, we both sat back and watched his daughters make decisions about his care. Although I am unsure why he chose not to articulate his wishes in either a formal or informal way, I concluded that it was in part a result of decreased power in the family (related to age). In truth, his decision may have been out of trust, contentment, and/or fatigue. My education and experiences led me to believe that his chronological age, gender, and status as a widow launched his daughters into caregiving and decision making roles – minimizing his voice (and of course placing added pressure on "the girls").

Since my mother, the younger of the two, assumed full-time, co-resident care of my grandfather for several years, I witnessed much of this arrangement first hand. I came to question how she, rather than her sister, became his caregiver. I also questioned what my grandfather would have arranged if he had been asked. Our family made logical statements such as, "Claudia is single, has a big house, and can afford to take Grandpa in." I also noted that several years prior, Grandpa had stepped in to help my mother after an emergency heart surgery, resulting in what I have come to call my first experience with reciprocity.

I came to be confused and amused by the different stories of care that existed in my family. My mother said, "Grandpa needed us a lot more than we needed him. He moved here because he had nowhere else to go." My brother complained that Grandpa was there because he needed care, often treating him disrespectfully. I concluded that Grandpa moved 600 miles (from his lifelong home) to live with me. I think he did this because he made this spontaneous move within a week of both my mom's and my brother's emergency hospitalizations – both of which left me temporarily alone at 13. I also determined that it was significant that Grandpa lived with us (following my mom and brother's recoveries) until the month I left for college. It was at that time that he moved into his own home and lived independently for six more years. Eventually, my grandfather began to need care. I watched as the cycle of care and reciprocity continued. Simply stated, it is my belief and consequently my bias, that the recipient is a valuable member of the caregiving system and should, when possible, be actively involved in decisions regarding care.

By training, I am a family scientist and marriage and family therapist, and my knowledge of aging individuals is rooted in family ecological and transgenerational family therapy theories. As a therapist, I have worked with countless females who were providing care to an aging parent. Given my interest and belief that relational therapy is ideal, as opposed to individual therapy, I advocated for work with caregivers and recipients. It was my observation that caregivers, physicians, and even other family science professionals viewed the caregiving relationship as unidirectional. This belief, combined with widely accepted stereotypes among adults 70 and older about mental health treatment, limited my ability to work with caregiving systems. I think that this is one example of how recipients can become invisible members of the care system.

Limitations

This study used the case study approach, was exclusively qualitative, and consequently had related limitations. Since this study involved a primary focus on recipients of care and one caregiving adult child, the perspective of family care came from only two family members. Although this allowed for an in depth examination of the recipient of care's perspective, it was a limited view of the complex caregiving system. Secondly, the sampling and data collection methods required participants to have the physical and cognitive abilities to participate in an interview. This method excluded individuals with advanced dementia, Alzheimer's disease, severe hearing loss, and/or other physical and cognitive limitations, which frequently characterize recipients of care. This research asked recipients of care to informally evaluate how their family (including their caregiver) made caregiving decisions. As a result of loyalty to family or caregivers, participants may not have provided thorough or honest responses. Finally, caregiving systems often include both family and non-family members. However, this study focused exclusively on how caregiving decisions are negotiated in families, eliminating inquiries about non-family support, and potentially excluding an important component of the caregiving system.

CHAPTER FOUR: RESEARCH FINDINGS

The findings of this study are described in two parts; a description of the sample and research findings. Provided in the description of the sample is a narrative overview of the ten families (20 informants) who chose to participate. In addition to the collective summary, the ten elder care dyads are briefly described in Table 4.1. Following the description of the sample, the segment on research findings outlines data from the 30 semi-structured interviews. In keeping with the case study design and for the sake of continuity, each research case (elder care dyad) is described individually. Each case description provides detailed reflections from interactions as well as data that address each research question. At the conclusion of this chapter, individual and cross-case themes are summarized.

Overview of Sample

All ten dyads that participated were mother-daughter pairs currently engaged in some level of elder care. The age of caregivers ranged from 36 – 68, with a mean age of 51.9 years. Recipients of care ranged in age from 72 – 92, with a mean age of 79.4 years. The majority of dyads (seven) were Caucasian, two were African-American, and one was Lebanese.

In all ten cases, mothers and daughters agreed that the identified daughter was the recipients' primary caregiver and had been for at least 11 months. Although two of the adult daughters were only children, all ten dyads described a care system that included three or more people. Four of the dyads were co-resident, with two dyads living in the adult child's home and two dyads living in the recipients home. Six of the dyads were not co-resident; five recipients lived in assisted living centers and one lived in her own home.

Most caregivers and recipients lived within close proximity of one another, with the greatest distance being 63 miles.

Table 4.1: Descriptions of Participants

Dyad #	*Name*	*Age*	*Ethnicity*	*Marital Status*	*Co-resident*	*# of children*
1	Veronica $_1$	52	African-American	Divorced	YES	1$_d$
	Karin	77	African-American	Widowed	ACC's Home	1
2	Martina $_1$	47	Caucasian	Remarried	YES	2$_c$
	Mona	76	Caucasian	Widowed	ACC's Home	5
3	Leda $_2$	54	Caucasian	Married	NO	2$_a$
	Bernice	72	Caucasian	Widowed	Own Home	5
4	Dena $_3$	49	Lebanese	Divorced	YES	1$_b$
	Vera	88	Lebanese	Widowed	Own Home	3
5	Abigail $_4$	52	Caucasian	Widowed	NO	1$_d$
	Beulah	80	Caucasian	Widowed	Asst. Living	1
6	Carrie $_2$	36	Caucasian	Single	YES	1$_c$
	Deborah	76	Caucasian	Widowed	Own Home	3
7	Sandy $_3$	51	Caucasian	Divorced	NO	2$_b$
	Anna	82	Caucasian	Widowed	Asst. Living	4
8	Idah $_4$	68	Caucasian	Remarried	NO	2$_b$
	Rita	92	Caucasian	Widowed	Asst. Living	3*/2**
9	Jana $_4$	51	African-American	Single	NO	3$_b$
	Tina	72	African-American	Widowed	Asst. Living	4
10	Dora $_4$	54	Caucasian	Married	NO	2$_d$
	Donna	80	Caucasian	Widowed	Asst. Living	1

Recruitment Sites:

$_1$ Community Adult Day Center; $_2$ Physician's Office;
$_3$ University Resource Center; $_4$ Assisted Living Facility

* # of living children; ** # of children who preceded mother in death

$_a$ Oldest Child; $_b$ Middle Child; $_c$ Youngest Child; $_d$ Only Child

In nine of the ten cases, mothers and daughters reported that a major event precipitated the current arrangement. In seven of the cases, the recipients' health declined dramatically, necessitating increased care. In three of the ten cases, the death of a spouse (and the family's subsequent concern) was the major event identified as precipitating care.

Recruitment and Contact With Informants

Participants learned about the project from one of four recruitment sites. A total of 17 families inquired about the project. However, through the screening process, it was determined that seven did not meet the study criteria. In those cases, four of the recipients were married, two recipients were unable to complete an interview, and one caregiver was a grandson rather than an adult child. Therefore, 100% of those who inquired about the project and met the inclusion criteria completed the interview process.

Eight of the ten caregivers contacted the principal investigator directly, whereas two of the recipients made initial contact for participation. All interviews were done in person and one-on-one, with each member of the dyad being interviewed separately. In all cases, the caregiver consultation interview was completed first, with the first recipient interview following anywhere from one hour to five days later. Since the recipient of care interview was conducted in two parts, the time between parts one and two ranged from five to 11 days. In all cases, each informant was offered a $10 gift certificate to a local retail store ($30 per dyad). In all cases, recipients accepted the gift card when it was presented as "a token of appreciation for your valuable time and willingness to share your experiences with me". All but one caregiving daughter accepted the incentive.

Interview Sites

In an effort to accommodate various scheduling and accessibility needs of informants, interviews were conducted at a variety of sites. In three cases, all interviews were done in the informants' homes (two cases were co-resident; one included visits to both the ACC's and the RoC's home). In two cases, the recipient interviews were conducted in the home but the caregiver interview was not. In two other cases, the reverse occurred, where the caregiver interview was conducted in the daughter's home and the recipient interviews were done at alternate sites. In three cases, neither interview was conducted in the informant's home. Alternate interview sites included the researcher's office (four interviews), the adult day center conference room (four interviews), meeting rooms at the assisted living facilities (seven interviews), and a caregiver's place of employment (two interviews).

There were benefits and detriments of each site used. One's residence and place of employment allowed for more distractions (phone interruptions, lawn mowers, salespeople, animals) than the researcher's office or a meeting room. However, these settings offered the researcher a unique perspective of the informants' context. In Rita's, Deborah's, and Tina's case, this was especially helpful as their homes offered information about quality of life and daily activities.

The above section introduced the ten cases as a whole, noting demographic similarities and differences across the dyads. The following section offers a review of each case / care dyad, addressing key components of the six research questions – namely care description and system, ecological factors contributing to care and decision making, messages / values about care, and the history of family care and comparison to others' experiences. This format was based on links between the concepts found in the guiding theories and previous literature. Each case begins with a brief description, introducing the reader to both the caregiver and recipient. This is followed by a description of the current care arrangement and related congruence issues. Then data are discussed relative to Family Ecology Theory, integrating ecological factors and decision-making since these were logically interconnected by the informants. Furthermore, although the concept of values is also tied to Family Ecology Theory, based on the data and the way informants discussed this concept values were addressed separate from other ecological concepts. Finally, the history of family care and comparison to other's experiences were addressed collectively as they were linked by informant's experiences of providing care over time and how they perceived other care experiences in their family. Finally, the individual case reviews are completed with a summary and reflections segment. At the end of this chapter, a discussion of emergent themes serves as a form of cross-case analysis.

Family Care Dyads

Family One: Veronica and Karin

Caregiver

Veronica, a 52-year-old African American woman, is single, works full time and has one adult son. Field notes indicate that Veronica is attractive, well educated, and articulate. Veronica, an only child, appeared to be very comfortable as her mother's primary caregiver and spoke fondly of their time together.

Recipient

Karin, a widowed 77-year-old African American woman, lives with her only daughter Veronica. Four years ago, after a sudden physical decline she moved from another state to live with her daughter. Prior to that time, she was retired from paid work but reported heavy involvement in volunteer work, specifically assisting older adults. Karin was pleasant to talk with and responded thoughtfully to questions posed in the interview. She was positive, reflective, and gracious as she spoke about various experiences. She smiled a lot and laughed during our visit as she reflected on little glitches in the caregiving process. She reported enjoying the interviews and asked to give me a hug at the end of our second interview.

Care Description & System (RQ1 & RQ6)

Since Karin's sudden physical decline four years before the interviews, she had been receiving assistance from her only daughter and two in-home aides. Karin and Veronica both included bathing, meal preparation, hair care, money management, laundry, and administration of medication in their descriptions of care tasks. Although their descriptions were highly congruent, Veronica added social time to her list of things she does with her mother. Walks and shopping for fun were included in these activities. Both Karin and Veronica were highly satisfied with the care system and were accurate in their perceptions of the other person's experience with care.

Given Veronica's status as an only child, the in-home aides were heavily involved in Karin's daily care and according to Veronica, "are like family". The two in-home aids work approximately three hours a day, which is split between the morning and afternoon. Karin attends an adult day program five days a week, and the aides assist her in both preparing to leave and in returning home. Although public transportation is provided for Karin to and from the center, the transportation staff does not assist her in or out of her home.

Both Karin & Veronica reflected on the current care arrangements, talking specifically about what they like and dislike about the current system. When asked what she liked most about her current arrangements, Karin reported, "For the arrangements at home, I can't think of anything I would change...and for the things I can't change, I have been able to accept them in a nice way." When asked if there was anything she would change about the current arrangement, Veronica quickly responded, "Absolutely not! I would not have her be any place but with me."

Karin and Veronica had a well-established care system, which was likely a result of the length of time in the current arrangement. Although the arrangement was established when Karin needed significantly more attention, they have remained flexible, adjusting things as needed.

Ecological Factors Contributing to Care & Decision Making (RQ2 & RQ3)

Several ecological factors contributed to Veronica and Karin's current care arrangement, declining health, dynamics among extended family, the medical community, geography, community context, and resources.

Veronica was very clear that her mother's dramatic physical decline warranted increased care. After 35 days at the Mayo clinic, Veronica and Karin's physician agreed that more intense care was needed. Although Karin had a strong support network in her home community, Veronica did not believe that this system would offer her mother what she needed:

> We were still thinking that she would be able to return home and just do stuff with visiting nurses and stuff like that but.... it was really obvious to us that that was not going to work. Their schedules were unpredictable and they can't guarantee that, 'I'll be there at eight o'clock' for example or what ever. They tell you that, 'I'll be there and I'll call in advance' and she didn't know to answer the phone and open the door to let them in. So that system just, it was obvious that it was not going to work for us.

Veronica also believed that her mother's role as a supportive family member put her in jeopardy of not getting what she needed, if she had stayed in her home area:

> [Mom] was the support person for lots of those people. So of course they were fairly reluctant to see her go, almost angry, somewhat belligerent, until anyone of them spent any time with her and could see the way that she was, that she was not the same person. But said, 'Well, we can help you we will step and in the place of

> these other people' and you know I had to just say, 'no'. I had to turn down their requests to be the people....I have....some extended family there but one of them was caring for her dying husband at the time....She of course, had a complete breakdown before that whole process was over and my mother was her support. My mother seeing how upset she was getting made her more upset so I really...that was really the key reason why I had to turn down all these other people's offers.

Veronica reported that her mother had an active role in the decision-making process leading up to her care:

> So, and by then, my mother was saying, 'Whatever you say is fine with me'. It was pretty sudden and she was OK with it. She didn't really know what was going on at that time but during that stage, even though it was quickly passing through that stage, it was with her consent that we went through that stage and onto the next stage.

Veronica reflected on what she believes her mother's decreased involvement means for her:

> I think she's become quite content with not being...My mother was very strong willed and quite the organizer and 'let me tell you how it's done' kind of person. On the other hand, I think it's almost come to be a relief for her. She's tired of that role I think after all these years (laughter).

Karin reflected on other care options that she could have considered, clearly stating her expectations for family care, "It's kind of hard I think if my daughter had told me she was going to put me in a nursing home or a home of some kind because she couldn't find me any of the other help. I would be very disappointed."

Karin reported the decision-making power that she feels she and other program attendees have:

> So that's the thing I really like about this program, they give you a chance to make up your mind even though the caretaker comes in with them, you too can decide. I like that idea, to know what you are getting into and you can decide. I think it's better that way. At least I like it that way.

Messages / Values About Care (RQ2 & RQ4)

There were several key messages that were stated by this dyad, namely care of family members is expected, utilization of formal care facilities would be a "disappointment" and should be considered only out of necessity, and in most cases care is reciprocal. Regarding her role as a recipient, Karin was very clear about her desire to live with a family member, which likely placed her only child in the caregiving role, "It would be hard for me to accept going somewhere else and staying with someone else other than my family and it's almost like grief or death to me." Veronica made a clear statement about her expectations in caring for her mother by stating, "I would not have her in any other place but here. I mean that's... I just wouldn't." Karin talked about the trust she has for her daughter and alluded to the mutually beneficial relationship, saying:

> Mentally I knew it was the best thing for me because I knew Veronica could take care of me. Even though I had to give my house away, I wouldn't be worrying about her worrying about me and she'd be worrying about me at the same time.

Finally, Karin reflected on the messages transmitted over time, "It was just a given, so to speak, that you do those things for your parents. You look after them. The fact that you just do it that's what you're supposed to do. It's like a religion."

History of Family Care & Comparison to Others' Experiences (RQ4 & RQ5)

Several messages emerged about the history of care in Karin's family. She was clear about the importance of taking care of family members, played a significant role in the care of her in-laws, and noted gender socialization in respect to the care of her parents. Reflecting on the messages of care in her family over time, Karin stated clearly:

> It's just a sort of... caring was just sort of cyclical. One generation cared for the next. Whoever was there took care of the next one and it was just a natural thing to do. Whether you wanted to do it or not - you did it.

In a more detailed description of her role as a support person / caregiver to her in-laws, Karin recounts her specific responsibilities:

> It was my job to try to find the things that would get her [my mother-in-law] to possibly rest so I would sit and talk with her about things or do other things to keep her busy….she would try to change the sheets for cleanup or do this or do that. I would do that just to keep her kind of quiet from doing too much around the house"

Karin was able to track filial responsibility back to her childhood, reporting:

> When I was a child, there was usually more than one generation house. It was usually your grandparents or grandfather or grandmother because the people didn't live too far from each other so they just stayed there. There was no choice but to take care of them but because the older person in those days, whether they knew anything or not, they were looked up to.

Karin even attributed the long line of filial responsibility to genetics, indicating in the statement below that they were passed from her mother-in-law to her own daughter, Veronica – without acknowledging her own role in that process:

> She [mother-in-law] was always doing something. She was a very giving person and always giving her services always wanting to do things for people. I think a lot of that I mean there must have been some genes in there somewhere with my daughter because she really takes good care of me.

One aspect of Karin's life that was somewhat unique, but very strong, was the level of responsibility she felt in giving to non-family members, specifically her neighborhood. The following statement reflects this value, specifically discussing it in respect to family loyalty:

> It's just a part of living that we need to take care of each other and especially our own. And if you have enough time you could help other people but so many times you are not able to help as many people as you wanna help.

Karin reflected on an experience similar to hers, noting the importance of resources in family care, by stating:

> I have a friend whose mother lived by herself until she wasn't able to take care of herself and she had someone to come into look after her until she got home from work the same way that Veronica does for me. Now because she had a good job, she could afford to pay someone to come and to look after her mother.

Summary and Reflections

Veronica and Karin had been in their current care arrangement for four years, an arrangement precipitated by Karin's sudden decline in health. Karin's physician played a significant role in the family's decision for co-resident care. Karin was vocal about her expectations for care, adding that she appreciated her daughter's ability to provide care. Karin had provided care to her mother-in-law and reported being more involved in her care than in the care of her own parents.

Although the focus of this study is on family care, this case challenged the limits of those parameters for several reasons. First, the aides hired to help Karin on a daily basis were clearly part of the functional family system, with Veronica stating "they are like family." Other non-family variables emerged as Veronica talked about her role as a community volunteer, reporting that a strong value she holds is related to helping others, family and non-family members. Finally, Karin's position as a support hub for her extended family was challenged when her health declined. Others, namely her niece, depended on her placing Veronica in a position of telling others no. This important yet peripheral conflict has not been addressed by the family care literature. Therefore this case offered much in the way of new directions.

Family Two: Martina and Mona

Caregiver

Martina, a 47-year-old Caucasian woman, is re-married, employed full time, and has two sons. She lives with her husband, two sons, and her mother (Mona). Martina was a petite, soft-spoken, yet energetic woman. She is the youngest of five children, one of two daughters, and reports that she and her mother had the most tenuous relationship over time. Martina reported being new to the caregiver role (just over a year) and admitted to learning something new every day. She reported that her Christian faith and self-care efforts are important resources in her role of caregiver.

Recipient

Mona, a 76-year-old widowed Caucasian mother of five was born in Europe and immigrated to the United States as a young woman. She was very talkative during the two interviews. Several months before our interview, she had been interviewed about an unrelated topic (D-Day), which seemed to weave its way into our discussion. Mona had provided care to her husband for a short time before he died and was able to thoughtfully compare that experience to her current care arrangement.

Care Description & System (RQ1 & RQ6)

Martina assists her mother in a variety of ways, including providing a home, bathing, meal preparation, money management, and socialization. Although her husband and two sons support Martina in some of these tasks, she is the primary caregiver. Martina described the amount of time she spends caring for her mother:

> I would say 20 hours a week is what I would, on average, spend and it's hard for me to put that in a capsule because it is interspersed throughout the day. I may be at the office and make a phone call to change an appointment.

Mona also included bathing and money management in her description of the assistance she receives from her daughter. She also specified that the space provided to her is a primary form of care although noting the limitations of the physical space, "I think they need to find something that I can do because I can't go outside because I can't walk out there because the steps." Mona, as a co-resident recipient, talked about her experience of living in her daughter's home, stating that the arrangement provides some things but also lacks others, "That's fine and dandy but the thing is that this isn't really my home."

Ecological Factors Contributing to Care & Decision Making (RQ2 & RQ3)

Several ecological factors led to the current care arrangement, including Mona's severe fall, Martina's concern about Mona living alone, geography, gender, and prior discussions between family members. Both Mona and Martina described significant conflict leading to the current care arrangement.

Martina reflected on a period of time where she and her siblings avoided the discussion about care, "It was easy to let Mom stay in the house after Dad passed away. It was easy to resist the arguments or avoid the argument that we knew would result from one of us saying, 'you need to leave'." Although the family admittedly avoided the discussion as long as possible, a bad fall was the final event that led Martina to take action. After hearing about her mother's fall and seeing her badly bruised body, she reports:

> I called all my siblings and said, 'It's time. She's coming back with me and if any of you think that she can stay in her home any longer, then you guys come up here and handle it because I can't leave her like this'. And they all agreed that it was time for a decision and that's how she came to be here.

Martina shared her perception of how she came to be her mother's caregiver, specifically in comparison to her siblings, "I think I was the one who was most interested and I don't say that from a, 'yeah me standpoint'. My three brothers all have other things going on that make their situation non-traditional." Martina talked about her role as a caregiver in respect to the brother that she thought would be the logical choice. The concepts of gender and relationship dynamics are alluded to in the following statement:

> She was much closer to the rest of the kids than she was to me and particularly one of my brothers. But he, he doesn't want to take care of his mother and he's so stated, 'I don't want it. I don't want to take care of her. I don't want to be tied down. I don't'. He says that I have more of a capacity for caregiving and I think that's true but I also think it's acquired; you learn how to care for somebody, you learn how to be the things that I'm learning how to be.

Mona talked specifically about Martina's role in discussing care needs prior to providing care, "Martina told my husband and I, 'you'll never be without a home....you'll always have a home'."

Martina and Mona both reported conflict surrounding care decisions, currently and over time. Mona talked about her perceived lack of involvement in decisions leading to care:

> They did that oh, so quickly they didn't really discuss it...Oh Martina says 'you're going back to Michigan'....they didn't give me much time to get anything. I'm still missing some of my stuff – stuff that may not be important to anyone else but it is something I used all the time....I mean and she just got a plane ticket and I thought I didn't have enough time to prepare.

Martina talked about the role that her mother plays in decisions, detailing two examples where her mother had varying involvement:

> The decision of what to do with her house is the biggest one out there right now. And it's the hottest one and she is adamant about not selling the house. And it doesn't matter that is not a practical thing and it doesn't matter how many people are inconvenienced because they have to take care of the property or worry about the property at a distance. She's adamant about that.
>
> She pretty much that goes along with whatever if I make a suggestion in the right way that I don't try to bulldoze her was that she'll at least... like the ear thing's a good example, we butted heads about it she said I'm not doing it and I said, 'OK'.

Martina talked about her perception of her mother's involvement, stating, "I think we always have to reevaluate whether or not she's getting what she needs and she's the best judge of that. She'll tell me what she needs if I'm not giving it to her." Martina reflected on her mom's changing involvement in decisions:

> Now she, she still has a hand in the decisions - that she's happy to turn it over.... she's not as not as questioning as she is about goings on because I think she's come to rely on [my husband] & I. To know that her checking account balance hasn't changed much since she got here so we must be doing something right (laughter).

Messages / Values About Care (RQ2 & RQ4)

Martina reflected on her experience as a caregiver, talking specifically about her previous relationship with her mother and the role that faith has played in their changing roles Martina said, "I still marvel and I just think it's God's way of making this thing become a place of peace for me rather then a place of torment." After having shared that she and her husband bought their current home several years prior, with the thought that it would be appropriate for their elderly parents to live in, Martina reflected the following:

> I think we are blessed that we have a place for her. The alternative is that she would be in a place that I wouldn't necessarily want her to be, that she doesn't really need to be right now. She's not there. And maybe that time will, and it will be difficult to make that decision. But we're not there yet.

Martina also alluded to the desire not to place her mother in a formal care facility, specifying later in the interview that she does not want to ever put her mother in a nursing home.

History of Family Care & Comparison to Others' Experiences (RQ4 & RQ5)

This was not a key factor for this family. Mona lived a long distance from her mom and dad and reports that her sister provided the majority of care to their parents. Although this component was not substantial for this case, some relevant data are included below.

Mona described an awareness of family care but described her role as peripheral, given her residency in another country (than her parents). She reports that her sister provided most of the care to her parents, indicating that after her mother died, Mona's father lived with her sister. In the next passage, Mona describes her own process in the days just before her mother's death:

> My mom got sick I think. Martina was small and she [mom] had a breast removed and I was going to come, I mean go, to see her but she passed on. I would've had to have taken Martina with me because she was only eight months old but my mother passed on.

Although Mona reports not taking care of elderly relatives herself, she reports that her grandmother lived with them for "as long as she can remember," going on to say, "All I know is that we only had two bedrooms in our house – my mother and dad in one and my sister, and I, and my grandma in the other one." Mona had minimal reflections as to how her experience compared to others in her generation or her family. The one reflection she made was in comparison to her husband's care. She said, "of course I'm a lot older than my husband was. My husband was 67 or 68 and had been active all of his life."

Summary and Reflections

At the time of the interviews, Martina and Mona had been engaged in co-resident care for just over a year. Mona had five children, and although Martina was the youngest and reported being least connected with her mother, she was the primary caregiver. Mona had moved from her home in another state, which she still owns. She reports that the transition was abrupt, saying she had little say in how the move happened. Martina approached the caregiving role as a challenge, reportedly using self-care efforts (spirituality and the five minute rule) regularly. In addition to living together, Martina and Mona shared the home with Martina's husband and two adult sons.

A key observation from the interviews, relative to the current arrangement, was that Mona had difficulty adjusting to living in someone else's home. Although she reported getting everything she needed, in terms of necessary aspects of daily life, her wants were not being met. Her daughter noted this dissatisfaction but possibly misinterpreted it as a resistance to care rather than difficulty adjusting to a new living context. This may be a result of established relationship dynamics (misunderstanding one another from years of conflict) rather than a complication of care.

Gender socialization seemed to be another key factor for this family, at least among the sibling sub-system. Martina noted the difference in the parent-child relationship between she and her brother. She framed caregiving as a choice and an acquired skill, reporting at first that her brothers had "non-traditional" circumstances, but finally concluding that (at least) one had chosen not to be their mother's caregiver.

Family Three: Leda and Bernice

Caregiver

Leda, a 54-year-old married Caucasian, employed mother of three, was very articulate and business like in our interview. She brought all of her mother's medical paperwork with her and referred to it three times during our visit. She was quick to say that she does not take complete care of her mother, who lives in her own home. However, Leda assumed management of her mother's health care three years ago, following her mother's diagnoses of lymphoma.

Recipient

Bernice, a 72-year-old widowed Caucasian mother of three, was timid and reserved during our interviews. She reported current care of her 20 year old, live-in nephew who has cognitive limitations. As she described it, they offer assistance to one another with various daily needs. Bernice had provided care to several family members and while reflecting on her role as a caregiver to her grandmother, Bernice became tearful.

Care Description & System (RQ1 & RQ6)

The primary assistance described by both Leda and Bernice included management of medical paperwork, physician visits, and medication handling, and they agreed that this care arrangement has been in place for three years. Leda has four siblings, one sister who is involved from a distance, one brother who is uninvolved and at a distance, and "two other siblings that live here in Lansing, that are males, and so they've kind of stayed out of it as well." Leda reported that she keeps all of her siblings up to date on their mother's care, namely sending them paperwork to document what is happening.

In addition to including herself as the primary caregiver, Leda reported that her mother's 20 year-old, live-in great-nephew Eli, functions as a secondary caregiver. She reports that Eli is there daily to be sure her mother has what she needs and to "nag her about her meds." Leda also reports that she and Eli communicate on a regular basis to be sure all aspects of her care are covered. It is important to note that Eli has lived with Bernice for most of his life and that he has both received care from and provided care to Bernice. The level of congruence was high on most accounts, outside of Leda and Bernice's reports of Eli's involvement. Leda reported that Eli was a resource and partner in caregiving, whereas Bernice reported a more unilateral relationship characterized by her caring for him.

Ecological Factors Contributing to Care & Decision Making (RQ2 & RQ3)

Several factors led to Leda and Bernice's current arrangement, including an inaccurate diagnosis by a physician three years prior, Leda's position as the oldest child and gender, and Bernice's long-time care of her great-nephew. Leda reports her perception of the role sibling position played in her selection as caregiver, stating:

> It was always assumed, I'm the oldest. So, and, you know, I just pretty much have, have always taken care of everything here cause....I'm the oldest, and I've just always handled everything that needed to be handled.... And I've always been closer to my mother.

When asked if she or anyone else ever challenged the rule that the oldest should provide care, Leda commented, "Nope, you just kind of assumed the responsibility (laughter)!" Bernice discusses her daughter's flexible work schedule, as well as her perception of her daughter's reasoning for providing care:

> She's fortunate that she can get out from work when I really need something because otherwise who knows. She has driven me back and forth to Ann Arbor and that was an all day session. Well, she wants to take me all the time....it just, kind of happened she lives close by...and she's just that type of person, she wants to.

Leda discussed her mother's role in decisions and talked specifically about barriers in their communication about Bernice's health care,

> "She's afraid to report certain things to me, because she's afraid that she's going to get put in a nursing home (pause) you know, she doesn't want to lose her freedom."

Leda provided the following description of how she and her mother breach conversations about her mother's living arrangements, specifically noting the influence of her mother's loyalty to Eli:

> I've been on her for a couple years that I think that she really would benefit, all of her friends have died, so she doesn't have any friends anymore and....I said, 'you know if you moved into one of those apartment complexes where they have bingo and they have all these social things going on, I think you'd really be happy'. But she really carries the burden of responsibility for my nephew.

Like Leda, Bernice acknowledged the role she plays in Eli's life, reporting that her decision to change her residence would be heavily influenced by his needs, "But I don't know where Eli would go. He and his family don't get along too well… So, that's part of my decision."

Messages / Values About Care (RQ2 & RQ4)

Leda and Bernice had a long line of care in their family. Bernice specifically had been heavily involved with family care of elders, beginning with her grandmother. Bernice became tearful when speaking about the importance of care in her family:

> It's just that you did what you had to do. There was no one else by my mother, my….my sister died first and then eight months later my brother died, so I was the only one that could take care of my mother. It was more or less, you just took over because you had to, and you wanted to. Same way with my husband, I mean I wasn't working at that time when he got sick so I just took over.

Leda and Bernice were aligned on their views regarding formal care. Leda reported, "I mean I haven't had to think about putting her into a nursing home or anything, and I hope I don't have to think about that for a while." Whereas Bernice said, "I don't know. The first thing they do is start looking for a home for the old lady. Now Leda isn't looking for a home for me to go to, but she's looking for one of these apartments"

History of Family Care & Comparison to Others' Experiences (RQ4 & RQ5)

Bernice reported an extensive history of care involvement, having cared in some capacity for her grandmother, mother, aunt, and husband. In each case, she was heavily involved with daily care tasks and became tearful when reflecting specifically on caring for her grandmother:

> Back there, I don't know whether they did have walkers, but I know I had to hold onto her and walk her to bathroom. And this one time, she, she kind of froze, and she stood there and said she couldn't go, and I wasn't anywhere close to a chair where I could pull it over for her, so, it, it was different back then when you cared for somebody. She's a very shy person, and I to wash her and dress her and everything…(beginning to cry).

Although subtle, Bernice made reference to family care norms or expectations, specifically in regard to family loyalty and gender, reporting:

> She was 94....she had a, a son-in-law who was taking care of her in a way, his, his wife died....he promised his wife that he would look after grandma. So he was taking care of her for, my gosh, 10, 15 years. He found a place for her to, to live, and he looked in on her all the time, which it was really unusual....I used to go down there once-in-a-while, sometimes I'd stay 4 days and take her to have her done and things like that take her to the grocery store.
>
> My mother got ill. I got, I was working at the post office, I worked over 20 years and my mother got ill, she had heart trouble, and I took a leave of absence and went to Toledo and took care of her before she died.

Bernice added that she also cared for her husband, "In the end, my husband got, well I don't know, he had a little bit of everything. He had heart trouble, he had a little bit of everything...So I had to care for him."

Summary and Reflections

Bernice was highly independent, continuing to live on her own and drive. Not only was she able to manage her own daily needs, she was actively providing co-resident care to her nephew Eli. Bernice's daughter, Leda, provided specific care tasks surrounding management of medication and health care matters. This care arrangement was established after Bernice's diagnosis of cancer and difficulty coordinating physician's visits and related information. In respect to the role of her daughter (as opposed to her other four children), Bernice indicated that Leda wants to help and has the easiest work schedule for assisting her. Although Leda agreed that Bernice is highly independent, she reported concern about her mother's social isolation. She had talked with Bernice recently about assisted living, but Bernice resisted this idea, indicating that was just one step closer to nursing home care.

In addition to care tasks, Bernice and Leda talked about their relationship beyond care. They both reported maintaining social activities they have engaged in for years, namely going to the theater. Leda alluded to the benefits of this for herself but mostly framed the positives in respect to her mother's needs.

This case challenged the conceptualization of this study in that Bernice was a recipient of care as well as a caregiver to a younger family member. Since Eli had lived with Bernice most of his life, she reported a strong filial obligation to continue caring for him. Although a physical condition keeps him from establishing his own home, it appeared that Eli helps Bernice in certain ways. Bernice did report concern about what would happen to Eli when she is no longer able to manage her/provide him a home.

A key observation from this family was a history of difficult elder care. Not only had Bernice cared for her husband and mother, she also cared for her grandmother. Bernice reported that these were difficult times but at the same time rejected the idea of nursing home care.

Family Four: Dena and Vera

Caregiver

Dena, a 49-year-old Lebanese mother of one, is the primary caregiver of her mother. She is employed full-time and lives with her mother (Vera) and only son. She has three siblings who have minimal involvement in the caregiving system. Dena was quick to tell me that she is a guest in her mother's home, even though she does provide her care. Dena seemed scattered during our interview, and field notes indicate that she was isolated from community resources.

Recipient

Vera is a widowed 88-year-old Lebanese mother of three. She was pleasant, talkative, and forthcoming during the interviews, although she did not respond directly to all questions. She was conflicted about her physical decline and the limitations she felt came with such decline. Vera spoke of the strain that her honesty (not wanting to live without a purpose) placed on her relationship with her daughter, Dena.

Care Description & System (RQ1 & RQ6)

Dena and her mother share a home and both report that care involves housework, laundry, meal preparation, bathing, and money management. In addition to the daily tasks provided by Dena, Meals on Wheels frequently provides lunch. Beyond that resource, there was minimal community assistance used by the family in support of care. Dena talked about her concern regarding the current arrangement, talking specifically about the amount of time her mother spends alone, "When she's sitting here alone, she thinks of my dad, and there's no way to bring him back. I have to be at work. I don't think she should be here alone so much." Vera was by far the most vocal participant, regarding her dissatisfaction with her current state. She was clear that her arrangements were adequate for her needs but also expressed displeasure in general. Her description of her current situation was as follows:

> I'm better here. I'm under one roof. It's me. I'm holding back. My daughter can't leave and take a vacation, because I can't travel any more, so how does that make me feel. Everyone around takes a vacation – goes somewhere. I'm not up to it anymore. I'm past it. The doctor went through all of this. There's nothing he can do. What's the difference? I'm not really depressed – I know what I'm saying.... I don't need a psychiatrist. I've talked to doctors more than once. In other words, I'm a pain in the neck.

When asked what she would change about her current care arrangement, Vera said, "A different social life, and close to friends. It's different here – there's no one here."

Ecological Factors Contributing to Care & Decision Making (RQ2 & RQ3)

Several factors led to the current care arrangement, specifically the death of Vera's spouse combined with her failing health, advice from Vera's friends, the meaning of Dena's position as a female in society and her family, along with reportedly unspoken assumptions about care.

In the following segment, Dena talks about the role her father's death played in the change in Vera's care arrangement, "He [my dad] was looking after her because she was the frailer of the two and then he became frail. Then when he passed, we went up for Thanksgiving and then he died in December." In sharing her perception of what led to her decision to move into her current arrangement, Vera stated:

> My daughter said, 'You have no one here. Who's going to help you?' My friend of twenty-five years – a young woman.... told me that I needed to go to my daughter's and not stay up north. So I owe my decision to my daughter.

In Dena's explanation as to why she became her mom's caregiver, gender was specifically identified:

> I always knew I would be my mom's caregiver. There was never a question. Always there. It just seems more appropriate for a daughter more than.....my brother and I had talked a little, you know. It's just more appropriate for a daughter to give. To give baths and things like that.

Interestingly, Vera reflected a very different gender message than her daughter, stating, "She [my mother] stayed with the boys, but she came to stay with us too. As a rule, mothers stay with their sons." Supporting the lack of congruence between Vera and Dena regarding gendered expectations and the history of care between mothers and daughters, Dena reflected on how she came to be her mother's caregiver, "Hardly discussed it, never discussed it. My mother took care of my grandmother, and I always knew that I would take care of my mother." Dena also talked about how various life stages/circumstances have affected her role as a caregiver, "Well, I think if I had been married now, it would have been more complicated looking after my mother. Being divorced, I've been free to do what I wanted."

Dena reflected on how she and her mother address decision-making. She seemed to be thinking out loud when she said:

> Well, I think, she should have a decision about what she wants. I'm not so sure I always include her because I'm so scattered that I might be making decisions without asking. Which is wrong....I told her that if she wants to go live somewhere else, she can. I'll sell my house and go live somewhere else and when the money runs out, she can figure it out. She has it in her mind that she can make all the decisions.

Messages / Values About Care (RQ2 & RQ4)

Vera reported a long line of filial responsibility stating, "Our background is doing. Without a big flair – you just do." Dena talked about both her and her mother's wishes in regard to formal care. She reflected on the experience of an extended family member, who was placed in a nursing home:

> We both hope that neither of us end up in a nursing home. My poor uncle, a bachelor, took care of a farm and doggone if they didn't get him into emergency and then into a nursing home. Poor man – I know he wanted to run away.

Vera spoke in general, and matter of factly, about the rules of family care, reporting, "You don't leave someone alone. You don't leave anyone alone. And you don't leave anyone without food in the house or without clothes." In respect to monetary, specifically government, support Vera talked about beliefs she has held throughout her life, stating:

> No way would I take help from someone. Absolutely not. It offended me. It wouldn't take much for medicine that I buy to get help. There's no way I want help. I worked and my social security has supported me not my husband's.

Despite reports of stress, conflict, and difficult times, Vera reflected on the benefits of care:

> I just love having my mother with me. I love my mother. We've been very close and she's always been my best friend. Every day she's with me I consider a blessing. I don't think she sees it that way.

History of Family Care & Comparison to Others' Experiences (RQ4 & RQ5)

Vera was both involved in elder care across her life, and specifically talked about caring for her mother. This care was done in the context of Vera needed some assistance, just following her divorce. Vera's needs and her mother's health decline seemed to make a natural progression:

> My mother helped me ....I put my children into day care. I learned to drive. It had to be done. I worked whatever I could without pestering my mother. She had a heart attack and was in bed for about 6 months, so I really had to take over.... I took care of my mother for ten years.

Vera reflected on the things that happened while caring for her mother.

> I would come back and call her at home and my mother wouldn't be at home. I'd be calling everywhere to find her. Then when I found her, then I'd scold her, "Do you know what you made me think? That you were lying on the ground somewhere?" And she'd laugh. She'd say, "I had to get out."

Summary and Reflections

Dena and Vera had been in their current co-resident arrangement for about a year. In the years prior, Dena had provided assistance to both her mother and her father as they resided in an assisted living facility about 200 miles from Dena's home. Both Dena and Vera reported that their religion and related rituals were central to life. With respect to decision making, Dena indicated that her mother's role in decisions was very important. Vera, although she brought it up and then adamantly denied it in the interview, exhibited signs of depression. She questioned her purpose in life and found the long days and nights painful (both physically and emotionally). Dena was overwhelmed with her full-time job, the management of the house purchased for the care arrangement, and general care of her mother. Overall the system was strained and although she wanted support, Dena did not have any strategy of how to address the difficulty.

Dena and Vera had the most involved care arrangement, with Dena assuming approximately 95 percent of the care responsibilities. Interestingly, both Vera and Dena were the least content, of all dyads, with their situation.

Family Five: Abigail and Beulah

Caregiver

Abigail, a 52-year-old, recently widowed, Caucasian mother of one, does not work outside the home and is the primary caregiver to her mother, Beulah. Abigail was soft-spoken yet open about her experiences. She reported that the current care arrangement is very good, but not without a long and difficult history. Despite some assistance from her aunts, Abigail reported that being the only child makes things difficult at times. She clearly stated that visiting with residents at her mother's retirement home was a social benefit for her.

Recipient

Beulah, an 80-year-old Caucasian widowed mother of one, lives alone in a retirement center apartment. Beulah was pleasant to talk with and was very curious as to why anyone would be interested in interviewing her. She said several times, "I hope I am telling you something that is helpful". She has two younger sisters that, in addition to her only daughter, provide assistance. However, she reports that her daughter, Abigail, is most involved in her care. Beulah expressed concern about her daughter, Abigail in light of recent death of her husband.

Care Description & System (RQ1 & RQ6)

Abigail talked about the role of her aunts (Beulah's sisters) in her mother's care. She noted the differences in their involvement, stating:

> Well, she has two sisters that live in the area. One is barely around, she doesn't really participate unless I need assistance and call her. You know, if there's something that I can't do, for whatever reason, and I need someone to help me, she will help me, but she doesn't voluntarily come around. I don't know why.

Abigail also noted her own expectations regarding her aunts' involvement, "I don't expect them to do doctors and things that I can do. I'm not working so, you know, I can do that." Noting some of the benefits of her role in care, talking specifically about some of the adjustments she has gone through since her husband's death, Abigail stated, "It's easier for me to do a lot of her things that I'm used to doing than some of this stuff of my own that I'm not used to doing."

Beulah talked about some of the social limitations of her current care arrangement, stating that she does not get to spend the time with her daughter that she would like, "So she really doesn't sit and visit with me, unless we go out to lunch or something like that, you know I don't get much chance to visit with her."

Ecological Factors Contributing to Care & Decision Making (RQ2 & RQ3)

Abigail laughed while pondering my question about how she came to be her mother's caregiver. It seemed that her status as an only child elected her automatically, but as she spoke, she seemed to reach another conclusion, "there's not much choice (laughter)...pretty much, just, you know, I'm the one, and, and I guess, that I, you know, I guess you can always have the choice to still not to do it, but I wouldn't do that."

Abigail and Beulah talked at length about their decision making process, revealing some distinct perception differences as to who made decisions about the current care arrangement. Abigail reported that her mother made the decisions, right down to the very building she is in at the retirement home. On the other hand, Beulah reported that her daughter took over the decision making. Abigail said:

> She just didn't want to do anything anymore, have any worries, and she wanted to have somebody around all the time, which was a good choice I felt....and this is where she wanted to come, this particular building.

Beulah described the following process:

> I was having an awful time, they were trying to figure out what to do about me, and you know, and....I couldn't do anything, for myself, I wasn't eating and I wasn't taking my medicine...So, she looked into the nursing home, or the, retirement home and I didn't get, I didn't look into them or anything. She just took right over and did it all and they decided that this was the best one and so that's how come I come here.

Beulah alluded to her preferred decision making process, where others will anticipate what she needs and then do it for her, without her asking:

> That really made me feel good, to come home and have somebody do that for you. You didn't have to ask them you know because I don't like to ask... I don't want 'em to think I'm taking advantage of them.

Abigail talked about her mother's decision-making ability, her tendency to defer to her mother at times, and specific examples where her mother's decision-making process made things easier on Abigail:

> She didn't want to drive again, so that made it easy for me to not have to discuss whether or not she should drive anymore, and so I was kind of glad that I didn't have to ask for her car keys either.

In regard to her mother's overall decision making, Abigail said, "She's, she's pretty sound of mind. I mean, as far as usually, decision making" adding that she deferred to her mother on one major decision, "She only sold [her house] 2 years ago, but....we just let her make the decision when she wanted to do that."

Messages / Values About Care (RQ2 & RQ4)

This family shared very little information about specific care messages or values. However, Abigail noted the changes in caregiving roles over time stating, “I think eventually we're all going to need some kind of help, and, just hope, you know, that I can be there as much as possible when she needs things”.

History of Family Care & Comparison to Others' Experiences (RQ4 & RQ5)

Beulah reported that although her parents had monetary resources and died within three months of one another, they both lived to be 94 and needed some level of care, “my brother really handled most of it, but it, the way it was done, everything was divided up evenly....we just really did a good job.” Beulah describes the role her father played in the care of his step-mother, noting relationship difficulties that preceded, but did not hinder, caregiving:

> The step-mother was never good to my dad. In, in-fact after she married my grandpa, she wouldn't even allow him to live with them, so, and then to turn around and my dad had to finish taking care of her so that was quite a thing, you know that my dad did.

Beulah's family care history seems to reflect an anomaly in regard to gender. In both of the above examples, males were the primary caregivers to elderly parents. Although this is not unheard of, her father's care of his step-mother is especially unique.

Beulah reflected on the differences between she and her sisters regarding care, “as far as a my sisters, they've got husbands yet to help them.” In one of very few statements comparing her experiences to others, Beulah said, “Sometimes there's so much jealousy between families that they have, they run into trouble but we don't. We never had any trouble.”

Summary and Reflections

Abigail, an only child, had been providing care to her mother for about three years. She assisted her mother with tasks such as money management, grocery shopping, and laundry. Both Abigail and Beulah reported care assistance by Beulah's sister but mostly in the social realm (i.e. taking her out to dinner). Abigail spoke about both the benefits and detriments of providing care to her mother. She reported that spending time at the center and knowing her mother had what she needed were both benefits to her personally. Beulah reported deferring decisions to her daughter, saying that it was just easier and time to do so. Beulah reported wanting more social time with her daughter.

A number of things stand out about Abigail and Beulah. First, when asked how long she had been assisting her mother, Abigail replied, "28 years – ever since my dad died." However, I was aware that Beulah had been in the assisted living facility for three years. It is likely that when Beulah went into the center, Abigail's care tasks decreased somewhat, as prior to that time Beulah owned her own home. However, I had a glimpse of what Abigail was talking about as she described her mother's health history as plagued with emergency room and rehabilitation visits.

Interestingly, Abigail and Beulah reported very different perceptions about what the establishment of the care arrangement entailed. Abigail reported that her mother led the effort, even selecting the very building she lives in. In contrast, Beulah reported that Abigail made all of the arrangements, specifically saying that she had never visited the center before moving in. Despite the lack of congruence about the conditions under which current care arrangement was established, both Abigail and Beulah were content in their roles. This contentment may have been related to the element of reciprocity.

Abigail had recently lost her husband, she reported a sense of isolation, and demonstrated normative bereavement. Her role as caregiver seemed to offer a great deal, as she talked about enjoying her visits to the center and reporting that it is easier to take care of her mother's business than her own. Furthermore, Beulah reported a strong sense of empathy for her daughter, indicating that she had been through a similar loss. It was interesting to witness the caregiver role as a source of enjoyment or comfort, rather than an added stress during an already difficult time.

Family Six: Carrie and Deborah

Caregiver

Carrie is a 36-year-old, single, Caucasian mother of two, whose sources of income include in-home day care and compensation she receives from the state to provide care to her mother. Carrie lives with her mother, Deborah, her two young children, and her partner in the home in which her mother resided for many years. Carrie has two sisters who help with medical emergencies but not on the "everyday stuff." Carrie reports providing co-resident care for the past 19 months.

Recipient

Deborah is a 76-year-old mother of three, who lives with her youngest daughter, Carrie, her two grandchildren, and her daughter's partner. Deborah has Parkinson's disease and is recovering from a recent hip replacement (three months prior to the interview). She was extremely soft spoken but alert as she spoke about the care she receives from and provides for her daughter. For six years, Deborah had been the primary caretaker of her husband who had Alzheimer's disease.

Care Description & System (RQ1 & RQ6)

This family's system included Carrie as the primary caregiver, with her two sisters playing important but very different roles than Carrie. This case was unique for several reasons – at 36, Carrie was the youngest caregiver in this study. Furthermore, Carrie and Deborah were one of two dyads that resided in the recipient's home. Finally, this situation was unique in that Carrie received payment, from the Tri-County Office on Aging, to care for her mother. In the following statement, Carrie describes the roles she and her sisters play in their mother's care:

> Those sisters have power of attorney over her; they make the final decisions on my mom; they need to know what's going on. The other thing is, they're older – like 13 and 16 years older than me. So, I'm just the baby.

Carrie emphasized how different her role is from her sisters. With a contentious tone, Carrie described how her sisters change when their mother is in the hospital, "They're up there saying, 'Well, mom's not with it today.' And I say to them, 'Well, girls, she has her good days and she has her bad days. She's never going to be perfect, you know?'" Carrie talked about how, because she has a child, it is difficult to be at the hospital all the time. She seemed frustrated when she explained that she is the one who is there every day, but the doctors and nurses do not see that when her mother is hospitalized.

In contrast, Deborah described a balanced care system, including all three of her daughters in the following statement:

> Carrie stays with me to help me and then one of them takes care of all the bills and the other takes care of all the doctor's appointments and all that kind of stuff. Kind of spread around. If I have to go to the doctor's, they all go with me.

Deborah said that she likes her current care arrangement, reporting, "Well, I like it, because it gave me a chance to stay home."

Carrie, having done in-home day care, had difficulty with the conflicting roles of caregiver and child care provider. In the following statement, she describes her line of thinking and conclusions about resources and her role:

> I couldn't get a job because I have to be with her, you know? I heard that you could get paid to be home with their families, so – they had an aide coming in all the time. And I'm thinking, 'Why can't – if I have to be here – this aide is supposed to be giving me this 2-hour break. I have to be here anyway, why shouldn't I be the one getting paid for this?'

Ecological Factors Contributing to Care & Decision Making (RQ2 & RQ3)

Several factors led to Carrie and Deborah's current arrangement: Deborah's fall resulting in a broken hip, her diagnosis of Parkinson's, the timing of Carrie's lease ending and need for a new residence, and Carrie's desire to keep her mother from living in a nursing home. In the following statement, Carrie addresses her desire to protect her mother from going into a nursing home:

> I said to my sister, 'What if I don't want to live here with Mom?' [she said] 'Well, we would make other arrangements for Mom and she would probably have to go to a home or something'. I can't do that....I'm the one who made the decision to be there all the time. Even though I was living on the other side of the state, I decided to come home and live....If I had the money to go out and find a place to live, I could, but then Mom would have to go back to the nursing home. And I don't want that.

The following two statements reflect Deborah's role in decisions. In discussing the decision to put an older sibling as power of attorney, Carrie said:

> I don't think she asked any of us. She just put her down and we didn't talk about it. Apparently if Mom was to have an attack and wanted to be left to die, and I'm like, 'You know, well, you can't just pull the plug.' And I say, 'Can't we make that decision when that comes, why do we have to make it now?' I spoke up.

Deborah was very clear about what role she sees herself having in decisions, saying, "I make decisions. We discuss....But I feel I have a say in those decisions."

Messages / Values About Care and History of Family Care (RQ2, RQ3, & RQ4)

The primary message from both Carrie and Deborah was the strong desire to avoid nursing homes as long as possible. Not only did Deborah talk about her fear of nursing homes, she also reflected a similar value in the care of others, namely her husband and her father. Carrie was closely aligned with her mother regarding nursing care and seemed to have made some sacrifices in her own life, just so her mother would not be placed in a nursing home. Carrie said:

> I don't like her to be in a nursing home, but in some way when she was in the nursing home this winter, I found that I was coming and going and had some freedom, and then all of a sudden she came home and I didn't like it....I don't want to take care of her – I get pretty down and depressed about it.

A similar value is reflected in the story of Deborah's father. She reported:

> He [my dad] could go home as long as someone was there that could help him. His wife done most of it, but we all helped as we could, and I at that time and point I lived here, so, I tried to get up every-other weekend and, and help take care of him....clean the house, do dishes, do shopping.

In the six years Deborah cared for her husband, she avoided placing him in a nursing home, even putting herself in danger as a result. "The doctor wanted to put him in a nursing home and I said I just can't do it, a day will come when I have to but I can't do it right now." Alzheimer's disease had affected her husband to the point where he was physically harming her. Deborah reluctantly made the decision to place him in a nursing home, and he died one week later:

> I took care of him. It was bad because he was, mind, a lot of it was gone you know, he didn't know one day to the next and you'd feed him lunch, or, I remember feeding him lunch one day and I had him in here in a hospital bed and came back in to pick up the dishes and he just started cussing at me, and, 'My God, don't you ever feed anybody around here?' and he just, I didn't even get out of the room yet, with his dishes, but things like that, and he, he just, he'd runaway, he ran away once, and we combed the neighborhood, and the neighbors helped, and we finally found him at a little restaurant up here (inaudible) oh, there was some moments. I didn't think I'd make it through all that. I think that bothered me most, I couldn't ever get away from the house unless someone was here.

Deborah talked about visiting her husband in the nursing home and she said that he had a moment where he looked at her, remembering who she was and asked, "why did you put me in here?" Deborah told me that she started to cry, showing him her black-and-blue arm where and said "Carl, I couldn't take care of you anymore". She reported that he looked at her and said, crying, "I had no idea that I had did that to you, I'm so sorry," and a week later he died. She became tearful in talking about the difficulty around the decision to place him in a nursing home. She also articulated a sense of pride in the amount of time she took care of him.

Summary and Reflections

Carrie and Deborah had been engaged in co-resident care for just less than a year. This arrangement was reciprocal in that both Carrie and Deborah benefited from the shared residence. Deborah was able to stay in her home and more importantly avoid nursing home care. Carrie was able to avoid eviction as well as help her mother evade nursing home placement. Although Carrie was Deborah's primary caregiver, her two older sisters helped their mother in more formal ways (e.g. power of attorney). Decisions about Deborah's care involved all three daughters and Deborah. Carrie reported a sense of frustration with her sisters' sporadic involvement. Finally, Deborah had engaged in care of her husband for six years. Her involvement was intense, and she was proud of the role she played in his care.

Since Deborah has Parkinson's disease, her needs may have seemed more noticeable or tangible than other recipients. In my opinion, Deborah's needs included at least an obstacle free floor and secure chairs. Her home offered neither and in addition, was visibly dirty. Field notes indicate that care needed did not seem possible, given the current arrangement.

The most notable message that emerged from interviews with Carrie and Deborah was the strong desire to avoid nursing home care. Not only did Deborah report appreciation for being able to stay in her home, Carrie stated that her primary motivation for moving in with her mother was to keep her out of a nursing home. This value appeared to span across generations, with Deborah reportedly providing six years of intense care to her husband, all to avoid placing him in a nursing home.

Carrie, the youngest of all caregivers, talked about her employment difficulties relative to her caregiving role. She reported that one small solution was receiving support from the local Area Agency on Aging but also indicating that this resource did not match her efforts.

Family Seven: Sandy and Anna

Caregiver

Sandy is a 51-year-old Caucasian, employed, mother of two adult children. Sandy was eager to visit about her caregiving role, and since she is new the role (11 months), she was interested in ways to connect with other caregivers. She has three siblings, who are involved in various ways with her mother's care, but not to the extent that Sandy is.

Recipient

Anna, an 82-year-old, widowed, mother of four recently moved to Michigan to be near her daughter, Sandy. Anna was extremely positive about her new arrangement and spoke excitedly about her residence and the activities there. She had minimal reflections about family care as she spent much of her adult life living outside of the United States.

However, she did provide care to her mother-in-law after she moved in with Anna and her family. She also reflected on her role as a peripheral member of caregiving systems for her parents and an elderly aunt.

Care Description & System (RQ1 & RQ6)

Sandy is the primary caregiver, and although she is the most involved, many of Anna's needs are attended to by the staff and the retirement home. Sandy describes a common occurrence, which characterizes her role as caregiver:

> She feels cared for and secure there. It gets boring. She feels confined. And, and, I'll call her up once-in-a-while and I'll say 'do you want to come home' and she'll say 'Yes (very emphatically), (makes exasperated sound) I need some fresh air.' I say 'okay, I'm coming to get you'

Anna reported being content in her apartment and with her current care but said, "I wish, that my boys were able to come and visit. They, they just can't. They're both working and can't get away and they have family to take care of, and so, I, I miss seeing my other kids."

Sandy was very concise about how she approaches caring for her mother, "I just simply take care of her, her needs, whatever she needs or wants." Sandy was very proud of her role and her record of attending to things over the past year without calling on her siblings, "I can call on them, but I haven't yet, in a year's time.... I was *determined* to prove to my siblings that this was going to work out just fine."

Ecological Factors Contributing to Care & Decision Making (RQ2 & RQ3)

Three primary factors led to the current care arrangement – the death of Anna's husband/Sandy's father, Sandy's state of residence, and her socialization and consequent desire to provide care. Sandy reported that decisions leading to this arrangement were made several years ago, not only talking about her role but also her older brother's position in the family, "Because of my nature, mom and dad made me the health care advocate officially, and they signed papers, that I would be the health care advocate for the family." adding "He's [my brother's] the power of attorney because he's the oldest."

Sandy insightfully acknowledged her socialization to care, noting that the history of missions work in her family and her gender were key factors. She talks about her role over time as she comments, "Well, whenever there has been a need in the family, I'm the one to provide the solution. I never hesitate to provide the solution, because that has been what I've learned."

Messages / Values About Care (RQ2 & RQ4)

One strong message that emerged was the theme of giving back. Sandy reported that this message was communicated through actions over time, and she had adopted this value. She talked specifically about her desire to give back to her mom while also reflecting on how her mother gave to the children and her spouse:

> when we, the kids weren't around to take care of anymore then she turned and took care of them, and he became very used to being taken care of, all his life, she feed him, put his pills down when he needed to take 'em, absolutely took care of him to the nth degree, and now she has no one to look after except herself.

Sandy reported checking in with her mother about the role she plays:

> I'll walk over to her lean over her and give her a kiss and say, 'is your daughter being too fussy for you', and she'll say 'I like it, I like it, it's okay' and I say to her, 'you know, we've never had a chance, you've always taken care of us and if you don't mind - I don't mind' and she said, 'I know you don't mind.' She can tell that I don't mind, because I don't.

Although Sandy provides a significant amount of emotional and functional support, Anna reported that, "They've [my children] always said if need be, they would always send money." It is important to note that Anna knows this resource is available, despite Sandy's wish not to use it unless absolutely necessary.

History of Family Care & Comparison to Others' Experiences (RQ4 & RQ5)

Anna reported minimal involvement in family care, struggling to think of examples where elderly family members had been cared for by younger generations. However, as she reflected, she described her involvement in both her mother's and her mother-in-law's care:

> I can remember shortly after we were married, my mother came down with what must have been either very bad cold, but it was really more like pneumonia, and I was so worried about her that I finally got on a Greyhound bus in Massachusetts, and went back to Michigan and my dad picked me up and took me home and I stayed for two weeks.
>
> I never actually had an adult member live with me except for my husband's mother, after his father died, came out [to the country we were living] for a year to live with us....she didn't have a good heart....I helped her wash her hair for instance, because she couldn't do that.

Anna shared other family care arrangements, indicating that her lack of involvement was due primarily to geography (living in another country):

> My dad was doing almost everything for my mother because she had Alzheimer's, and she couldn't cook, he had to hide all the knives, hide the salt or he couldn't eat what she tried to cook, it was quite a task for him.

When her father needed assistance, Anna's brother became the primary caregiver, "He continued living in that house until my brother persuaded him that he had to sellout and come and live in a retirement community near him."

Summary and Reflections

Sandy was one of four children and one of two daughters. When Anna's husband passed and the family was concerned about her needs, Sandy was eager to assist her mother. Sandy's role in her mother's care was not a surprise to anyone, given that the siblings had discussed care arrangements prior to the need. Anna's care involves money management and medical assistance (e.g. medications and physician visits). Both Anna and Sandy reported that spending time together was important. Sandy reported a sense of role reversal and reciprocity, wanting to give back to her mother.

Sandy and Anna, although relatively new to the current care arrangement, appeared comfortable in their roles. Sandy was especially pleased with the level of care she provides her mother, without the support of her siblings. She reported feeling strongly about not asking for their help, which I felt was unique compared to other families. Whereas some siblings quarrel over individuals doing their part, Sandy was reveling in being able to do it alone.

Another key message that emerged was the relationship that Sandy and Anna have, beyond the care arrangement. Both talked about enjoying their time together, citing their weekends at Sandy's home as a source of enjoyment. Furthermore, Sandy reported that her mother had cared for her and other family members, noting it was her turn to receive care.

Family Eight: Idah and Rita

Caregiver

Idah is a widowed/remarried 68-year-old, Caucasian mother of two adult children. Idah has been retired for two years, and although she spoke of her own health concerns, she appeared healthy and much younger than her chronological age. She reports that although she has three siblings, she is the primary caregiver of her mother, Rita. Idah reported frequently partnering with her own daughter in the care of her mother. Idah was articulate and enthusiastic about sharing her experiences, seeming very content in her role as caregiver.

Recipient

Rita is a 92-year-old, Caucasian mother of three. She has been receiving care from her youngest daughter for 21 months, after moving from her home state of 48 years. Rita was alert and very easy to talk with, despite her difficulty hearing me initially. She answered questions directly and clearly, smiling a lot. Rita reported minimal activity with individuals at the center, choosing to read and watch TV instead.

Care Description & System (RQ1 & RQ6)

Idah and Rita gave similar descriptions of the care system, indicating that Idah with support from her daughter (Rita's granddaughter) is the primary caretaker. Rita indicated that in addition to the support she receives from Idah, she utilizes some services at the retirement home (e.g. cleaning service). This family was one of few that overtly addressed the issue of monetary costs of care. Idah reported that, if the current arrangement continues, her mother's savings would be gone in approximately 18 months. In an effort to make this money last as long as possible, Idah reported supplementing that savings by buying her mother's groceries. She indicated that spending a little here and there is easier than paying for all of her mother's care in the future. Although Rita did not express a concern about her money running out, she did indicate that her other daughter provides financial support in leiu of other types of care:

> My other daughter up north in, in Newago has emphysema very, very bad. So, the only reason she can't do (sic) is because of that. But, she does send me a check about once a month, so that helps too (chuckles). Her part of it you know.

Ecological Factors Contributing to Care & Decision Making (RQ2 & RQ3)

Several factors contributed to the existing arrangement for Rita, Idah's good health (compared to her sister), Rita's status as a widow and declining health, geography, lifestyle factors of Idah's brother, and Idah's history of providing care. In the following statement, Idah reflects on the process that led to her mother coming to be near her:

> She started falling, it was two, three times she fell....and just little things. We, we could see what was coming, and my brother lived two hours away from her, but he didn't get up there as often as I got there from Michigan, and my brother's quite a bit younger than I am, he has three, well right now three college-aged children, they're all three in college.

After deciding that something needed to change, Idah reports what the next steps entailed, "My daughter and my husband kept saying, you know, you're going to have to move her here. So finally my daughter and I just started looking around without saying anything to my mother." After making the decision that her mother should come to Michigan, Idah talked to her siblings and other family members:

> I just told them we were coming down and, and that's what we had to do. Take the bull by the horns and go with it. And they all agreed, you know, they didn't, they knew it had to be done too, so. We had no problem with anybody.

Idah reflects on what the experience of adjusting to the current care arrangement may have been like for her mother:

> It was hard for her to come but I think she just made up her mind, and I told her that we could look for a place down there and my brother could be the caregiver, but his wife has elderly parents to, so she, I think knew, or she would have to come back up to Michigan.

In respect to decisions, both Idah and Rita reported collaborating. Idah noted a change in her mother's involvement, surprised by how often her mother defers to her:

> Her and I talk about anything that, that involves her. And, uh, she'll say 'what do you think', (chuckles) she's always made her own decisions. In fact, when my daughter and I and my sister moved her up here, we thought she would be a little more independent than she is. She really relies on me now, to do everything....I don't know, I guess because I kind of took over some things then, she's just really more dependent on me than she was. But, but I discuss anything with her.

Rita noted, "I think it's 50-50 really. You know what I mean? We do all the, talk things over, and decide whether we should or shouldn't, you know." Rita also reported making a key decision about her current arrangement, "I made up my mind to be satisfied regardless, you know, of anything, and I, I'm happy here though"

Messages / Values About Care (RQ2 & RQ4)

Both Idah and Rita were very matter of fact about family care values. Although neither of them talked at length about this topic, the following two segments capture key messages in their family:

> Well, it's, it's just one of those things, to me, you just naturally do it. People need it, and that, you just naturally do it. It's like Idah doing it for me. Of course, my other daughter would to, if she was able to.

Idah reflected on her role as a caregiver over time:

> Somehow, through my life I've been everybody's caregiver (laughter).... my husband and....were caregivers to his mother, his sister helped out to though. My first husband, who's deceased, he had a...my kids always called her grandma, and she was like an aunt, but she was really no relation, she raised my first husband.... when she got elderly somehow I took care of her and her aunt...I don't know how I get in to this (laughter). Somehow I'm always the one that's around and able to, I guess.

History of Family Care & Comparison to Others' Experiences (RQ4 & RQ5)

Rita and Idah both talked about the role of family care over time. As previously mentioned, Idah stated she had been involved in the care of several elderly family members. Idah also reported that her mother cared for both her husband and her father. As Idah reflected on her mother's role in the care of her grandfather, she seemed to hypothesize why her mother didn't ask for co-resident care, "She had my grandpa for years, he lived with us, and so she never really mentioned coming here and staying."

Rita didn't talk much about her role as a caregiver to her father but shared some information about the decade of care she provided to her husband. Rita said:

> He had Alzheimer's for 10 years....I took care of him all on my own, yeah. 36 hours a day ....you know they didn't have any support groups then...the only place I could leave him was a place that's down in town it cost me $10 an hour and I used to leave him there if I had to go to the dentist or things, when he got bad....Outside of that, that was all the help I ever had.

This role was not questioned, likely due to Rita's belief that care of the elderly is "just something you do" and that it comes "naturally".

Summary and Reflections

Rita and Idah had not been in their current arrangement long. However, Idah had been assisting her mother from a distance for several years (flying back and forth frequently). Although Rita lives in an assisted living facility, Idah tries to do all she can to eliminate added expenses, assisting her with bathing, money management, and medical appointments. Idah noted that if her mother continues to live at this level of need, she will outlive her resources in 18 months. Idah was concerned about her mother's lack of social involvement at the center. However, Rita reports maintaining her normal activities (e.g. playing with her cat and watching tv). The decision making system included Rita but not necessarily at her request. She reported a level of contentment in having Idah take over.

Rita and Idah were the oldest informants in their respective roles (recipient and caregiver). However, the care arrangement was more recently established than in other dyads. Key observations included financial strain, multigenerational support, and a significant shift in the process of making decisions. Both Idah and Rita talked about the limited monetary resources available for Rita's care, indicating that her money will "run out" in 18 months. Idah talked about supplementing her mother's financial resources by buying things "here and there", in hopes of extending her financial options.

Another key element for this care system was the involvement of Idah's daughter / Rita's granddaughter, Hannah. Both Idah and Rita were clear that Hannah is heavily involved in her grandmother's care, namely in supporting Idah. This example illustrates the transmission of family care values in more tangible ways than in other dyads. Finally, Rita was very clear about her decision to be happy with the current arrangement. When asked what role she plays in decisions about her care she felt an adequate amount of involvement but added that the most important decision was choosing to make the best of it.

Family Nine: Jana & Tina

Caregiver

Jana is a 51 year-old, single, African-American mother of three adult children. Jana is also a grandmother of three. She works full time in the human service field and articulated both a personal and professional interest in this project. During our visit, she appeared to be responding much more like a professional in the field, rather than from a daughter's standpoint. It was clear to me that her training was an asset to her family and specifically to her mother. However, I found it difficult to ascertain the depth of her experiences as a daughter.

Recipient

Tina is a 72 year-old, widowed, African-American mother of four, grandmother, and great-grandmother. Tina described a number of recent transitions, some resulting from declining health and others for familial reasons. The most notable adjustment came after her experience of being financially exploited by a family member. Before moving to the retirement center where she currently resides, she was living in a sub-standard apartment with this family member. She reports that she was simply "trying to help this person".

Tina was candid in our interview, talking about how she leans on her three children for different things. She postulates that her daughter, Jana is most helpful with the things she needs but that her "fun time" comes when her other daughter visits. Tina is very active in center activities and highly social with other residents. She takes great pride in knowing everyone and helping them in some way.

Care Description & System (RQ1 & RQ6)

Jana and Tina described similar care tasks, including some meal preparation and medication management, but primarily overseeing finances. Although Tina has three children, she and Jana agree that Jana is her primary caregiver. In the following statement, Tina talks about the unique relationship she has with her other daughter:

> I have another daughter (Dava) that comes from out of town. She lives in Georgia, and she really comes up to see about me almost every month, and so when she does, she flies up, she has to rent a car, she'll take me out, we'll go shopping, we'll go to movies, we'll go to dinner....that's when I have my fun.

Jana agrees that her mother's time with Dava is much different than the time she spends with her. Jana reported having to "clean up" after one of Dava's visits claiming to hold the role of stickler in regard to her mother's health.

Ecological Factors Contributing to Care & Decision Making (RQ2 & RQ3)

Several factors precipitated the current care arrangement, namely Jana's financial and emotional security, formal education related to the elderly, sibling position and gender, along with her own daughter's role in Tina's financial exploitation. Tina's history of depression and tendency to cycle in and out of sub-standard living arrangements also seemed to contribute to Jana's hyper vigilance.

When asked if anyone else assists her, Tina said:

> Not really….he's [my son's] got to be working towards retirement. Now Dava has really given up a lot to help me. But you know, sometime her and Jana, because Jana'll say 'you could take care of a little bit more' and I tell Jana she can't, she's not making the money your making, you know, and I said, 'you can of get by with a little more,' but see I had a little problem that's why they have to use some money.

This statement supports the idea that Tina sees Jana as most fit to provide her care. Jana expressed frustration and struggled to understand why her siblings are so quick to abdicate their responsibility:

> I was always accommodating everybody else's needs and wants, you know…. so, if anybody should have issues it would be me. But, you know, you've got to put that aside because she's got needs….somebody's got to tend to them….and he [my brother] has four kids and his wife helps my mom but you know, she's busy…. they don't have to deal with it….He's in grad school right now so, you know, he's busy, well we all are busy.

Jana compared her involvement specifically to her brother's, "so for [him] to say, 'well, you know, when I get around to it,' what if I say, 'when I get around to it'? She'd be up a creek."

Jana reported her hopes for her mother's involvement in decisions, stating, "I'm trying to give her the dignity of maintaining as much control over situations as possible and she's choking me. And so, like I said, she went and spent the last dime, the last dime, has not one penny." noting that it is difficult to step back after her mother makes poor choices. Jana also acknowledged her role in decisions, stating, "I moved her here, because I got tired of flying, to her home for the emergency of the week or the month." Jana also reflected another element of self care in talking about the consideration of co-resident care, "I knew that she could not live with me. It just wouldn't work" adding that their relationship would have suffered.

Messages / Values About Care (RQ2 & RQ4)

There were two primary messages about care in this family, the consistency of daughters providing care to their mothers and the level of conflict between siblings. Both Jana and Tina had contributed to the care of their mothers. Both valued care of others, pursuing professions that served the elderly or the unwell, and in both cases their training helped them provide care. However, the difference between them is that Tina did not have any siblings (her only brother died at a very young age), whereas Jana has a brother and two sisters. Jana reflects a primary message of conflict between she and her siblings in the following statement, "I'm getting resistance from siblings that are critiquing from miles away....she praises them to no end. That's what really gets to me. She praises them to no end and they don't do anything!"

History of Family Care & Comparison to Others' Experiences (RQ4 & RQ5)

Tina reported losing her father at a very young age but maintaining a close relationship with her mother until her death. When her mother needed additional care, Tina reports having moved her into a nearby apartment and providing her with daily assistance (e.g. grocery shopping, meal preparation, laundry):

> I had lost my husband, so....I had my own apartment with my own children, but I would go over and help my mother. I didn't have a car but I would see that she had her food, her groceries, and then, like I said she was of a different religion, so I had one of the ladies to come in with her and do cleaning, but she always says 'nobody does things like you do', you know. So I would cook for her and do whatever I could for her, you know, buy her clothing that she needed and anything like that.

Interestingly, just as Jana's profession is closely aligned with the support she provides to Tina, Tina's training as a nurse aided her in the care she provided to her mother. Tina described how the care of her mother overlapped with her schooling:

> I didn't finish because my mother came down with diabetes and I didn't know she was a diabetic, and she had cancer of the pancreas, so I went, I stopped to take care of her and my doctor said, my mother's doctor said, 'Tina, are you going to finish school'. I said, 'no I was only going to help her so she'd have money'. I said, 'I'm getting a good income,' I said 'I don't need the money' at that time I didn't need it. I said, 'I only wanted to help her, so she could have things' and uh, he said, my, my average was 4.0, he said, well, you know, he says 'you may not get your degree, but you have already proved yourself to be a nurse' you know. And I said, 'well that may be good in nursing stuff, but I have to see about her first' and she didn't last too long.

Both Jana and Tina were proud of their professional knowledge and how it assisted them in their caregiving roles. Tina even acknowledged her daughter's professional knowledge, reporting, "she's taught all my children different things, you know."

Summary and Reflections

Jana and Tina had been in the current care arrangement for about 18 months. Jana assists her mother primarily with money management, taking care of all of finances. Tina, a diabetic, also receives assistance from Jana with her medical care. The current care arrangement was implemented out of necessity for Tina's health and safety. Although Jana reports that her mother could likely live alone, her decisions warranted concern. In addition to this support, Jana seems to be hyper vigilant about Tina's social activities, reporting that Tina's other daughter can disrupt the consistency in her life. Jana reported consistent conflict with her siblings with regard to their mother's care, often wondering what would happen if she "stepped down" from the caregiving role.

Jana was the most vocal of all the participants about her level of frustration with the caregiving role, reporting that the distribution of care tasks was inequitable between her and her siblings. A primary factor leading to the current care arrangement was the recent financial exploitation Tina experienced. Although Jana did not reveal who exploited her mother, Tina revealed that it was Jana's daughter. I suspect that the level of care provided by Jana is partially a result of rectifying what her daughter had done.

Finally, this dyad was unique in that the recipient's mental health was a factor in her care. Given Tina's diagnosis of manic depression many years ago, she has had mental health resources in the community. These resources have continued into her current care arrangement, and both Tina and Jana report that these resources are invaluable.

Family Ten: Dora & Donna

Caregiver

Dora is a 54 year-old, married, Caucasian mother of two and grandmother of two. Dora is a health care professional and works long, concentrated shifts. She reported some professional knowledge of the caregiving process, but she remained primarily in the role of daughter during our interview. Dora is an only child and reports never thinking twice about her role in assisting her mother. She was clear that care was just something that her family offered to one another, something that Dora learned specifically from her maternal grandmother.

Recipient

Donna is newly widowed, Caucasian, and had turned 80 just before our interviews. She reported receiving minimal assistance from her daughter, talking more about the time they spend together as enjoyment. She reports that her current arrangement was needed because of her late husband's declining health, not her own. She appeared to be independent, active within her retirement home community, and still drives her own car.

Care Description & System (RQ1 & RQ6)

Dora reports assisting her mother with some personal care tasks (e.g. bathing), money management, and social time. Although Donna did not perceive herself receiving assistance from her daughter, she did tell me that Dora helps her clean and manage her "business." Given this perception, the women's reports of the care arrangement were fairly incongruent.

Ecological Factors Contributing to Care & Decision Making (RQ2 & RQ3)

Several factors influenced the details of Donna's current care arrangement: her late husband's declining health and her "near death" experience, Dora's position as an only child and relationship with her grandmother, and the recent death of Donna's husband. Although Donna had difficulty describing how her daughter helps her, she did acknowledge that when she moved into the assisted living facility it was a result of both her and her husband's declining health. Although her husband recently died, at the time they moved into the center Donna experienced a near death experience. She reports that her own health concerns and her temporary inability to care for her husband, necessitated the move and their daughter's assistance. She said,

> I wasn't physically capable of doing it anymore and the house was becoming a big burden to keep clean. We just, so I (pause) one day Dora and I, I had talked to Tim [my husband] about going into an independent living situation, and where we could have meals prepared for us and this just fit the bill.

Dora reported being very close to her grandmother, who taught her the value of caring for others. Dora said, "I loved her so much and when she needed care, I wanted to help because of what she taught me and showed me, to love other people."

Messages / Values About Care (RQ2 & RQ4)

Both Donna and Dora talked about the natural act of caring for family members. Donna said, "It was just, it, it just seemed natural, and maybe that's why it's so hard to recall." Dora became tearful as she talked about the love in the family, she said, "mom did a great job with dad, you know, helping him and taking care of things...my daughter gets it from her just like I did from my grandma."

Donna went on to say that the level of care was constant in her family, noting that everyone helped everyone, despite their age. She said, "If anybody was hurting physically, we were in the hospital. If they were financially in trouble, we were always there to supply, to help supply their needs." Dora shared a similar message saying, "I was close, really close to my grandma. She was the one who taught me about taking care of family....and even though mom and I have had our bad times, she knows I will take care of her, take care of things."

Interestingly, Dora told me what she anticipated about her own late life needs, noting that caregiver selection had already taken place in younger generations:

> You would love her, Whitney (pointing to a photo of her youngest daughter), she has such a great spirit; you can just see it in her. She is a lot like my grandma was, so kind and giving. I know she'll be the one who takes care of me...not that my other daughter wouldn't, it's just, Kate's made for it.

Finally, Dora was very clear that her relationship with her mother extended beyond the provision of care. She stated this clearly by saying, "I get to do the fun things, like sort yarn....anyone can be her caregiver but only I can be her daughter."

History of Family Care & Comparison to Others' Experiences (RQ4 & RQ5)

Overall, this family served in a number of care roles. Dora provided care to her grandmother, her father, and now her mother. Donna reports providing care to both her mother and her husband. Donna had difficulty talking only about care of older family members. She reported that care of family members was central to her family's survival, since she had three siblings with extensive health problems. She also reported that most elderly relatives were very self-sufficient:

> I can remember the concerns for what will happen with the boys. As far as the elderly people in my family, my mother's parents lived next door to us for years and years. And before they built that house next door to us they had just lived a block up the alley on the next street over. So, but they were very independent too. ….I can remember my great-grandparents on my father's side and they were, they were independent they live alone until they died. And then the grandparents on both sides lived alone.

Donna added a reflection about her mother's care:

> My mother was very ill. So [another family member] was there to take care of the house. Everything just happened. Nothing was a planned thing. The Lord just saw that the right people were in the right place at the right time.

Summary and Reflections

Donna and Dora have been in the current care arrangement since the death of Donna's husband about seven months prior to the interview. Although Dora (an only child) had assisted both of her parents, the current arrangement includes care only to Donna. Donna's health had changed significantly in recent years. At the time of the interview she was doing well, still driving on her own, and did not need as much care from her daughter. Dora assisted her mother with some care tasks but tried to focus her time on being with her mother. Both women reported that Dora's daughter also assists Donna with certain tasks. Both women were clear that care was something that was central to family life and that there was no question about providing it.

Both Dora and Donna reported two primary aspects of their family, reciprocity and socialization of care. Both had provided care to other family members, young and old alike. Donna's experience of having three disabled siblings led her to provide care early in life. Later experiences of caring for her mother and her husband continued the legacy of care, which Donna reports came very naturally. Dora had a similar reflection, that the desire to care comes from a spirit or value, not an obligation. Both reflected some sense of value in providing care, demonstrating an element of reciprocity.

Emergent Themes

When reviewing the data collectively, several themes emerged. Some related directly to the research questions, while others did not. The themes that were most prominent from this case study data included: immediate need for care, fear of nursing homes, expectations for family care, gender socialization and previous familial roles, contentment with caregiver role, and a shift in the decision process. Selection of emergent themes was based on saturation and the fact that themes emerged in more than half of the dyads. It is also important to note that range of emergent themes was defined by theory and that utilization of other theories may have yielded different themes.

Immediate Need for Care, Related Transitions

In nine of the families, care was necessitated on very short or no notice. These recipients required immediate physical care and needed alternate living arrangements within a matter of days. In some families, primary caregivers were concerned for a period of time before care was implemented. However, the establishment of the current care arrangement happened quickly and frequently involved the recipient moving several hundred miles. Despite the urgency of the situation, recipients and caregivers hoped to avoid nursing home care.

Veronica and Karin's arrangement was a good example of the urgency for care. Karin's health declined so rapidly that she went from coordinating volunteer events to losing her memory and use of her legs in a matter of days. After a month in the hospital, without much improvement, Karin's physician talked with Veronica about permanent arrangements. Just after being released from the hospital, Karin moved to Veronica's home which was 800 miles from her own.

Mona's situation was similar to Karin's in that a medical emergency led her family and physician to decide that living alone was no longer safe. Mona reported that her transition into her daughter's home happened very quickly. Martina bought her a plane ticket and it was done. She moved more than 500 miles from her beloved home, which she still owns and where her husband's ashes are placed. Mona reported that keeping her home is important to her and that this desire is a point of contention between her and Martina.

After losing her husband and being unable to manage daily household tasks, Rita moved 1,700 miles to live with her daughter. Rita indicated that the home she had lived in for 50 years was listed and sold within a week. She wished she had more time to pack and say good-bye, but indicated that she was able to adjust. Rita did report that although her family wanted her to get rid of all of her furniture, she insisted on returning some specific items.

The urgency surrounding the need for care often required dramatic adjustments on the part of caregivers and recipients. Many daughters and other relatives seemed to dominate the care relationships. Although this support was needed by the recipient, it often negated the recipients' role in decisions about the sale of their home, what belongings to keep, or where they would move.

Gender Socialization and Previous Familial Roles

The majority of informants alluded to the concept of gender, with most messages emerging in comparisons between themselves and male relatives. Although this theme related primarily to caregivers, three recipients also reflected gender messages.

When reflecting on how they came to care for their mothers, more than half of the daughters reported that they had been socialized or raised to be nurturing. Three daughters specifically reported that gender guided them into the caregiving role, as opposed to their male relatives (namely brothers). Caregivers who had siblings often added that their mother received assistance from each adult child but maximized individual strengths. Several daughters felt that being socialized as a nurturing female led them to provide more intense care and to be attuned to their mothers' needs in general.

Martina shared a conversation she had with her brother who said he did not want to provide care to their mother. She asserted that his rationale was that she (Martina) was better equipped to provide elder care. Martina indicated that the ability to provide care is learned and that she was learning along the way. Bernice reported that her daughter, Leda, found herself in the caregiving role because she wants to provide care, adding that Leda's work schedule lends itself to care. Interestingly, Bernice saw this as a result of convenience rather than a deliberate effort by Leda to assist her mother. As an observation about Leda's work schedule, in our interview she wore a pager and two cell phones and reported working 13 hours the day before. Finally, Dena was overt in the meaning gender had relative to care. She reported that her whole life was to take care of her mother and that care of mothers by daughters was more appropriate than care by sons.

A related theme was that more than half of the caregivers had provided care to other family members. Some reported embracing this role throughout their lives, while others were unsure (and humored when asked) how they repeatedly found themselves in this role. For example, Idah reported (laughing) that she has always found herself in this role. She went on to list five individuals for whom she had provided care, indicating that she is just good at providing care.

Expectations for Family Care

A common theme from both caregivers and recipients was the expectation for elder family care. Although this may seem implicit to this study, the simplicity or seemingly obvious nature of this theme warrants discussion. Whether a result of avoiding less desirable arrangements or a long history of care expectations, such values were evident for each dyad. Caregivers and recipients alike reported expectations for family care or filial obligation. For example, Karin clearly stated that she would have been disappointed if her daughter had considered other care arrangements. She also added that care is cyclical and that it is something that you just do. Donna explained how difficult it was to reflect on family care because it was so central to how her family interacted. Carrie struggled with the conflict of having a "normal" life and providing care to her mother. She was disgusted with her sisters for not offering family care options for Deborah. Finally, although she was the most independent of all recipients, Bernice reported that family care would be the only desirable option, adding that she believes families are too quick to send the elderly to nursing homes.

Avoidance of Nursing Home Care

Overwhelmingly, recipients and caregivers agreed that nursing home care was to be avoided at almost all costs. Only two informants reported that nursing home care would strain them financially, while all informants indicated it would be a personal or lifestyle decision not to consider nursing home care.

Specifically, Bernice and Deborah spoke clearly about their desires to avoid nursing home care. Bernice reported not wanting to move into an assisted living facility for fear that it would be a step toward a nursing home. She also reflected on several negative experiences of elderly relatives, leading her to conclude that nursing homes are completely out of the question. Deborah reflected her gratitude to Carrie for moving in, as it was the only way for her to avoid being placed in a nursing home.

In most cases, recipients' desires to avoid nursing homes were supported by caregivers. For example, Leda was grateful that she had not had to think about nursing home care and reported wanting to avoid it at all costs. Idah hoped that as her mother's needs changed, the assisted living center would continue to add resources so her mother would not have to move into a nursing home. Carrie validated her mother's report, indicating that had she not moved in, her mother would have gone to a nursing home. Carrie was explicit that this was her primary motivation for providing care.

Contentment with Caregiver Role

Eight caregivers reported a clear level of contentment in providing elder care. Although some talked about the strain or related lifestyle shifts, stress was not the predominate message. Instead of a focus on stress and strain, caregivers reported a comfort with their role. Several talked about cherishing time with their mothers, seeing this role as a natural extension of their relationship.

Veronica, Leda, Dena, Abigail, Sandy, and Dora all reported enjoying time with their mothers and furthermore wanting to maintain the mother-daughter relationship.

Veronica noted that she enjoyed braiding her mother's hair and taking walks with her. Leda made a concerted effort to continue socializing with her mother, maintaining the activities from years prior. Dena, although the most overwhelmed caregiver, noted that her mother is her "best friend." Sandy spoke fondly of the weekends that her mother comes to stay with her. Although she reports that these weekend trips are respite for her mother (from the center), Sandy talked at length about how much she enjoys this time. Dora gave the best example of how she defers to her role as daughter, not allowing the caregiving role to overwhelm her. She reflected on a time when she and Donna were sorting yarn, adding that only she can be her daughter.

Shift in Decision Processes

Seven recipients reported a shift in how decisions were made during and after the establishment of care. Although one of the assumptions of this study was that elderly family members unwillingly give up their decision making power, this assumption was not supported by these data. These recipients clearly reported making a conscious decision to defer power to their daughters (and other family members). Although recipients appeared content with this transition, three caregivers were discontented by this change. Caregivers wanted to assist in maintaining their mothers' independence in any way possible and continued to include them in decisions.

Anna, Rita, Beulah, and Karin clearly reflected contentment in deferring decision making power to their daughters. Rita and Beulah both made a conscious decision to relinquish this power, reporting that at "their age" it was time. Karin indicated that she trusted her daughter and that she was happy to turn to Veronica. Veronica, on the other hand, was concerned about her mother's contentment, seeming to characterize it as a lack of independence. Like Veronica, Idah was concerned about her mother's lack of involvement and wondered if her own ability to step in led to her mother's lack of participation.

The emergent themes served as a form of cross-case analysis and reflected the points at which data reached saturation. Although each case had unique characteristics, some common messages emerged. Most of the themes related to the original research questions. However, the urgency of care, deliberate avoidance of nursing home care, and the shift in recipient's decision processes were not linked to the original research questions but emerged as important, reoccurring themes. Research question number one (current care arrangement) was developed to glean how dyads described their arrangement. It was not expected that precipitating factors would include the urgency and warrant significant geographical moves. It was expected that families would reflect on their options (RQ 1 & 2) considering ecological factors and decision making. It was not expected that the overwhelming majority of recipients and participants would explicitly report their desire to avoid nursing home placement. Furthermore, it was not expected that families would go to such lengths to avoid nursing care. Finally, in respect to the decision making process, research questions two and three were established. Although these questions were developed to better understand the decision making process and the recipient's role, the recipients' level of contentment with decreased involvement in decisions was not expected.

Summary

The findings of this study were presented in two parts, ten case summaries linked to the original research questions and emergent themes. Families were unique in some ways but also reported overarching themes. The results of this study have implications for future research, the fields of family science, gerontology, and specifically marriage and family therapy.

CHAPTER FIVE: DISCUSSION

Introduction

The purpose of this study was to explore the experiences of elderly recipients of care in the context of informal care dyads. This study aimed to understand the experiences of recipients relative to family caregiving from both a current and historical perspective. A particular focus was placed on the process that led to the current arrangement – ecological influences and the decision making process. This study was designed to examine the current care system as well as the history of family care – namely the recipient's role in and perception of care over time. The purpose of this chapter is to reflect on all aspects of this study – anticipated and unanticipated findings, the theoretical framework and previous research which informed the foundation of the study, methodological insights, suggestions for future research, implications for family science and specifically the field of marriage and family therapy, and my general reflections.

Key Findings

Several key findings emerged from the semi-structured interviews, some linked with the original research questions and some that were new to the conceptualization of this study. Each is linked to the previous literature and offers a foundation for future research. Key findings include the role of the primary caregiver and congruence issues, ecological factors, decision making processes, and history of family care. Each finding includes additional sub-findings and is described below.

The Role of a Primary Caregiver and Congruence Regarding Care Tasks

> "I always knew I would be my mom's caregiver. There was never a question. Always there. It just seems more appropriate for a daughter more than…..

> my brother and I had talked a little, you know. It's just more appropriate for a daughter to give…to give baths and things like that." ~Dena

This key finding relates to research questions one and six. Current arrangements included tasks ranging from management of medical paperwork to co-resident care. Although there was a wide range, most dyads acknowledged weekly or daily assistance of some kind. In all cases, recipients received assistance with IADLs, namely management of medical affairs or money. In six of the cases, daughters assisted their mothers with personal care tasks (e.g. bathing). Recipients and caregivers were highly congruent in their reports of care tasks. The details of the care arrangement support previous research, specifically the role of daughters in the care of mothers. Harris (1998) reported "that mothers do not select sons as primary caregivers because of their concern for modesty" (p. 343). Since more than half of recipients received assistance with bathing, this supports research indicating that daughters are more likely to provide care to mothers.

The current care arrangements described in this study closely align with previous research on elder care. Cicerelli (1992) and Ingersoll-Dayton, et al (2003) report that although family members often collaborate in the care of elderly family members, a primary caregiver can be identified in most cases. In each of these families, an adult daughter was both self-identified and named by the recipient as the primary caregiver. These care systems also were characteristic of others described in the research in that they included additional members, both family and non-family.

Ecological Factors

> "I get to do the fun stuff, like sorting yarn. It may sound corny but it's important to me, to keep on laughing with her, to keep creating memories. Anyone can do her laundry, only I can be her daughter." ~Dora

Several ecological factors led to the current care arrangement and the process of family interaction around care. Crises, caregiver selection, gender, reciprocity, relationship beyond care and fear of nursing home placement were central to the dyads' processes. The data discussed below addresses research question two and integrates key findings from chapter four such as the immediate need for care, fear of nursing homes, and gender socialization.

In nine cases, one event precipitated the current care arrangement. Although more than half of daughters already were assisting their mothers in some way (even at a distance), seven dyads reported that a sudden decline in health led to the current arrangement. As mentioned previously, several recipients required added assistance as a result of the death of their husband, contributing to the decision for care.

One element that emerged was caregiver selection, or the process by which the adult child perceived that she became a caregiver. Several either explicitly stated (some with pride) that they were socialized to provide care or alluded to such a process. Seven made reference to or alluded to gender as a primary factor, comparing their involvement to male family members. Both of these findings support previous research, that gender and previous experiences in providing care are predictors of the caregiving role (Cicerelli, 2000; Piercy & Chapman, 2001; Ungerson, 1987).

Five caregivers talked about the desire to give back to their mothers, for the care that they had received over time. Four caregivers reported that they gain something from providing care to their mother. These data support the idea that reciprocity, as discussed by Lewinter (2003) and Treas & Mazumdar (2004), is an important factor in care systems. Specifically, caregivers described deferred or immediate reciprocity (Lewinter, 2003). The most commonly described form was deferred, where caregivers saw their activities as a way to pay their mother back for the years of care.

Another ecological factor included the benefits of the current care arrangement (e.g. immediate reciprocity), that spending time with their mother or even having something to do (e.g. caring for someone) was a valuable aspect of their role. Four caregivers reported that no one else was there to take over, leading them to conclude that their mother would have gone without care if they had not stepped in. In addition to the limited number of familial resources, two caregivers discussed the limited number of other resources (e.g. unpredictability of visiting nurses, limited monetary support), leading them to conclude that family care was the best option.

Although related to reciprocity, the relationship between mothers and daughters was mentioned somewhat differently than through giving back. Six daughters spoke of their relationship with their mother, beyond the role of caregiver. This finding was not linked to the six original research questions but does relate to existing information in the caregiving literature. It is important to note that in these cases, the care relationship was not unilateral as often assumed in the literature. This widely held assumption supports Treas & Mazdumar (2004) in their statement, "In family roles, older Americans are widely perceived as care recipients, rather than caregivers" (p. 107).

In four cases, both the mother and daughter talked about enjoying their time together. Several researchers (Bleiszner, Usita, & Mancini, 1996; Fingerman, 1996) discussed mother daughter relationships in the context of care, some asserting that care relationships are conflicted. However, Bleiszner et al (1996) claim that existing dynamics prevail in care relationships and caution scholars not to attribute conflict to the care relationship itself. In several cases, daughters talked about continuing to engage in social activities with their mothers. Mona talked about knitting with her mother, and the uniqueness of the mother daughter relationship. Veronica reported setting aside time every week to share with her mother, outside of care tasks. Sandy spoke fondly of bird watching with her mother and although her mother's sight has diminished, they have shifted their focus to flowers. Leda and her mother have had tickets to the local performing arts center for decades. Leda reported that this activity was important one-on-one time for her and her mother and that she hoped to continue this tradition for many years. The deliberate efforts of caregiving daughters to maintain an element of the existing relationship relates to Horton & Arber's (2004) assertion that carers are concerned about protecting the parent-child relationship.

Although caregiving daughters were more deliberate about setting aside time to be with their mothers, the recipients also talked about enjoying this time. Leda's mother, Bernice, mentioned the performing arts tickets, saying that this was an enjoyable time for just her and her daughter. Sandy's mother, Anna, talked about enjoying weekends at her daughter's home. Veronica's mother, Karin, reflected on how much she enjoys taking evening walks with her daughter.

Although these findings seem to be related to the reciprocity literature, they varied enough to discuss them separately. Although daughters talked about a mutually beneficial process, it still appeared somewhat unilateral. These activities seemed to be linked to the role of caregiver rather than the role of daughter (e.g. the care was out of concern for the mother). Although this distinction is subtle, it is an important dynamic and may unveil a new element of caregiving research.

Another ecological factor that contributed to decisions about care arrangements was the pervasive fear of nursing home care. All ten dyads (caregivers and recipients alike) shared the expectation that nursing homes were a last resort. Although I did not expect informants to say that they wanted to go to/see their parent in a nursing home, I was surprised at the efforts families employed to avoid such placement. Not only did caregivers push themselves beyond their ability to care in order to avoid nursing home placement, several recipients articulated a clear expectation that nursing home care would be a disappointment.

Carrie reported that her decision to move in with her mother was solely to avoid nursing home placement. Carrie was upset that her two older sisters would consider placing their mother in a home and felt that the only way to avoid it was to become a co-resident carer. Bernice reflected on the experience of a great aunt who lived in a nursing home, saying that the residents were heavily drugged and just waiting to die. Although Bernice was one of the most self sufficient recipients, even caring for her nephew, she reported thinking that her family was planning to place her in a home. Her daughter, Leda said she hoped that time would never come. Rita reported moving from her lifelong home in Florida to Michigan, to avoid isolating placement. Even though she resides in an assisted living facility, she is connected with her daughter and has a steady stream of visitors, making her current arrangement different than what was available "back home".

Although this value was articulated by most dyads, in two of the cases I believed that the level of care needed extended beyond the abilities of the caregivers. For example, in Deborah and Carrie's home there were several pieces of furniture that were unstable as well as various tripping hazards (e.g. multiple small animals, toys, blankets on the floor).

Given Deborah's diagnoses of Parkinson's disease, these hazards were especially concerning to her physical safety. Vera and Dena seemed to struggle with a different type of issue, mental health and general satisfaction. Vera exhibited signs of depression, and the family appeared to be isolated from resources. Although Dena acknowledged her mother's state, she reported not knowing where to go for help. Secondly, the care being provided by Dena appeared to be straining her immensely. Although Vera's mental health was not a primary concern in and of itself, her level of isolation combined with Dena's management of daily life (e.g. being overwhelmed) was.

Decision Making: Role of the Recipient & Lack of Congruence

"I guess because I kind of took over some things then,
she's just really more dependent on me than she was." ~Idah

In respect to the current care arrangement, crises played a significant role. When care was implemented, it was often at a time when the recipient was unable to actively participate in decisions. In four cases, after the recipient recovered, the care rarely changed and often exceeded the needs of the recipient. It is important to note that there was a disctinction in the data between the decision making process that led to the care arrangement and the decision process since the care arrangement was implemented. Brubaker, Gorman, & Hiestand (1990) reported that a recipient's perception of his/her involvement and control in care decisions is related to stress level. The greater control one feels in care decisions, the lower the stress reaction. Therefore, it is important to adjust the care arrangement, and more importantly the process of care decisions, as the recipient's abilities change. This was noted in two of the dyads, where care had been provided for at least three years.

One of the assumptions of this study was 'younger generations are more overtly involved with care decisions than elderly recipients of care'. Although this assumption was supported by the data, it was expected that recipients would be discontent with a lower level of involvement. However, despite decreased involvement in decisions, several recipients were clearly satisfied with their current arrangement.

Four recipients were actively involved in decisions about their care. Although some described their involvement as "50-50" and others as "heavy", several reported deferring decision-making power to their daughters. Although initial assumptions of this study included concern about caregivers having most of the decision making power, it is notable that many recipients made the choice for their daughter to be the primary decision maker. Therefore, despite the recipients' lowered involvement in decisions, they had played an indirect role by choosing to have their daughters make decisions for them (see Figure 5.1). Again, the source of the decisions leading to the current arrangement was a greater area of contention and less likely to be congruent than the current decision making process.

Interestingly, some caregivers reported being concerned about the level of contentment that their mothers had with not being involved in decisions. Namely Veronica, Abigail, Jana, and Sandy reported concern about their mothers' level of contentment with regard to decreased involvement in decision making. This supports Horton and Arber's (2004) statement that a primary concern for caregivers is to "protect the parent's identity" (p. 77).

In two cases (Abigail & Beulah and Idah & Rita) the lack of congruence regarding the process and decisions leading to care was marked. Abigail reported that her mother had a major role in care decisions, saying that Beulah even picked out the very building in which she lives. Beulah reported that her daughter and late son-in-law made all of the arrangements, adding that she had never even seen the facility before she moved.

The issue of congruence is a difficult one and can imply that there is a right or wrong answer. However, it is important to note Litvin's (1992) statement regarding the importance of accounting for the "differences in the meaning of the caregiving experience for each member of the dyad" (p. 75). A lack of congruence may not indicate conflict or problematic dynamics. Rather it is important to understand how each person perceives the process, paying attention to each person's story without an investigative eye for the 'truth'.

Karin reported that her daughter takes good care of her and that she trusts her decisions. Karin's daughter, Veronica supported this by saying that she feels like her mother has become used to deferring to her. In the context of this conversation, Veronica said laughing, "Sometimes I think, I just want my mommy back!" Beulah said that after she became ill the last time, she told her daughter to "take over." Anna reported being "very happy" in her current situation but alluded to happier times. Since she moved to Michigan, she has not been in contact with good friends "back home." This had been an adjustment for her, and she reported that "this arrangement" was a good way for her to get her needs met. Rita also reflected this theme, stating, "When you get to be my age, you just have to do what you have to do…my daughter wanted me to move here and I didn't have all that I needed in Florida, so…"

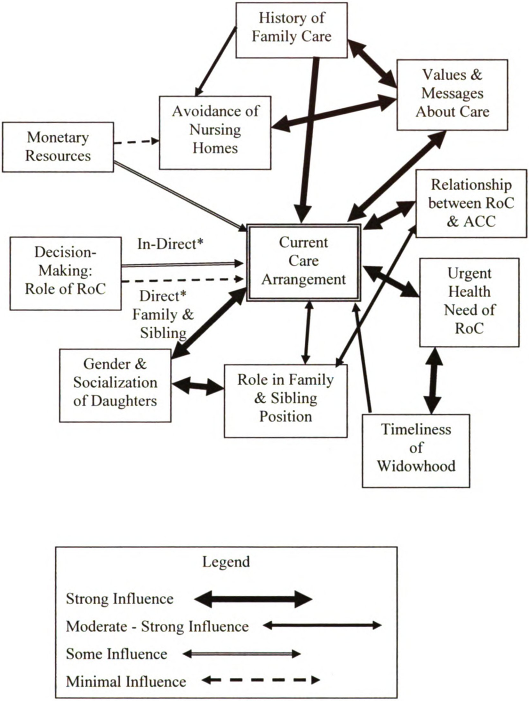
Extensive Care History & Multiple Roles for Recipients

The majority of recipients described care of elderly family members as a normative family task, reporting that caring for the elderly is just something that comes "naturally," is "cyclical," or expected. Most recipients had provided care to an elderly spouse and/or parent, parent-in-law, or grandparent. For example, Veronica's experience in observing the care of her grandparents by her parents, her role as a caregiver to her mother-in-law, and her current role as a recipient supports the idea that family care is a dynamic process. Pillemer, Suitor, & Wethington (2003) reported that "caregiving has often been viewed as a specific activity, rather than as a social status that individuals move into and out of at various points in the life course" (p. 24). Bronfenbrenner's concepts of the ecological transition and the chronosystem relate well to the care history of recipients and to Pillemer, et al's (2003) statement. Research on the dynamic state of care systems is necessary, specifically to include all system participants to review the role transitions over time.

Summary of Key Findings

Key findings include four over arching themes and several sub themes. Figure 5.1, the process model, illustrates the relationship between each of these factors. Since this study was done over a short time period, a key focus point was the current care arrangement (placing that theme in the middle). Although the current care arrangement was important to the study and certainly a current view of family care for each dyad, other important themes are included on the map. For example, family ecological factors are illustrated such as values and decision making. Sub themes of these categories include messages about care, relationship between RoC and ACC, and gender socialization. For decision making specifically, there was a discrepancy between what recipients and caregivers reported, resulting in two different lines for that factor.

Figure 5.1: Process Model



*Recipients had little direct decision making power about the current care arrangement. However, they were directly involved in decision-making in that many deferred decision-making power to their daughters.

Theoretical Framework

Family Ecology Theory

Family Ecology Theory served as the foundational theory for this research and informed this study through four primary concepts: boundaries, values, decision making, and resources. Two of the concepts (decision making and values) emerged from the data and a third (resources) was somewhat present in the data. The concept of boundaries, although alluded to, was not a primary finding. For example, some of the elements related to self care were linked to boundaries but did not emerge as a primary theme.

The data from this study supported Paolucci, Hall, & Axinn's (1977) assertion that decision-making is a process humans learn over time, based on environments and interactions. Central elements related to decision making included collaboration, deferment of decisions to younger generations, and prior relationship dynamics. The decision making process paralleled patterns from the family care history. Many caregivers adopted care strategies that had been employed by their parents. This was not surprising since all of the caregiving daughters were raised by their recipient mothers, supporting the importance and process of socialization.

As stated in the key findings section of this chapter, several recipients deferred their decision making power to their daughters. For example, Karin reported trusting her daughter completely and knowing she would take care of her business, leading her to defer decisions to her. Beulah reported turning everything over to her daughter, saying that it was time to do so, mostly because she was tired of managing the checking account and physician bills. Rita also said that she has her daughter take care of things because she knows what is needed, adding that her daughter knows the geographical area best (e.g. physicians, resources). This comment spawns an interesting point about the process of moving closer to adult children for the purposes of care. By doing so, Rita seemed to transfer decision making power to her daughter simply because she moved to her daughter's home area. Such a move likely necessitates active involvement on the part of the adult child who has been living in the area.

The history of family care (Bronfenbrenner's Ecological Transition) and specifically the role of the recipient over time seemed to be directly linked to the decision making process. Several dyads reported a history of care that mirrored the current arrangement, and although few recipients were able to reflect on this directly, these parallels emerged from the data. For example, Deborah reported making the decision to provide co-resident care of her husband instead of placing him in a nursing home. Her daughter, Carrie, reported the same justification for choosing co-resident care for her mother. Idah and Rita reported that the care of Rita's husband mirrored the care she was receiving from Idah. In some cases, the current care arrangement was chosen from a framework of what does not work. For example, Leda and Bernice both reported a family history of unfavorable experiences with nursing home care. Consequently, they agreed to avoid this arrangement as long as possible.

Since decision making is a dynamic process, based on communication, interactions, and perceptions, it was extremely important to hear from multiple system members (Bubolz & Sontag, 1993; Griffore & Phenice, 2001; Paolucci, Hall, & Axinn, 1977, p. 2). This position was supported not only by previous research (Horton & Arber, 2004) but also by the lack of congruence in the data relative to decision making. In several dyads (Abigail and Beulah, Martina and Mona, Carrie and Deborah, Sandy and

Anna) reports of decision making surrounding the current care arrangement were incongruent. As mentioned in the findings section, both Abigail and Beulah reported that the other had selected the assisted living facility. Sandy reported making the decision with her siblings that moving her mother to Michigan was the best option. Although this was done behind the scenes and the move did not take place until Anna was "ready," their reports of this process were incongruent. Sandy reported that she and her siblings made the decision whereas Anna reported that she made the decision.

The decision making process was the most rich portion of these data, given the lack of congruence, links to the family history, and in respect to how decisions were made. It is likely that these data are most enchanting because they challenged the theoretical conceptualization of this study (based on both Family Ecology Theory and Feminist Theory), that recipients would be displeased with their decreased role in decisions.

The concept of resources is important to Family Ecology Theory and decision making. Knowing that consideration of options is central to decision making, it is relevant that families may be unaware of the options available to them (Bubolz & Sontag, 1993). Generally, there are three aspects to decision making in families: ranking – the classification of options based on preference; elimination – based on various factors, the list is reduced; closure – when one option is selected, without conflict (Griffore & Phenice, 2001). However, system members can only consider options about which they are aware. Resources may limit options or knowledge of options and consequently, system members are unable to fully consider what might be best. Recipients perceived limited options for care support, which was affirmed by caregivers. For example, Rita and Mona said outright that there were no other options, and they had to adapt to what was available. Although addressing this dynamic less directly, Tina reported that her other children were "very busy" with work or young children. Many other informants alluded to the idea that their current care arrangement was their only option, quickly adding that they were not necessarily unhappy. It is possible that recipients who perceive limited care options are likely to defer to the person who offers. For example, after her mother's fall, Martina stepped in and moved Mona to Michigan, being the most vocal member of the five siblings. Therefore the family seemed to defer to her as she had made adequate arrangements. However, other arrangements may have been feasible or may have met Mona's needs better than the arrangement that was put into place. This dynamic may lead recipients to fail to consider other options, consequently limiting their part in decision making.

Messages about family values and responsibility for elder care also emerged. As stated in Chapter One, values reflect what individuals determine to be right or moral and are influenced by society, culture, religion, and other environments (Bubolz & Sontag, 1993). As caregiving is being viewed as a normative family task, it is a common societal value that younger generations will care for aging family members (Cicerelli, 2000; Sherrell, Buckwalter, & Morhardt, 2001). It was common to hear recipients and caregivers report that caring for others comes "naturally". Although caregivers and recipients did not directly link this value to society, some said, "It's just what you do" or "It's cyclical." However, the fact that this was a common theme across cases may support the assertion that care of older family members is a widely held societal expectation. In most cases, providing family care was a strong value and also was seen as a way to avoid nursing homes.

It is important to note that the concept of values, and certainly in respect to elder care, is linked to the decision making process. Essentially, we make decisions based on what we deem important. It is also relevant to note that the transmission of values is commonplace in family relationships. We learn what is important from family members and often adopt similar values. For example, Donna's comments reflect this well when she stated that it was difficult to share much about family care because it was so much a part of the way her family operates that it did not seem noteworthy.

Use of Family Ecology Theory allowed new findings to emerge from this data. The lack of congruence between caregivers and recipients in respect to decision making was noteworthy. More specifically the distinction between decisions leading to and following the care arrangement was marked. Although caregivers and recipients were highly congruent in their reports about decisions since the care arrangement was implemented, there were distinct differences within dyads regarding decisions at the time care was necessitated. This distinction and related congruence differences were not expected. These findings warrant additional inquiries into the process of decision making for elder care dyads. Furthermore, the ecological factors leading to care may also justify further investigation of a care trajectory. This research from a family ecological perspective would necessitate the inclusion of recipients as informants.

Feminist Theory

Feminist Theory was central to this study for a number of reasons. First, Feminism and qualitative methods compliment one another and partner well with gerontological research (Falicov, 1998). Therefore, this paradigm offered a framework for the organization and philosophy of this study. Secondly, Feminism was used to view Bronfenbrenner's macrosystem, acknowledging that old age often is equated with decline and consequent dismissal of the elderly by society. Finally, this lens was used with respect to females, namely daughters and mothers in the family care system. Feminism specifically acknowledges that women are socialized to provide care to the elderly (and other family members), placing them at greater risk for stress and overload (Blieszner, Usita, & Mancini, 1996). The feminist framework acknowledges women and the elderly as being oppressed in American society, which was a concept central to this study (Brewer, 2001; Lee, 1992; McGoldrick, 1989).

In addition to informing the methodology and primary assumptions of the study, feminist concepts also were reflected in the data. The two elements, gender and power, were central to this study (see Figure 5.3) (McGoldrick, 1989). Several informants talked about gender being a primary selection variable in the care system. Many compared their involvement to male relatives, and some wondered what would happen if they chose to stop providing care. Although some challenged their position as primary caregiver, many felt a sense of duty and pride. The process of vacillating between honoring one's position and questioning one's ownership of responsibility, characterizes the experience of many women.

Power, although less overt than gender, was still present in the data. There appeared to be a transfer of decision-making power from recipients to caregivers. Although several recipients talked about this power transfer, the struggle anticipated to follow that transfer did not come. Further examination of the transfer of power from recipients to caregivers would be well served by Family Ecology Theory and Feminism.

Contextual Theory

Contextual Theory contributed a clinical, marriage and family therapy perspective to this study. Although Family Ecological Theory offers an important framework from which to study families overall, Contextual theory better integrates concepts related to families in a clinical realm.

As stated in Chapter One, Contextual Theory considers issues of fairness and equality relative to the family of origin (Boszormenyi-Nagy, Grunebaum, & Ulrich,1991; Goldenthal, 1993). Individuals have experiences in their family of origin that may lead them to feel a sense of entitlement in later relationships. The concepts of Contextual theory relate to these data in two ways.

First, a small number of recipients reported dynamics similar to contextual concepts. When they did, recipients were very clear about their expectations, some reporting that they fully expected their daughter to provide care. Contextual theory would support the idea that this entitlement is a result of an unbalanced ledger earlier in the recipient's life, leading the recipient to expect a child to pay back something someone else owed. Although this element was not specifically included in the interview protocol, a self-report history of care was. This is relevant because so many recipients were caregivers at one time, and this entitlement for family care may be linked to the fact that they had once provided care to another family member.

Secondly, about half of caregivers with siblings were frustrated by the lack of equity in the distribution of care tasks. However, only one of the caregivers reported having challenged this position with their siblings. Instead, caregivers described a level of defensiveness with siblings when care was needed. Martina's comment to her siblings represents this concept well. She reported telling her siblings that if they thought the plan she had for their mother's care was wrong, they (her siblings) could come up and take care of things themselves.

According to Nagy, et al (1991) this type of defensiveness and related action/reaction is a precursor to an unbalanced ledger. Over time Martina (and other caregivers with similar reactions) will build a sense of entitlement, feeling that their siblings owe something in return. Nagy would add that this ledger would cause problems in Martina's future relationships, as she would look to others to right this wrong (1991).

One case in particular echoed concepts from contextual theory. Jana and Tina both reported a difficult history where Tina had been financially exploited by her granddaughter (Jana's daughter). Although Jana intervened several times to "save" her mother from bad choices, this exploitation seemed to spawn loyalties. As Jana spoke about her mother's experience of being exploited, she appeared to take a significant amount of responsibility for repairing her mother's credit and protecting her from a similar situation. Although this may not seem unusual for an adult child, her investment in managing her mother's money and activities was much more intense than any of her siblings or the nine other caregivers interviewed.

From a Contextual perspective, this level of involvement would be viewed as an effort to correct the system or the wrong that Tina experienced. Jana's efforts are notable since it was her daughter who exploited her mother. Jana seemed to be taking responsibility for "cleaning up" the "mess" that her daughter created. This is also notable because Jana had been providing care to her three grandchildren for a time just before the interview.

Theoretical Maps – Original and Emerging

The original theoretical map is reflected in Figure 5.2. Family ecology theory was used as the foundational theory, applying decision making, values, resources, and boundaries equally. These family ecology concepts were linked to both feminist theory and society by the macrosystem. The original map illustrated that feminist concepts, specifically gendered expectations and age related power differentials, were central to family life and family ecology concepts. Feminism also was directly linked to the macrosystem as the original model illustrated the influence between feminism and societal expectations in American culture. Bronfenbrenner's ecological transition and chronosystem was placed at the bottom of the diagram to illustrate the passage of time. It was expected that this factor would allow for an examination of roles over time. Contextual theory was used to integrate clinical components, specifically Marriage and Family Therapy, into research about elder care dyads. The original map included contextual concepts as outcomes.

The emerging theoretical map (Figure 5.3) illustrates how the current data reshape the relationships between theoretical constructs. Concepts from family ecology theory emerged at varying levels, with decision making and family care values being the most notable themes. Both were strongly influenced by gendered expectations in the family and role related power shifts (feminist concepts). Unlike the original map, the concept of resources was somewhat related to how families operated but not heavily. The concept of boundaries was related minimally to how families interacted surrounding elder care.

Feminism was clearly linked to expectations of society, supporting the relationship between feminism and the macrosystem. Feminist concepts were more clearly distinguished from one another as some other concepts related to one or the other more distinctly. Gendered expectations related as expected in the original theoretical conceptualization. However, the way that age was used in respect to feminism was changed from 'age related power differentials' to 'role related power shifts'. This change reflects the difference between ageism as a construct in families that leads to a weakened and discouraged voice and the theme that emerged related to family roles and related power shifts. The role related power shift is linked directly (bi-directionally) to the ecological transition as caregivers and recipients often held multiple care positions over time. The feminist concept related to this was power, as recipients often deferred power to caregivers. This was viewed as a result of changing positions in the care system that was related to power differentials but not in the way originally thought. The importance of these role shifts and related dynamics warranted the decision to move the ecological transition into the core of the model, indicating its relationship to family ecology concepts.

Contextual concepts were divided into two areas, loyalties and entitlement. Loyalties were often linked with family care values as daughters reported wanting to and expecting to care for their mothers. Entitlement did not emerge as clearly as expected or in the format described in previous chapters. The influence linking decision making and entitlement was unidirectional and was linked by more than family of origin ledgers, as described by Nagy (1991). Entitlement emerged as an issue as mothers expected daughters to provide care although it was not clear from where this emerged.

Furthermore, of the seven caregivers who had siblings, many reported a sense of entitlement to receive help from siblings. Again, entitlement was not utilized as originally discussed by Nagy (1991), but it is clear from these data that entitlement between and across generations is relevant.

The changes in the theoretical map highlight the relationship between the chosen theories. Bronfenbrenner's macrosystem was aligned with feminist concepts, specifically gender socialization in families. This supports the assertion that feminist power differentials exist in broader society, and integrating family ecology supports the examination of such differentials relative to family dynamics. The links between these concepts were strong and supported by data where caregivers and recipients reported strong filial expectations both within the family and from the broader societal context.

Figure 5.2: Original Theoretical Map

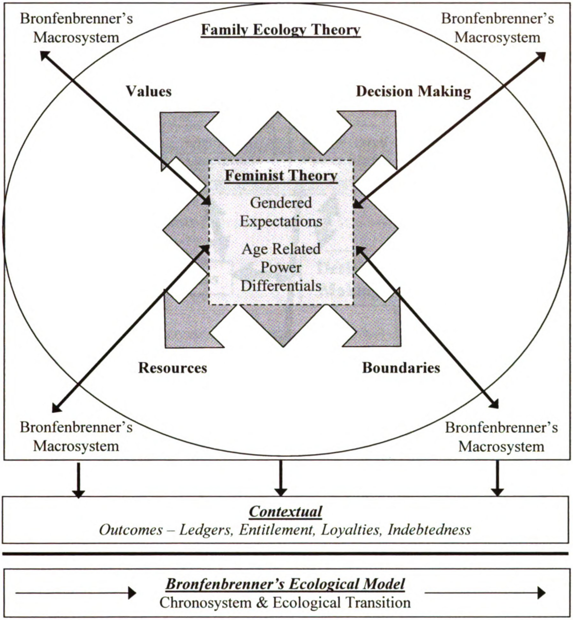
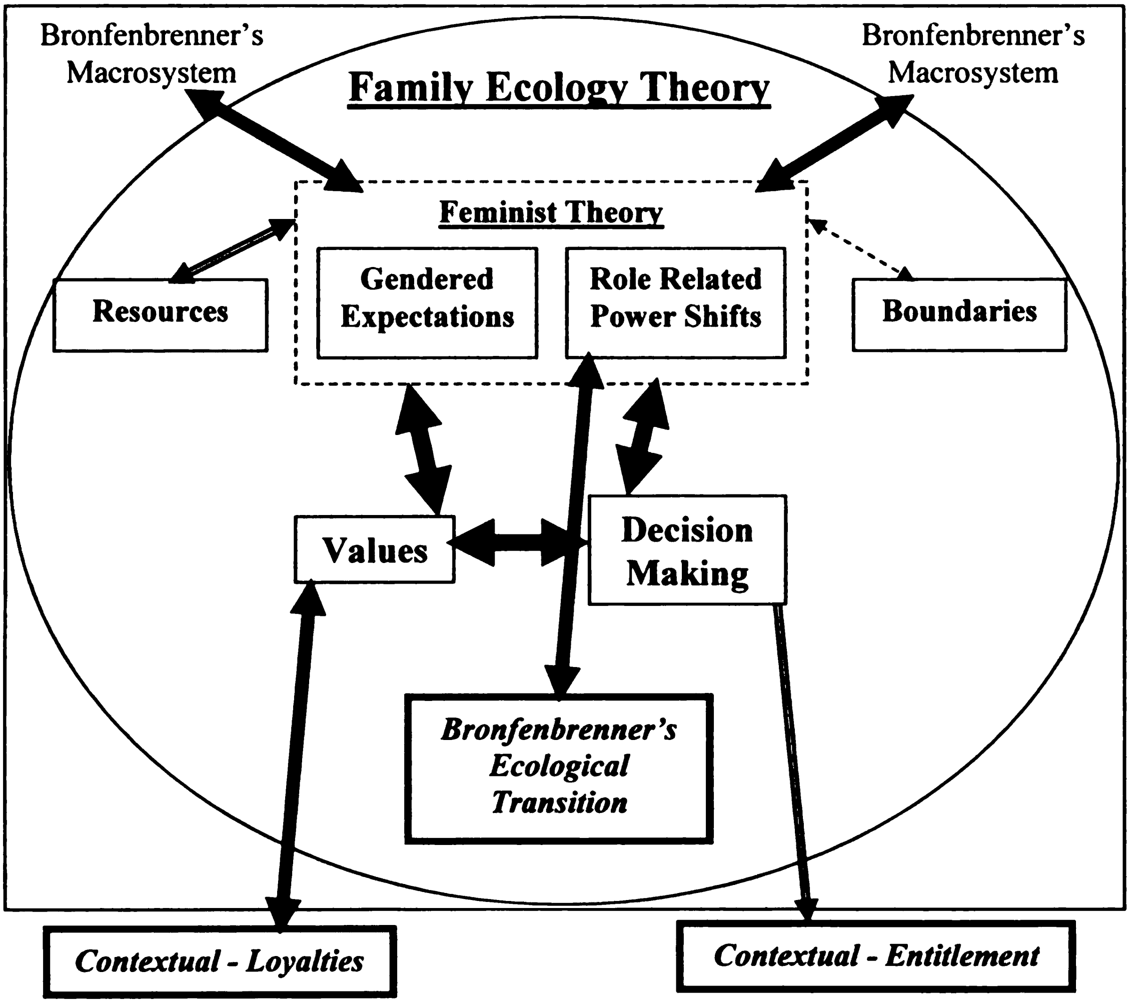


Figure 5.3: Revised Theoretical Map



Methodological Issues and Limitations

As with any research project, there are methodological considerations in conceptualization, interpretation, and writing. Although there are strengths to various methods, there are also inevitable limitations.

Self-Selection

This project included 20 volunteer informants who were participating in elder family care to some degree. It was necessary for recipients to be able to sit in a 45 minute interview, which limited the sample to individuals who had minimal hearing, mobility, and transportation barriers. Individuals who were physically able to participate likely had a different care experience than those with more substantial limitations. It is also important to note that individuals who volunteer for interviews (despite the small monetary gift) are likely to be happier in their current arrangement. Individuals who are unhappy with their current situation may be less likely to talk with a stranger about their experience. This is even more true in dyadic research where one participant knows that the other member also is being interviewed. In dyads where problems exist, one or both members of the dyad may not want their displeasure revealed to someone outside the family.

Differences Between Dyads

Although homogeneity of participants was not a goal of this study, it is important to note some of the differences between dyads. The primary differences included the type of assistance provided, living arrangements and age. Although generalizability is not an expectation or appropriate concept to use in case studies, it is important to note demographic and lifestyle differences of recipients.

The first difference was in regard to the living arrangements of and care received by recipients. Living arrangements are important to consider in care dyads because living circumstances and care reciprocally influence one another. For example, one recipient was highly, independent whereas another was dependent on her daughter for most of her needs. Five of the ten recipients lived in assisted living centers, four lived with their caregiving daughter, and one lived separate from her daughter (but not alone as her nephew lived with her). Although each recipient received care from a daughter, the involvement of other care system members (e.g. assisted living staff) likely altered family care. For example, Dora talked about the importance of enjoying time with her mother rather than doing her mother's laundry. Since laundry services were available to Donna, Dora was able to utilize that resource. For dyads engaged in co-resident care, the same resources were not available. Jana reported a goal similar to Dora's, to spend more quality time with her mother. Although Jana provided co-resident care to her mother, she hired aides to assist with various tasks, including housework. It is important to note that the availability of resources between assisted living and co-resident care are different and may limit access for co-resident dyads. This may be confounded by individuals' (caregiver's and recipient's) desires not to have strangers in their home as well as the costliness of in-home services.

The second notable difference between dyads was the age of both mothers and daughters. Caregivers ranged in age from 36 – 68, and recipients ranged in age from 72 – 92, with the oldest caregiver only four years younger than the youngest recipient. Although chronological age is not the only factor to consider in family roles or in the need for care, it certainly influences resources (e.g. retirement/work status) and can relate to other family positions (e.g. grandparenthood, widowhood, etc.). For example, two caregivers had been widowed themselves which likely influenced the way they related to their widowed mothers.

Reflection on the Chosen Methodology

As I reflect on this project, I believe the selection of qualitative methods was a good decision. Specifically, the individual, semi-structured interview fit well with the goal of this study, rather than focus groups or dyad interviews. The decision to interview recipients more than once, leaving at least five days between meetings, was a strong point of this study. In the second interview, recipients often would report having thought about something discussed previously, sharing an added point or reflection. The original proposal included several forms of field notes, including an ecomap, genogram, and timeline. These would have duplicated and been constructed from the interview narratives. Although the ecomap was used in the final stages of the project, being constructed after each interview, it was not found to be useful in the data analysis. Since this study was focused on the family care system, entries on the ecomap were minimally related to the study and analysis. The genogram and timeline, although more specifically related to the family, were not used as they did not offer anything more than the interview narrative.

If I were to pursue a study similar to this one, I would either limit the time of care or categorize the groups by time intervals of one year. I believe that the length of time in the current arrangement influenced several factors in each of the ten dyads. I would also limit the sample to families where caregiving daughters had at least one living sibling.

This would allow me to inquire more about within generation decision making, specifically related to the sibling relationship.

Limitations

This project was exclusively qualitative and although a coding consultant and faculty oversight committee was used throughout, I was the primary investigator. With that came inherent biases that, although expected and accepted in qualitative research, must be acknowledged. Although some of my biases were reflected in the assumptions (Chapter One), there are others shared in the reflections section.

Although a semi-structured interview protocol was used throughout the research process, no two interviews were exactly the same. The unique experiences of each dyad led each interview in its own direction, and the interview narrative progressed somewhat differently with each informant. Although the order of questions was not deliberately changed, some questions led informants to answer others. When this occurred, the original question was asked in the appropriate order. However, the organization of data may have differed for each informant.

Recipients had difficulty with two of the interview questions. When asked "How would you compare their experience with yours? If it is different, why do you believe it is different?" recipients seemed to struggle with this comparison. In hindsight, it seemed that recipients perceived a varying level of care between these scenarios and their own and may have had difficulty seeing themselves in the same light. When asked, "Have you ever provided care to a family member who was your age or older?" several recipients minimized their role, reporting that they did not help the older family member but went on to describe weekly or even daily assistance. Difficulty with this question was confounded by the presence of another, often primary, caregiver. For example, Bernice talked about being responsible for bathing her grandmother but reported that she did not provide care, that another family member did all the work.

Recommendations for Future Research

The primary recommendation for future research is to include recipients in both quantitative and qualitative research. Although limited studies include recipients, it is still uncommon. In order to successfully complete gerontological family research, elderly members must be included in data collection. Whether the study is on family caregiving or other important topics such as community programs or the patient-physician relationship, elderly family members should be included.

In respect to caregiving research specifically, more information needs to be obtained about how recipients experience and participate in the care system. In order to pair what we know about caregivers, research on other care system members needs to be better established. Without this multi-perspective literature, we will continue to know substantially more about caregivers and shape programs to meet their needs, instead of the needs of the entire system.

The informants were all female (mother-daughter pairs). Inclusion of other gender combinations may have yielded cross-case comparisons and would be beneficial to view from a feminist perspective. Although findings on mother-daughter dyads are important, particularly from a feminist lens, research rarely includes fathers or sons, and therefore limits our knowledge of such systems. Future research should include male family members, specifically including male-female dyad combinations.

A difficult yet important task for researchers will be to better understand the decision making process relative to family care. Combining the first two recommendations for future research, with a focus on intergenerational processes would make a substantial contribution to the literature.

Implications for Family Gerontology

Knowledge about the aging adult is expanding in many arenas. Medical professionals, psychologists, social workers, and anthropologists study aging from their respective paradigms. Family gerontologists have a unique perspective and responsibility: to investigate the way aging families organize and respond to gerontological issues. The family is the core unit in the caregiving system, and family gerontologists have the unique ability to review the family care system as the unit of analysis.

Family care systems are complex and vary significantly based on ethnic affiliation, socioeconomic status, and other important factors. Reviewing family care from a family ecological perspective, rather than from a reductionistic view, complicates yet expands our understanding of care.

With respect to how these data influence the field of family gerontology, they support two assertions that are relatively new to the literature. First, dynamics from the long standing relationship prevail, and caregiver stress may be more a product of that dynamic than an outcome of care. Secondly, care is a dynamic process that happens over time and one is not a participant for a definitive amount of time. Specifically, the appreciation of care as a dynamic process validates the family gerontology perspective and necessitates the paradigms used by family scholars. Finally, implications for outreach and family life education also are central to implications of this study.

Implications for Family Life Education

Family life education is an important and applied use of caregiving research. Although there are many arenas for education, linking families with information about an aging society is critical. As adults live longer and the nature of families change, disseminating information to families and communities is one of the most important tasks of research.

Scholars know a great deal about aging from a medical standpoint. A good example of this phenomenon is the number of outreach efforts that exist surrounding health care screening and prevention of medical conditions. Just as important for families is the need for information concerning issues they will face at various stages. Family life education as a field addresses many aspects of family life (e.g. financial planning). The process of aging and related changes is inevitable. Families will face the issue of aging that reaches far beyond the medical aspects of aging. A primary effort in family life education should be to facilitate discussions among family members about the care system. Although there are efforts to educate families about durable power of attorney and other legal decisions, there are aspects of family care that are less formal and require attention. These data not only offer a specific way to look at families, they validate the need to continue learning about care from aging families.

Implications for Marriage and Family Therapy

The key implication for MFTs is the need to integrate aging families into all aspects of training. Although there is a well-accepted justification as to why MFTs are not well versed in working with aging families, specifically elderly family members, there is more that can be done. A commonly cited, widely held assumption is that older adults are not open to seeking mental health services. There may be cohort differences that make our traditional sources of information less valuable for the elderly, but that does not mean that the profession has done all it can to access this potentially vulnerable population.

I assert that the same societal constructs that impede researchers' likelihood of including the elderly in their research plagues the field of MFT. Many therapists have told me that their lack of knowledge about the elderly and coinciding fear that the older adult will not respect them, leads them to shy away from any opportunities to work with this population. Therefore, one of the first tasks of the profession should include psychoeducation on many levels, including work with therapists in training programs along with education in families about aging issues. Intergenerational relationships and recognition of related dynamics are central to clinical work and research. Therefore, educating families about aging and related issues could be a valuable part of the therapy process. Although there is a common assumption that the "Depression Era" children will not seek therapy services, the baby boomer cohort will have a different perspective. The attitudes about mental health services, utilization, and needs of this generation will differ from the current cohort, and the field must adapt accordingly.

This study provides a strong justification for the use of Narrative Therapy with aging families. It is important to acknowledge creation of stories over time, acknowledging each members' story. Although this is done in therapy clinics across the world, there is little written about using narrative therapy with the elderly. In addition to working with aging families and integrating the voices of elderly recipients of care, it also would be beneficially to examine the issue of congruence from a narrative standpoint. Specifically viewing congruence issues from a narrative perspective allows for shifts in interpretation, from a discrepancy standpoint to framework of varying realities.

Finally, feminist ideals related to this study in a number of ways. Not only did feminism guide the methodology and use of qualitative research, feminism heavily informed the theoretical framework (as discussed throughout chapters one and five). In addition to these contributions, feminism is critical in applying this study to the field of marriage and family therapy.

The use of Feminism enables therapists to view power differentials in each system. Therapists who use the feminist lens note that each member has a voice, attending to the differences between each member's voice. The feminist therapist notes that certain family members have weaker voices and less power than others. Namely women, children, and the elderly have less power (and consequently weaker voices) than other family members. This dynamic is central to the way families operate, affecting decision making, exchange of resources, and other family processes.

With respect to this population, mother-daughter elder care dyads, feminist concepts relate not only to the dyad itself but to the context in which the dyad is imbedded. Within the dyad, the feminist therapist would note that the daughter holds more power than the aging parent, simply as a result of age. This may be perpetuated by the common exclusion of the elderly family member in therapy sessions. I am cautious to note the benefits of providing care, citing added power as the role of caregiver can be extremely difficult. Caregivers may not want added power that comes as a result of a parents' aging process. However, the shift appears to inevitably occur. Veronica noted this by saying, "I just want my mommy back!!! (laughter)" indicating that she missed the relationship they once had.

Feminist concepts are central to the family and societal context in which mother-daughter care dyads are imbedded. In addition to power differentials that exist within dyads, there are many layers of the same dynamic within families and society. The feminist therapist would note that the care dyad includes two women who have likely been oppressed as a result of being female in society. Therefore, a task of the feminist therapist would be to assess the family system for values and beliefs that perpetuate the decreased power of females, helping clients to challenge problematic yet well-established patterns.

Feminism is critical to the study and practice of marriage and family, gerontology, and qualitative research. Any research on aging families will lead to marriage and family therapy implications and therefore feminism should be used as a foundation perspective.

Case Perspectives

Two cases illuminated marriage and family therapy concepts and offer data that support the integration of research, theory, and practice. Specifically, Abigail and Beulah and Sandy and Anna are described from a therapy perspective.

As noted in chapter four, Beulah had been receiving care from her only daughter Abigail for several years. At the time of the interview, Abigail was newly widowed and reported enjoying the time she spends taking care of her mother. Abigail specifically said that it is easier to take care of her mother's things than her own. From a systems and therapy perspective, it was interesting to note that Beulah worked hard to find tasks for her daughter to complete. She reported wanting to help her daughter "stay busy," leading her to space out her requests. Beulah framed these requests as being needs of her own, however she seemed to be offering something to her daughter. Although there were implicit benefits for Beulah (e.g. her daughter visited more often), she reported concern for her daughter and appeared to appreciate her daughter's desire to attend more to her mother than to her own work.

Sandy and Anna seemed very comfortable with their care arrangement. An interesting dynamic was present where Sandy seemed to experience significant benefits from caring for her mother. Sandy reported being proud of the time she spent with her mother, namely on weekends and dinner outings, and it seemed to validate Sandy's position in the family. She even spoke about her role as a caregiver solidifying her position in the sibling sub-system, establishing her as a responsible member.

Both of these cases demonstrate the subtle exchange of resources within dyads. In both cases, daughters seem to benefit from the caregiving role. Despite the theory used to discuss this case, previous literature on mother-daughter relationships (Allen & Walker, 2001; Bleiszner, et al, 1999) calls for more research on the state of care relationships. Researching dyads from a marriage and family therapy framework would offer an assessment of dynamics (problematic or not), making a contribution to the literature and the field.

Finally, the field of marriage and family therapy could make a significant contribution to family science and family therapy by integrating multiple care system members into therapy. On many occasions, caregivers present for therapy and the therapist pursues individual therapy with them. This model, although sometimes appropriate, may perpetuate the stress and burden perspective of care as well as limit therapists knowledge about aging recipients.

Researcher Reflections

Although research stretches us in rewarding yet (sometimes) painful ways, qualitative research requires a significant amount of reflection through all stages of the process. As I complete this project, I find that I have changed - as a researcher, a therapist, a female, and even as a family member. Throughout data collection, I found myself humbled by the informants' experiences. I felt honored to be invited into their lives and to have them share their stories and emotions. Although as a therapist I experience this every day, my role as a researcher was notably different. As a therapist, individuals consult me for my perspective in addressing their concerns. As a researcher, I was consulting informants about their knowledge and experiences and asking them to participate in my research.

Prior to this project I had read about conducting research with the older population and had completed two quantitative studies with elderly participants. However, I had not done qualitative interviews with the elderly. Throughout the process of data collection, I was keenly aware of my chronological age. This was often spawned by informants' perceptions of my age, in some cases leading them to ask me how old I was or why someone "so young" was interested in "old folks." Although I, as a researcher, was there to learn from them, the mention of age humbled me even more. As I reflect on this, I am struck by the irony of this dynamic and how I made sense of it. Although one of the assumptions of this study was that as people age, they lose power in society, I had tremendous respect for the recipients (and caregivers) simply because of their life experiences. Consequently, I saw them as people with tremendous knowledge and power.

Specifically, as a researcher, I became aware of the communication among family members. Although I am privy to varying patterns of communication in my work as a therapist, I was struck by how covertly this happens. I realized that after decades of interacting, these dyads had well-established communication patterns that I may not have been able to discern. This has two primary implications for this work – that over time families may collaborate in ways they are unaware of and that my interview questions and perceptions may not have been in tune with such established processes.

As a scholar, my struggle to integrate the existing research on the developmental process of aging into a family framework continues. As I try to learn more about the aging individual from a family ecological framework, I find few resources that do this well. In my opinion, the medical model of aging continues to dominate what we know about aging, and I struggle to acknowledge that as a part of the aging process. My scholarly understanding of family gerontology is enriched yet challenged by my training as a marriage and family therapist. As a therapist, I study clinical aspects of intergenerational dynamics. However, as stated before, the MFT field is limited in its offerings with respect to the aging family. I do not claim to be a pioneer in any way. In fact, I know it has likely been done before, possibly in another field. However, given my resources and training at this point, I struggle as a developing scholar to integrate the study of aging as we know it, family ecological theory, and family therapy. I am certain my learning curve will be steep, and the good news is I am nowhere near ready to give up integrating these valuable perspectives.

As a female and a daughter, I was struck by the ways in which the mothers and daughters adapted over time. Almost all recipients had been caregivers at one time, some describing years of intense care. I was amazed at how natural and normative caregiving seemed to be to both caregivers and recipients. It was not questioned, and although not described as an easy task, in most cases care was not viewed as a burden. In my realm as a daughter, I found myself thinking about caregiver selection. Having recently lost my only sibling, I identified with the only children of the group. Although I do not consider myself a caregiver, I found myself empathizing with these daughters, who reported some sense of isolation in caring without the help of a sibling. In truth, I expect that the experiences of caregiving only children would be somewhat different than that of caregiving children who had lost a sibling – as a result of sudden shifts in expectations, elements of loss, and possible resentment of 'going it alone' when that had not been the expectation.

Summary

This study explored the experiences of elderly recipients in the context of receiving care from their adult daughters. Each case offered unique perspectives and saturation was reached on several factors. Feminism and family ecology were central to the theoretical and methodological frameworks. The findings of the study, although not generalizable, provide the groundwork for additional research in family gerontology, marriage and family therapy, and implications for family life education.

APPENDICES

Appendix A: Study Information Sheet

Study Information Sheet

This project is being done through Michigan State University to learn more about individuals' experiences with the care of family members both currently and over time. Participation will include one interview with an adult child and one, two-part interview with his/her parent. Each individual that participates will be given a $10 gift certificate per interview (total of $30/per family). If you are interested in learning more about this project, please contact me for more information.

Sincerely,

Whitney Brosi
(517) 377-8798

Appendix B: Consent Form (Parent)

Consent Form
Parent / Recipient of Care

You are being invited to participate in a study focused on adult's experiences with their adult children and family caregiving. Questions will specifically be related to the history of care in your family and your current experiences of receiving care from your child(ren). The interview questions are about your personal experiences and some may be unpleasant to answer. Your answers are given on a voluntary basis and refusal to answer questions will be respected and will not result in penalty. You may refuse to answer any questions at any time. Participation in this study will involve two audiotaped interviews, lasting approximately 45 to 60 minutes each. Audiotapes will be kept in a locked cabinet and only used by the researchers.

Participation in this study is completely voluntary. If you decide to participate, you will be given two - $10 gift certificates to a local retail store (one at the end of each interview) in appreciation for your time. Should you decide not to participate in this study, you will not be penalized in any way. If you decide to participate in this study, you may withdraw at any time without penalty. If you decide to participate, your privacy will be protected to the maximum extent allowable by law.

If you have questions of concerns about this study, please contact the principle investigator:

Barbara Ames, Ph.D.
Professor
Department of Family & Child Ecology
13F Human Ecology
East Lansing, MI 48824
(517) 432-3324

If you have any questions or concerns regarding your rights as a study participant, or are dissatisfied at any time with any aspect of this study, you may contact – anonymously if you wish:

Peter Vasilenko, Ph.D., Chair
University Committee on Research Involving Human Subjects
Michigan State University
202 Olds Hall
East Lansing, MI 48824
(517) 355-2180
ucrihs@msu.edu

Your signature below indicates your voluntary agreement to participate in this study.

Signature ____________________________________ Date___________

Printed Name ________________________________

Appendix C: Consent Form (Adult Child)

Consent Form
Adult Child / Caregiver

You are being invited to participate in a study focused on adult's experiences with their adult children and specifically their aging parent. Questions will specifically be related to the history of care in your family and your current experiences of providing care to your parent. The interview questions are about your personal experiences and some may be unpleasant to answer. Your answers are given on a voluntary basis and refusal to answer questions will be respected and will not result in penalty. You may refuse to answer any questions at any time. Participation in this study will involve one audiotaped interview, lasting approximately 30 to 45 minutes. Audiotapes will be kept in a locked cabinet and only used by the researchers.

Participation in this study is completely voluntary. If you decide to participate, you will be given one $10 gift certificate to a local retail store in appreciation for your time. Should you decide not to participate in this study, you will not be penalized in any way. If you decide to participate in this study, you may withdraw at any time without penalty. If you decide to participate, your privacy will be protected to the maximum extent allowable by law.

If you have questions of concerns about this study, please contact the principle investigator:

Barbara Ames, Ph.D.
Professor
Department of Family & Child Ecology
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If you have any questions or concerns regarding your rights as a study participant, or are dissatisfied at any time with any aspect of this study, you may contact – anonymously if you wish:

Peter Vasilenko, Ph.D., Chair
University Committee on Research Involving Human Subjects
Michigan State University
202 Olds Hall
East Lansing, MI 48824
(517) 355-2180
ucrihs@msu.edu

Your signature below indicates your voluntary agreement to participate in this study.

Signature ______________________________________ Date____________

Printed Name ___________________________________

Appendix D: Direct Quote Consent Form

Consent to Use a Direct Quote

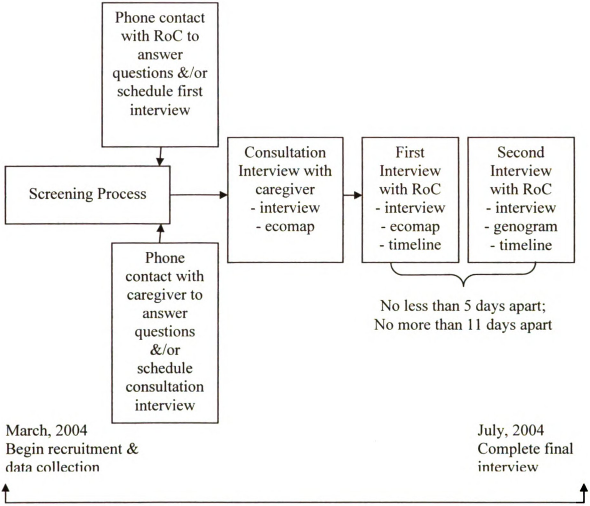
This form gives your consent to use direct quotes, from this interview, for the purposes of publishing this study. Your identity will be kept confidential and a false name will be used to protect you. Only the researchers will know the name assigned to you. If at any time during the interview you would like to share your comments but not have them used for direct quotes, please indicate this by requesting to go 'off the record'. You may refuse to answer any questions at any time. By signing this form you allow the use of direct quotes in publications of this study and understand that your privacy will be protected to the maximum extent allowable by law.

By signing below, you give your voluntary consent for the use of direct quotes in the publication of this study.

Signature ______________________________________ Date____________

Printed Name ___________________________________

Appendix E: Methodology Timeline



Appendix F: Caregiver Consultation & Interview

Orientation to Process:

Consent procedures

What questions can I answer for you about this study, your involvement, and/or your parent's involvement? (Review confidentiality of interview content, even between participants)

Caregiver Interview:

What type of care do you provide to your father/mother?
    Specific tasks?
    How much time do you spend on these tasks each week?

Who else is involved in the care of your father/mother? (caregiving ecomap)
    What type of care do they provide? How often?

How long have you been providing care to him/her, this type or any other type of care?

How did you become his/her caregiver?
    Discussed ahead of time? Other people involved?

What role does your father/mother play in decisions about his/her care?
    Does his/her role differ based on the type of decision (i.e. medical care, social life, living arrangements)?

Has you father's/ mother's role in these decisions changed over time?
    How? Why?

What do you like most about your father's/mother's current care arrangements?
    What would you most like to change about his/her current care?

Is there anything else you would like to add about your experience in providing care to your father/mother?

Closing

I want to thank you for your time. I have enjoyed talking with you and appreciate your wiliness to share your experiences with me. (If not already scheduled) I will be contacting your father/mother to set up our meetings. If you have any questions, please feel free to contact me.

Appendix G: Recipient of Care Interview (part 1)

<u>Orientation to Process:</u>
Consent procedures

What questions can I answer for you about this study, your involvement, and/or your adult child's involvement? (Review confidentiality of interview content, even between participants)

<u>RoC Interview (part 1):</u>

What is a typical day like for you?

> What do you enjoy doing? Who do you spend time with? Has your typical day changed in the past year, past two years? If so, how?

Who, in your family, assists you when you need things?

> What types of things do you receive help with?
> How do they assist? How long have they been providing assistance? (info. for caregiving ecomap)

How was the decision made for that person/those individuals to assist in that way?

> How were you involved in that/those decisions?

Are decisions made differently based on the kind of decision (medical care, social life, living arrangements, etc)?

> Do you believe that your role in decisions is different based on the topic/kind of discussion?

What do you like about the assistance you receive right now? What do you dislike?

Do you have any siblings? Are they/have they received assistance from their adult children or other family members?

> How would you compare their experience with yours? If it is different, why do you believe it is different?

Do you have any friends/peers who are receiving assistance from their adult children/family members?

> How would you compare their experience with yours? If it is different, why do you believe it is different?

Appendix H: Recipient of Care Interview (part 2)

Review of last meeting:
Last time we met, we focused on your recent experiences with family care. Is there anything else about your experience of receiving assistance from your son/daughter that you would like to share today? (Specific prompts will be used)

After we met last time, I started to document your family tree and today I would like to learn more about the history of your family. I am going to ask questions specifically about family care/caring for older generations. I am interested in anything you remember observing or stories you have heard over time.

RoC Interview (part 2):
When you were a child, do you remember your parents/other adults talking about the needs of older generations?

> What do you remember about those discussions?

Can you think back to a time when one of your family members helped take care of another family member? Who? When?

> How did this story/experience shape your ideas about family care? How was that decision made in your family? What did you like / dislike about how that decision was made?

How does that experience compare to your experience in receiving care from your adult child?

As an adult, were you involved in discussing the needs of older family members with others?

> What do you remember about those discussions? What role did you play?

Have you ever provided care to a family member who was your age or older?

> What role did you play? What type of assistance did you provide?

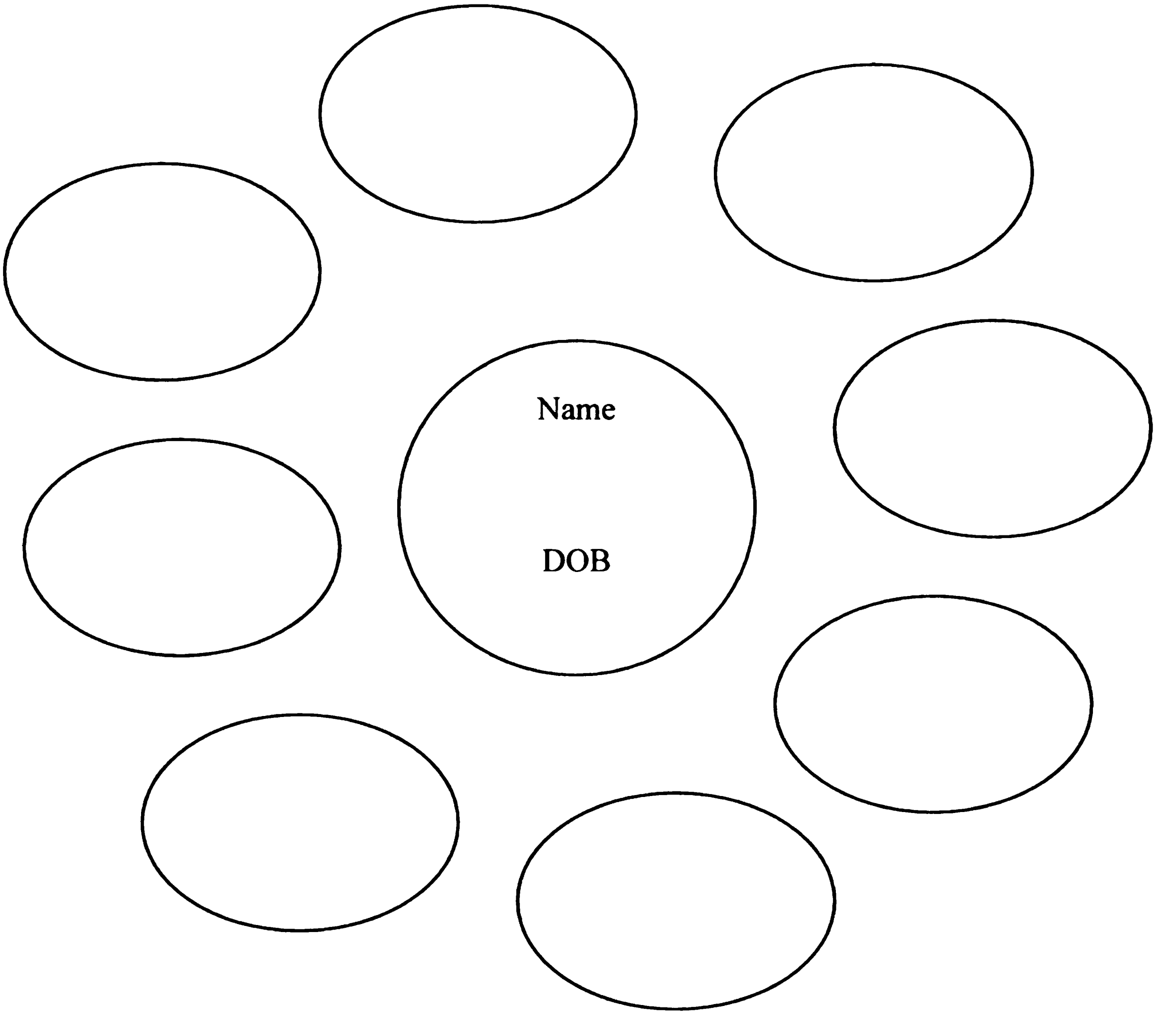
How does that experience compare to your experience in receiving care from your adult child?

Is there anything else you would like to share about the history of caring for older generations in your family?

Thank you for your time. I have sincerely enjoyed talking with you and learning about your family and experiences. (Give gift certificate & answer questions)

Appendix I: Caregiving Ecomap

Participants: ________________________________



Describing Relationships

Very Close	≡≡≡≡≡≡≡≡≡≡
Good	══════════
Distant	- - - - - - - - - - - - - - - -
Conflicted	∿∿∿∿∿∿
No Relationship	- - - - - - - -⧵-⧵- - - - -

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