This is to certify that the

dissertation entitled

Families that Care: an ethnographic study of families engaged in the provision of elder care

presented by

Loretta Brewer

has been accepted towards fulfillment
of the requirements for

Ph.D. degree in Social Sciences

Duane D. Lerande
Major professor

Date 1-7-02

FAMILIES THAT CARE:
An ethnographic study of families engaged in the provision of elder care

By

Loretta Brewer

A DISSERTATION

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

INTERDISCIPLINARY DOCTOR OF PHILOSOPHY

Social Sciences

2002

ABSTRACT

FAMILIES THAT CARE: AN ETHNOGRAPHIC STUDY OF FAMILIES ENGAGED IN THE PROVISION OF ELDER CARE

By

Loretta Brewer

This project utilized ethnographic methods to explore the culture of caregiving, situated within the context of families that are actively engaged in the provision of elder care. The project was designed to test the hypothesis that families utilizing a team approach to caregiving experience more positive outcomes than those utilizing the primary caregiving approach.

Twenty-two families were recruited from two agencies that provide services to older adults. Of these families, twelve represent the primary caregiving approach and ten represent the team caregiving approach. Semi-structured interviews were conducted with care recipients, when feasible, as well as with all available caregivers. In addition, a representative from each family completed a participant survey in order to collect pertinent demographic data.

Participants utilizing either the primary caregiving approach or a team approach were able to identify both positive and negative effects of caregiving on their personal sense of well being. While team caregivers reported experiencing difficult emotions similar to those reported by primary caregivers, they also had more immediate access to support from other family members. This support seemed to moderate the negative effects of those emotions.

The issue of quality of care was addressed in interviews with both care recipients and caregivers. There was no evidence of substantial differences in the quality of care provided by families using a team approach as compared to those using a primary caregiving approach. The findings also suggest that caregiving approaches are rarely the result of a deliberate decision-making process. Rather, they appear to evolve over time as families adapt to alterations in both internal and external conditions. In addition, role definitions changed over time as caregivers occasionally became care recipients and as family members who had been only tangentially involved with caregiving assumed more central roles.

Future research must focus on caregiving systems rather than primary caregivers. Only then can we begin to build caregiving networks that not only provide quality care to those in need, but also enhance the well being of those who care.

This dissertation is dedicated to the memory of my grandmother, Mildred Finley, and her siblings. This family provided my first case example of a team approach to caregiving. Their memory served as the inspiration for the project reported here.

ACKNOWLEDGEMENTS

I gratefully acknowledge the support and constructive criticism provided by the members of my Guidance Committee: Dr. Diane Levande, Dr. Margaret Nielsen, Dr. Jacob Climo, and Dr. Barbara Ames, all of Michigan State University. I also want to acknowledge the support provided by the Pearl Aldrich Endowment in Gerontology for my pre-dissertation project, "A Qualitative Study of Family Care Models for Older Adults" (Brewer, 2000). That project laid the foundation for the study reported here. In addition, I want to thank the Care Management staff of Region IV Area Agency on Aging for their assistance in recruiting project participants as well as the twenty-two families who participated in the study. Finally, I want to thank my spouse, Larry Brewer, for the emotional support and technical assistance he provided throughout my doctoral studies as well as during this project. Each of these people, in their own way, has contributed to the successful completion of the following dissertation.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

Chapter 1

The Problem

This research project utilizes ethnographic methods to explore the culture of caregiving, situated within the context of families that are actively engaged in the provision of elder care. Scholars have suggested that families have distinct traditions and ethos that partially account for the different ways they respond to the needs of their older members (Gubrium, 1991). Furthermore, specific patterns or "cultural systems" of caregiving have been described (Albert, 1990).

The project reported here was designed to test the general hypothesis that families utilizing a team approach to caregiving experience more positive outcomes than those utilizing the primary caregiving approach. Specific outcomes explored include caregiver well being and the quality of care provided. It has been repeatedly demonstrated that primary caregivers endure high levels of stress, fatigue, and exhaustion in addition to financial hardship, social isolation, and loneliness (Atchley, 1994; Zarit, 1992; Toseland and Rossiter, 1989). Not infrequently, the caregiver's health suffers as a result, especially in the case of elderly spouses who are providing care (Haley, 1997; Brody, 1985). It remains to be seen, however, whether team caregivers experience similar effects.

In addition, quality of care issues within formal caregiving systems have been explored on many levels, including basic medical care, in-home health care, and long-term care institutions. Less attention has been given, however, to the quality of care provided by informal, family caregiving systems, despite the fact that the majority of care for older adults is provided by such systems.

Available studies do suggest, however, that the quality of care is less than optimal for many care recipients, resulting in unmet physical, emotional, and social needs

(Phillips and Rempucheski, 1986). Furthermore, a substantial number of care recipients are at risk for abuse, neglect, or other forms of maltreatment (Pillemer, 1986; Pillemer, K. and Finkelhor, 1988; Wolf, 1999). Bergeron (2001) has recently examined elder abuse from the perspectives of caregiver stress and domestic violence theories. Case examples were used to illustrate the reciprocal nature of violence within some caregiving systems and to emphasis the need for a thorough understanding of the historical context of caregiving relationships.

Finally, it is anticipated that this project will result in a better understanding of how caregiving systems are constituted, how roles within such systems are defined, the meanings that participants ascribe to caregiving responsibilities, and the effects of caregiving on individual and family well being.

Problem Statement

This project explores systems of family care for elders. The aim is to identify caregiving systems that preserve the well being of caregivers while maintaining an acceptable quality of care for older adults. The goal is to determine whether there is a difference in the subjective well being of those providing care and the quality of elder care provided by families using a team approach to caregiving as compared to families using a primary caregiving approach. In addition, implications for supporting and strengthening the caregiving functions of families will be addressed.

The following questions serve as a framework for inquiry:

1. What factors influence the selection of caregiving approaches?
2. Is there a relationship between the caregiving approach utilized and the subjective well being of the caregiver(s)?

3. Is there a relationship between the caregiving approach utilized and the quality of care provided to older adults?

4. What type of interventions or supports do family caregivers believe they need in order to strengthen their caregiving capacity?

The importance of this project lies in its potential to provide a deeper understanding of family caregiving systems as well as to illuminate the perceptions of families regarding the types of supportive services they need in order to enhance their caregiving capacities. Such knowledge could make a positive contribution to the quality of life and well being of current and future generations of elders and their caregivers. In addition, since the availability of family caregivers is a critical variable in the institutional placement of older adults (Arendell and Estes, 1994), strengthening family caregiving systems may help to delay or avoid the need for such placement, thereby reducing the private and public costs of institutional care.

Furthermore, this project contributes to the development of family ecology theory by testing the usefulness of basic theoretical constructs and terminology in relation to our understanding of family functioning in late life. Specifically, the project helps to more concretely define abstract concepts, such as how families perceive and/or define "quality of care" and "well being". In addition, the project tests the compatibility of family ecology theory with ethnographic methods of data collection and a hermeneutic approach to data analysis and interpretation.

This study is also valuable to the profession of social work because it holds implications for the full range of practice with aging families, including micro, mezzo, and macro levels of intervention. That is, it suggests strategies for working with older adults and their families as well as needed changes within social policy and community-based services. These implications will be discussed further in Chapter 5.

Limitations of this research project include the small sample size and the use of purposive rather than random sampling procedures as well as informal participant selection processes, which will be described in Chapter 3. Sufficient demographic information regarding the sample has been provided, however, to enable readers to determine whether the findings may be applicable to other populations of interest.

Furthermore, this sample may be more reflective of families that are knowledgeable about available services for elders or more aggressive in seeking out and utilizing such services. This is supported by the fact that 91% of the families were utilizing at least one formal service at the time of the interviews. Their responses may not be consistent with the experiences of families that are providing elder care without the benefit of formal services.

In addition, while every effort has been made to accurately represent the lived experiences of all participants, there is likely to be some degree of distortion between observation and representation. Denzin and Lincoln (1994) state, "There are no objective observations, only observations socially situated in the worlds of the observer and the observed...any gaze is always filtered through the lenses of language, gender, social class, race, and ethnicity" (p. 12). Consideration must be given to the fact that the researcher is a middle class, middle aged, Caucasian female and the daughter of aging parents. Furthermore, while conclusions are based primarily on the responses of families participating in this project, they are also shaped by the clinical experience of the researcher with hundreds of families facing similar circumstances. Provision for review and comment by participants would considerably strengthen the trustworthiness of the findings and conclusions that follow (Denzin and Lincoln, 1994; Tutty, Rothery, and Ginnell, 1996). Unfortunately, this is not feasible at present due to time and financial constraints.

Definition of Key terms

The following list provides working definitions of key terms used in this project.

- Family: A unit of intimate, transacting, and interdependent persons who share some values and goals as well as resources and responsibilities and who have sustained a commitment to one another over time (Ames, B., 11/1/98). The concept includes family of origin, including parents, siblings, cousins; family of procreation, including, spouses, children, grandchildren; and family of affiliation, including companions, domestic partners, fictive kin. A family system consists of the patterned interactions of family members, including their communication, roles, beliefs, and rules. Families can also be viewed as energy transformation systems that are interdependent with natural, human built and social/cultural environments (Bubolz and Sontag, 1993).
- Family ecology theory: A delimitation of human ecology theory that focuses on the subsystem of the family. Units of analysis include the family ecosystem, the transactions that link families to the broader environment, and the decisions that families make in order to foster human development and adaptation (Bubolz and Sontag, 1993). Theoretical constructs of particular interest to this project include *boundaries*, which distinguish the informal caregiving system from the environmental context. Such boundaries are comprised of the "significant human activity" (Bubolz and Sontag, 1993, p. 432) of caregiving behaviors. In addition, the construct of *adaptation* is used to

describe how families adjust their interactions, both within and across system boundaries, in response to the changing needs and abilities of family members. Finally, the construct of *dynamic interaction* is used to describe the mutual exchange of energy between families and their environments. While it is assumed that environments do not determine human behaviors, it is also acknowledged that they often impose constraints as well as provide opportunities to family systems (Bubolz and Sontag, 1993). Conversely, family systems have the capacity to influence their environments in both positive and negative ways.

- Caregiving: A variety of activities addressing the survival needs of dependent individuals of any age. Such activities may include the provision of nourishment, shelter, medical care and social stimulation.

- Elder care: Caregiving activities performed for the benefit of older adults. In this context, the term is used in reference to the care provided by families to their older members.

- Caregiving models: Strategies or approaches used by families to meet the care needs of older adults. Such models include the primary caregiving approach as well as partnership and team models of caregiving.

- Ethnographic methods: An interpretive, naturalistic approach to inquiry that focuses on the daily experiences of a distinct group of people and the meanings they ascribe to those experiences.

These definitions will be further elaborated in the following chapters.

Theoretical Orientation

Family ecology, as described by Bubolz and Sontag (1993), provides the theoretical orientation for this project. As stated in the preceding section, family ecology theory represents a delimitation, or subcategory, of human ecology theory. While human ecology encompasses the full range of human populations, the focus of family ecology is the subsystem of the family. The broad scope and multilevel framework provided by family ecology theory offer the flexibility necessary for analysis of the complex relationships found within family caregiving systems. Theoretical constructs such as boundaries, adaptation, and dynamic interaction (described in the previous section) are of particular interest to this project. In addition, family ecology theory is compatible with an emphasis on the person/environment interface, which has been the traditional focus of social work practice.

Basic assumptions of the theory include the interdependence of parts and wholes within ecosystems. In addition, families are viewed as dynamic, adaptive systems with the capacity modify their environments. Furthermore, it is assumed that families interact with multiple environments, including natural, human-built, social/cultural environments in order to access essential resources. Resources are defined as "energy and information converted into specific forms for attaining goals" (Bubolz and Sontag, 1993, p. 434). Resources utilized by family caregiving systems include skills, knowledge, commitment and cohesion as well as time and money.

Interactions between families and their environments are guided by two sets of rules: the "laws of nature", such as the laws of thermodynamics, and human-derived rules, like social norms. These rules influence the allocation of resources, role expectations and the distribution of power within families and society. An ecological analysis must address interactions at each of these levels (Bubolz and Sontag, 1993).

Furthermore, family ecology theory assumes that while environments do not *determine* human behavior, they do impose limitations and constraints as well as provide possibilities and opportunities (Bubolz and Sontag, 1993). It also acknowledges that families have varying degrees of control with respect to environmental interactions and that these variations are often related to ethnicity, gender, and/or economic status. Berger and Luckman (1966) have observed that "knowledge must always be knowledge from a certain position" and that "the object of thought becomes progressively clearer with [the] accumulation of different perspectives on it" (p. 10). This project, therefore, explores family caregiving systems from multiple perspectives with respect to ethnicity, gender, and/or economic status.

Values underlying family ecology include the concept of human betterment as described by Boulding (1985). *Betterment* is defined as a system change that is evaluated as being for the better or that increases the ultimate good. Boulding identified four virtues that contribute to the ultimate good. These include economic adequacy, justice, freedom, and peacefulness. Bubolz and Sontag (1993) also maintain that the value base of family ecology is grounded in the interdependence between human betterment and environmental quality. These values are consistent with the values expressed by the Code of Ethics of the National Association of Social Work, such as service, social justice, and the importance of human relationships as well as the dignity and worth of individuals (National Association of Social Workers, 1996).

Finally, family ecology recognizes the legitimacy and utility of the "hermeneutic philosophy of science perspective, grounded in interpretive rationality" (Bubolz and Sontag, 1993, p. 427). The aim of this perspective is to achieve intersubjective understanding and mutual agreement on meaning, despite cultural differences. The subjectivity of experience and knowledge on the part of both the researcher and research participants is acknowledged. Ideally, participants are active co-partners with the researcher as they reflect on their experiences and respond to the interpretation of those experiences. The hermeneutic perspective is highly compatible with the ethnographic design of this project.

The following chapter provides a thorough, although not exhaustive, review of scholarly literature addressing the topic of elder care provided by families. Chapter three describes the methodology used to explore the hypothesis and research questions outlined in the preceding section. Chapter four presents the results obtained through participant contacts and Chapter five discusses the conclusions and implications of the project.

Chapter 2

Literature Review

Despite the common misperception that Americans abandon their elders to institutional care, a number of studies have found that families actually provide the vast majority of elder care (Brody, 1981, 1985; Cantor, 1983; McAuley, Jacobs, and Carr, 1984; Kaye and Applegate, 1990; Coward, Horne, and Dwyer, 1992). It has been estimated that approximately 22.5 million families are currently providing assistance to older relatives or friends (McFadden, 1999). A survey conducted by the National Alliance for Caregiving (1997) found that in almost one in four households, at least one member was providing care to an older adult or had done so within the past twelve months. While caregiving chores consume an average of four hours per day, one in ten caregivers provide twenty-four hour care (Atchley, 1994). It also should be noted that women comprise more that 80% of family caregivers (Hooyman, 1992). Of these women, 65% are spouses and 73% are themselves over 65 years of age (Levine, 1997).

It is likely that the need for elder care will increase in the future as the population of older adults continues to expand. Estimates project that the number of elders needing assistance with activities of daily living may grow from the current 7.3 million to 14 million by 2020, and to 24 million by 2060 (U.S. General Accounting Office, 1996). Furthermore, this increase in the population of care recipients is occurring simultaneously with demographic trends that reduce the number of available caregivers. These include decreased birth rates, resulting in fewer individuals per generation, as well as increased female participation in the public labor market (Kain, 1990). In addition, these trends are not limited to the United States but can be observed in virtually every country throughout the world (Climo, 2000).

It has been noted that scholarly literature addressing family caregiving has undergone phenomenal expansion in recent decades (Kahana, Biegel, and Wykle, 1994). For example between 1987 and 1991, there was a 200% increase in caregiving articles included in Sociological Abstracts and an increase of 307% in caregiving articles cited in Medline although the total number of articles abstracted in these databases increased by less than 10%. Such proliferation has led some scholars to question the merits of further scientific investigation of the topic (Zarit and Toseland, 1989; Kahana, Biegel, and Wykle, 1994). However, close scrutiny of the existing literature reveals significant limitations and gaps in knowledge. For example, the majority of articles offer a very narrow perspective, focusing on "the ill effects on the designated family caregivers of patients suffering from a specific disease", such as Alzheimer's Disease. (Kahana, Biegel, and Wykle, 1994, p. xiv).

A recent study by Meshefedjian, McCusker, Bellavance, and Baumgarten (1998) illustrates this type of research. These scholars examined variables associated with increased severity of depressive symptoms among 321 primary caregivers of dementia patients living in Canada. Primary caregivers were defined as "the person who was ordinarily responsible for day-to-day decision making and care of the index subject" (p. 248). This definition included both paid and unpaid caregivers.

Depressive symptoms of caregivers were measured by the Center for Epidemiological Studies Depression Scale (CES-D). Multiple regression analyses indicated that a higher CES-D score was significantly associated with the following three caregiver characteristics: being the spouse or child of the patient, ethnicity "other" than English or French Canadian, and lower education. In addition, patient characteristics, such as greater behavioral disturbances and moderate-to-severe functional impairment, were also associated with higher CES-D scores among caregivers. The investigators acknowledged, however, that "...a substantial amount of variance in caregiver depression was not explained by the risk factors in our model" (Meshefedjian, McCusker, Bellavance, and Baumgarten, 1998, p. 252).

This type of research, although well designed, tends to decontextualize the caregiving experience. While the investigators were unable to fully explain the variance in caregiver depression, they did suggest that it might be due to the availability, or lack thereof, of caregiver supports and opportunities for sharing caregiving duties. However, this explanation could not be verified due to the narrow focus on primary caregivers and the lack of data regarding the caregiving system.

A second example of research focusing on the detrimental effects of caregiving is provided by Ho., Weitzman, Cui, and Levkoff (2000). These scholars expanded upon the caregiver stress model developed by Pearlin, Mullan, Semple, and Skaff (1990) by adding a new measure for quantifying non-caregiving stress. The sample of 117 primary caregivers was composed of individuals from four ethnic groups (African American, Chinese, Latino, and Caucasian) living in the Boston area. Each participant was responsible for the care of a family member with dementia. The hypothesis investigated was that caregivers have greater need for services when presented with stressors associated with caregiving. The investigators concluded that non-caregiving stress, or stress associated with other responsibilities, was also a powerful predictor of unmet needs. This was particularly evident among Chinese and Latino caregivers. Language barriers and acculturation issues were believed partially to account for differences in service utilization among these caregivers. However, the study was unable to account for variability within the ethnic groups. Such variability may relate to informal supports and shared caregiving arrangements available to some participants but not to others. Again, due to the narrow focus on primary caregivers, data regarding the caregiving system was not collected so this interpretation cannot be verified.

These examples support the observation made by Kahana, Biegel and Wykle (1994) that there is a gap in knowledge regarding the process and context of caregiving. They state, "caregiving generally has been explored in terms of individual care providers without regard to the broader social system within which caregiving interactions are embedded" (p. xv.). Finally, these scholars assert that ecological approaches permit the consideration of previously neglected areas of the person/environment interface.

Such an approach was utilized by Tebb and Jivanjee (2000) in their study of caregiver isolation. This project used qualitative methods to explore the effects of social isolation among eight female caregivers whose spouses had Alzheimer's Disease. The aim of the project was to increase understanding of the multiple dimensions of caregiver isolation as well as the complex factors that contribute to it. The investigators were able to describe the interaction between individual and environmental factors, and they concluded that the biophysical dimension emerged as a primary isolating theme. That is, isolation increased as the physical health of caregivers deteriorated, resulting in what has been called the "hidden patient" (p. 65.).

Although this study produced an elegant ecological model of caregiver isolation, it did not look beyond the primary caregiver to identify potential sources of support and assistance within the kinship and/or friendship network. Therefore, it reinforces the assumption that the spouse *should* assume all caregiving functions despite obvious negative effects.

Although the primary caregiving model has long dominated research on family caregivers, alternative models can now be found in the research literature (Keith, 1995; Piercy, 1998; and Pyke and Bengtson, 1996). These include caregiving partnerships and caregiving teams or networks. In the primary caregiving model one person, usually a spouse or a daughter, assumes all caregiving responsibilities. The partnership model, in contrast, usually involves two siblings who make relatively equal contributions to caregiving. The third model, team caregiving, involves multiple caregivers who not only share authority and responsibility, but also "perceive themselves to be organized in a planned and integrated manner" (Keith, 1995, p. 184.). Caregiving teams may be composed of an elderly spouse, adult children and their spouses or companions, grandchildren, and other relatives as well as close neighbors and family friends. As with other teams, participants function in a variety of roles and coordination of efforts is essential in order to achieve mutual goals.

Since both the partnership and team models involve multiple caregivers and similar dynamics, they have been combined in a single category referred to as team caregiving or caregiving networks for the purposes of this project. The term, caregiving team, has been used to refer to participant families who identified multiple informal caregivers via the participant survey or during personal interviews (see Chapter 3 for a detailed description).

The studies cited above that described alternatives to the primary caregiving model were all exploratory in nature. Some suggest factors such as ethnicity or family history that may influence the type of caregiving model utilized by a given family. However, none of these studies provide evidence of qualitative differences among the models; that is, whether one model is more likely than the others to result in positive outcomes for both care recipients and care providers. For example, Pyke and Bengtson (1996) identified and explored the dimensions of individualist and collectivist systems of family care. These dimensions include variations in family beliefs and behaviors regarding interdependence/independence, attachment/separation, commitment/autonomy, and hierarchy/egalitarianism. In their discussion of the implications of the transfer of caregiving responsibility from formal, public systems to informal, family systems, Pyke and Bengtson (1996) predicted that since collectivist families tend to be less dependent on formal, public services they are better able to cope with this transfer of responsibility. They did not, however, specifically address the issues of quality of care or caregiver well being.

In addition, Piercy (1998) explored the meanings of *filial* and *familial* responsibility. Her findings suggest that, while filial responsibility focuses on the older parent/adult child dyad, familial responsibilities encompass other family members as well as the older parent. In addition, she found that it is not uncommon for families to share the responsibility of caregiving among several members. However, implications for quality of care were not addressed, although she did advocate that future research explore the effects of assistance provided by family networks for both the care recipient and the caregiver.

Cicirelli (2000) also examined the construct of filial responsibility by conducting structured interviews with fifty-three pairs of adult children and aging parents. The questionnaire included measures of parents' physical and emotional health status and cognitive functioning as well as the caregiving behaviors of adult children. Data analysis resulted in the identification of three stages in filial role development that culminate in caregiving behaviors The first stage, *concern,* was characterized by increased awareness of the growing frailty of an aging parent. Behaviors observed in this stage included increased telephone contacts, more frequent visits, and monitoring for additional signs of declining health. The second stage, *urging,* occurred when symptoms of declining health were directly observed. Behaviors of this stage included advice giving and admonishing the parent to address the symptoms in a direct manner. The final stage, *action,* occurred only after symptoms affected the functional abilities of the parent. Behaviors in this stage included various degrees of assistance with daily activities and special needs. These findings suggest that entry into the role of "caregiver" is a gradual process that begins with awareness of need or potential need. However, the design, which included the perspectives of an aging parent and one adult child who they identified as "the child to whom they would turn for help, if needed" (p. 170), tends to reify the concept of *the* primary caregiver.

Sherrell, Buckwalter, and Morhardt (2001) have also conceptualized filial maturity from a developmental perspective. These scholars maintain that filial maturity occurs when adult children learn to view their parents in an objective manner and can engage in effective decision-making regarding when to provide care, when to allow parents to maintain autonomy and when to ask for outside help. Based on a longitudinal case study with a 44-year-old woman who was the primary caregiver of her father, a dementia patient, the investigators concluded that parent-care may provoke a revisiting of the separation-individuation task and result in filial maturity. They also argue that ignoring the history and complex dynamics involved in caregiving relationships results in misconceptions regarding the nature of this experience for both caregivers and recipients of care. Although this study perpetuates a narrow focus on dementia care provided by a single individual, it does underscore the complexity of caregiving relationships and suggests the possibility that they can be growth enhancing, in contrast to the emphasis on negative effects previously mentioned.

Finally, Keith (1995) examined the division of caregiving labor within families and identified three types of caregiving systems. She also identified several family characteristics, such as the number and gender of offspring, which may contribute to the development of a specific type of caregiving system. For example, within her sample, she found that in the case of brother/sister dyads, the sister was always viewed as the primary caregiver for elderly parents. However, in families with two or more daughters, there was a greater incidence of shared caregiving arrangements.

These findings are consistent with those presented by Matthews and Rosner (1988). However, in addition to family size and gender composition, these scholars suggested that the nature of ties among siblings and parents as well as commitments siblings had to those outside their family of origin, such as employers, also influence the type and level of assistance provided to older parents. Matthews and Rosner also discussed the influence of birth order. They noted that in some families, "being the oldest carried certain expectations of routine involvement in parent care" (p. 190). In other families, however, the influence of sibling seniority was mitigated by other factors, such as the "favorite child" status of a younger sibling.

The process of caregiver selection was also explored by Ikels (1983) among families of Chinese and Irish ancestry living in Boston. The aim of her research was to assess the relative value of certain factors in predicting patterns of family support for older adults. She identified certain "rules" that appeared to transcend cultural differences. That is, she found that probable caregivers could be predicted, in most cases, on the basis of a few variables, regardless of ethnic origins. These variables were the marital status of the care recipient (if available, spouses were the most likely caregivers), and the sex and geographic proximity of adult children at the time when elder care was required.

Ikels (1983) also found that cultural values influenced the process "primarily with reference to the sex of the child expected to assume the caretaking role...Irish parents will look first to their daughters while Chinese parents will look first to their sons" (p. 492). In both groups, however, women usually provided the hands-on, physical care. Similar patterns also have been observed among Korean families (Levande, Herrick, and Sung, 2000).

In summary, the following categories of factors influencing caregiver selection have been identified (Ikels, 1983). They are listed in the approximate order of their power to predict caregiver selection.

- Demographic imperatives: The caregiver is the only child, the only child of the preferred sex, the only geographically proximate child, or the only unmarried child.
- Antecedent events: These include special obligations of reciprocity or the gradual emergence of caregiving. This usually occurs while the child is still living at home, as in the case of early widowhood.
- Situational factors: The caregiving child is the least inconvenienced or is highly motivated by affection for the care recipient. It should be noted, however, that other scholars have disputed the importance of affection as a factor in caregiver selection (Silverstein, Parrott, and Bengtson, 1995).

Although these and other studies have added much to our understanding of how caregiving labor is distributed within families, implications for quality of care and caregiver well being remain unaddressed. In addition, excessive emphasis on the detrimental effects of primary caregiving has resulted in deficit focused research.

Berg-Weger, Rubio, and Tebb (2000a; 2000b; 2001, p. 263) have recently challenged this deficit-based focus in caregiving research. These scholars maintain that such a focus produces deficit-based interventions rather than empowering strategies. Their work foregrounds positive aspects of caregiving, such as increased satisfaction and self-respect, which have also been observed by others (Horowitz, 1985a). They incorporated a Caregiver Well Being Scale (Tebb, 1995) into a survey mailed to caregivers of chronically ill family members. Well being was conceptualized as “the caregiver having at least some periodic states of security and structure within the turbulence of life” (Berg-Weger, Rubio, Tebb, 2000a, p. 163).

The analysis of 142 surveys suggested that caregiver well being is multidimensional, having both positive and negative components. It also reflects both caregiver and care recipient characteristics, such as residential arrangements and relationship to care-recipient. For example, it was reported that adult children scored higher on perceived well being than did spousal caregivers. It was also noted that an increased sense of inner strength was reported by many caregivers, but was more frequently reported by adult children than by spouses.

The well being of spousal caregivers was also addressed by Kramer and Lambert (1999). In one of very few studies focusing on male caregivers, these scholars analyzed longitudinal data from the National Survey of Households in relation to older husbands who had assumed the responsibility of caring for a disabled spouse. Their findings suggested that when compared to non-caregiving peers, husbands who entered the caregiving role demonstrated significant differences, including a decline in marital happiness and a decrease in psychological well being. This stands in marked contrast to the increase in well being reported in the studies that included adult children as well as spousal caregivers.

Very little is known, however, about the potential benefits and risks to caregiver well being associated with alternatives to the primary caregiving model or how best to support families utilizing these alternatives. Toseland and McCallion (1997), in their meta-analysis of caregiver intervention research, reviewed eighty-five studies conducted from 1979 to 1997. Interventions targeting primary caregivers were dominant in this analysis, underscoring the assumption that a single individual is usually responsible for care. However, sharing the responsibility for caregiving via caregiving networks or teams may reduce the burden of care, minimize the detrimental effects on individual caregivers, and perhaps result in improvements in caregiver well being as well as in the quality of care provided. On the other hand, the additional strain of joint decision-making and coordinating the efforts of team members may offset these advantages.

To summarize, despite the rapid expansion of family caregiving research in recent decades, gaps in knowledge regarding the process and context of caregiving remain. Specifically, little is known about alternatives to the primary caregiving approach, including the benefits and risks associated with such alternatives. Many of the scholars cited in this review of the literature have called for adding qualitative methods to the more traditional quantitative approach to family caregiving research in order to deepen our understanding of the complex relationships involved. The study reported here responds to those calls by addressing the concepts of quality care and caregiver well being from the perspectives of both care recipients and caregivers. In addition, the quality of care provided by families utilizing both team and primary caregiving approaches is examined. The methods used to explore these issues are discussed in the following chapter.

Chapter 3

Methodology

As stated in Chapter 1, this project explores systems of family care for elders. The aim is to identify caregiving systems that preserve the well being of caregivers while maintaining an acceptable quality of care for older adults. The goal is to determine whether there is a difference in the quality of elder care provided by family caregiving teams as compared to the family primary caregiving approach. The subjective well being of those providing care within each caregiving system is also examined. Finally, implications for supporting and strengthening the caregiving functions of families are addressed.

Geertz (1973) stated that ethnographic analysis "...is not an experimental science in search of law but an interpretive one in search of meaning" (p. 5). Furthermore, it has been said that ethnography is principally defined by its subject matter – *ethnos*, or culture – rather than by its methodology (Chambers, 2000). Ethnography is one of several methods of inquiry utilized within the broad domain of qualitative research.

According to Denzin and Lincoln (1994), "Qualitative research is multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them" (p. 2). Qualitative research can be distinguished from quantitative research in its epistemology, its forms of representation, and its evaluative criteria.

For example, Tutty, Rothery, and Grinnell (1996) discuss the importance of establishing "trustworthiness" when conducting qualitative research. They suggest that the following concerns must be addressed in order to establish trustworthiness: credibility (truth-value), transferability (applicability), dependability (consistency), and confirmability (neutrality). Furthermore, they point out that these concerns are only roughly equivalent to the quantitative concepts of internal validity, generalizability, reliability, and objectivity.

The term, *ethnography*, represents both a method of data collection and a style of writing, focusing on the culture or "shared meanings" (Chambers, 2000, p. 852) of a distinct group of people. Although ethnography originally grew out of the interests of Westerners in the cultures of "primitive" peoples, it now encompasses a "...vastly expanded subject matter, limited only by the varieties of experiences in modern life..." (Denzin and Lincoln, 1994, p. 42). In addition, classical ethnography required the total immersion of the ethnographer in the culture of the *other*. Although this project does not utilize such immersion, the writer will attempt to provide a rich description of caregiving experiences and to represent as accurately as possible meanings ascribed to those experiences by both caregivers and care recipients.

The following questions serve as a framework for inquiry:

1. What factors influence the selection of caregiving approaches?
2. Is there a relationship between the caregiving approach utilized and the subjective well being of the caregiver(s)?
3. Is there a relationship between the caregiving approach utilized and the quality of care provided to older adults?
4. What type of interventions or supports do family caregivers believe they need in order to strengthen their caregiving capacity?

Data Collection

These questions were explored via semi-structured interviews with families actively engaged in the provision of eldercare. The researcher conducted interviews with care recipients, whenever feasible, as well as with all available family caregivers. A broad definition of *family* was utilized for the purpose of this study, including family of origin, family of procreation, and family of affiliation. While recognizing that formal service providers often play an important role in caregiving systems, they were not interviewed for this study (1). Utilization of such services by participating families was documented, however.

This study seeks to define and assess quality of care from the perspectives of participants. Rather than using an "objective" measure of quality, the subjective perceptions of care recipients and caregivers were elicited during interviews. The elements of quality care identified in a previous study (Brewer, 2000) were reviewed with care recipients to introduce the topic and provide a basis for comparison. In addition, questions regarding the adequacy of care and level of satisfaction with care were included. Finally, participants were given the opportunity to identify areas for improvement in their situation.

(1) In a previous project, "A Qualitative Study of Family Care Models for Older Adults", (Brewer, 2000) focus group interviews with formal service providers were utilized to explore similar issues.

Sampling Procedures

A purposive sample of twenty-two families was recruited from two sources in order to reduce the potential bias resulting from the use of a single recruitment site. In addition, it was anticipated that adding a second recruitment site would result in more participant diversity in terms of ethnicity and socioeconomic status. The investigator met with agency staff at each recruitment site in order to provide an overview of the project. The overview included the following participant selection criteria:

1. Care recipients must be age sixty or over.
2. There must be at least one family caregiver, although this person need not live in the same household with the recipient.
3. Participants may not be current or former clients of the investigator.
4. Participants may not be referred to the investigator for clinical services for at least six months following their participation in the project.

Criteria number one was selected as an indicator of the "older adult" status of care recipients. While it is acknowledged that chronological age alone is a poor predictor of functional ability, age sixty has been designated the age of eligibility for most services funded by the Older Americans Act. Although scholars have suggest an earlier age would be more appropriate among some ethnic groups, such as Native Americans (Stanford and Schoenrock, 1992), functional limitations resulting in the need for long term care do not usually occur prior to age sixty.

Criteria number two was included in order to ensure access to at least one family caregiver since family caregiving is the primary focus of the study. It was anticipated that providing for the participation of non-residential caregivers would allow for a broader perspective of caregiving systems. Criteria three and four were necessary in order to avoid conflicts of interest and potential bias since the investigator also engaged in clinical social work practice in the same geographic area at the time of the study.

In addition to the criteria discussed above, the investigator provided staff at each recruitment site with a Memorandum of Introduction, explaining the nature of the project (see appendix #1). Staff at each site were then asked to distribute these memos to appropriate patients and/or caregivers. Staff also were asked to relay to the investigator the name of a family representative, telephone number and/or address for each family that indicated an interest in participating in the project. The investigator then contacted the family representative to schedule an initial meeting. At this meeting, a detailed explanation of the project was provided and the appropriate consent forms were completed (see Appendix #2). Additional consent forms were completed, as necessary, for each family member interviewed.

The recruitment sites referred a total of twenty-six families. Of these, twenty-two families (86%) actually participated in the project. Of the four families that were referred but did not participate, three dropped out due to scheduling conflicts and the fourth family representative chose not to participate due to her concern that the interview might cause emotional distress for her elderly mother.

It should be noted that participant selection occurred on at least two levels, in addition to the selection criteria designed by the researcher. First, staff at the recruitment sites were able to select families from among their contacts that they believed not only met the criteria specified by the researcher but that would be most likely to participate in the project. In addition, each family representative approached about the project had the opportunity to refuse participation or to withdraw from participation at any point.

This selection process probably resulted in a pool of participants that were relatively comfortable and confident regarding the caregiving practices of their families. On the other hand, families that were struggling to fulfill their caregiving functions may have been less inclined to participate. This, in turn, could skew the findings in a more positive direction than may be true for the general population.

The Care Management program of Region IV Area Agency on Aging (AAA) recruited twenty families that subsequently participated in the project. This program is recognized at both the state and national level for its work in the management of in-home care for older adults who are at risk of nursing facility placement. In 1999, Care Management staff worked with over 1000 families providing care to elderly relatives. In addition, Intercare Community Health Network (ICHN) recruited two participating families. ICHN is a community and migrant health center that provides primary health care services at several clinics in Allegan, Berrien, Cass, and Van Buren counties as well as medical outreach to area migrant labor camps. Individuals utilizing the services of ICHN are predominantly low-income Hispanics and African Americans.

The two families recruited by ICHN were compared to the families recruited by AAA to determine whether there were substantial differences among the families. They were similar in most respects, with one exception. One of the ICHN participants had a caregiving system constituted entirely of friends and neighbors. This elderly, Native American woman had no children of her own and her only living relatives, a brother and two elderly nieces, were unable to provide needed care. After an episode of financial exploitation, she turned to her friends for assistance. Since the families recruited by the two sites were similar in most respects, data were analyzed and reported as a single unit.

Participant Interview Procedures

Separate semi-structured interview guides were developed for care recipients and caregivers (see appendix #3.A and #3.B). This format was selected because it provides moderate structure as well as considerable flexibility (Tutty, Rothery, and Grinnell, 1996). Interview topics included identification of the family caregiving system, the history of family caregiving relationships, perceived changes in quality of life and subjective well-being over time, quality of care ratings, current utilization of formal services and perceived need for additional supports.

An effort was made to interview the care recipient and caregiver separately. However, in many cases this was not feasible due to the size and arrangement of living quarters, communication deficits, and other factors. Fifteen care recipients were interviewed in the presence of at least one caregiver. Three additional care recipients were interviewed separately and four care recipients could not be interviewed due to the severity of their cognitive limitations. It should be noted that the responses of both parties were probably affected when joint interviews occurred. For example, caregivers may have been less candid regarding the effects of caregiving on their personal well being when the care recipient was present during the interview. On the other hand, care recipients may have been reluctant to acknowledge poor quality care in the presence of caregivers.

The investigator conducted all interviews. Participants were offered a cash payment of $10.00 per interview. Several of the participants refused to accept this payment. Some explained that they did not need to be compensated for their time but that they wanted to support the project in the interest of better understanding the experiences of family caregivers.

Of the thirty-three caregivers interviewed, twenty-nine were interviewed in person. Of those, sixteen were interviewed in the presence of the care recipient and thirteen were interviewed separately. Due to scheduling constraints, four caregiver interviews were conducted via telephone. Nine additional caregivers were identified by family representatives but were not available for interviews. In the case of telephone interviews, detailed notes of the conversation were made during the interview and subsequently transcribed by the investigator. All other interviews, with one exception, were audio taped and transcribed verbatim by Office Services staff at Michigan State University. The transcripts were subsequently spot-checked for accuracy by the investigator. In the exception noted above, the caregiver agreed to be interviewed but refused to be audio taped. The procedure used for telephone interviews was also followed in this case.

Participant Survey Procedures

In addition to the interviews, a representative for each family was asked to complete a brief participant survey (see Appendix #4). These individuals were self-selected by the participating families. Information collected via the survey included the age and gender of the care recipient as well as ages and genders of all family members involved in the caregiving system. An estimate of the hours per week of care provided and the nature of the caregiving tasks performed also was obtained. In addition, an estimate of the economic status of the care recipient and the ethnic identity of the caregiving system was requested. Finally, the nature and severity of the care recipient's disability was documented along with the duration of the current caregiving system.

Data Analysis

SPSS was utilized to analyze data collected via the participant survey in order to generate descriptive statistics for the sample. Such data is necessary in order to permit potential readers to assess the fit between the sample and other populations to which the findings may apply (Meloy, 1994).

Interview transcripts were analyzed using Non-numerical Unstructured Data Indexing, Search, and Theorizing (NUD*IST) software, developed by Qualitative Solutions and Research. NUD*IST contains both a document system that facilitates management and exploration of project documents, such as interview transcripts, and an index system for storing and sorting concepts, categories, and patterns as they emerge from the data. Both systems can be searched and queried to support data interpretation and theory building.

The results obtained from the data collection and the data analysis procedures described above will be discussed in detail in Chapter 4. First, responses to the participant survey will be presented and compared to data obtained from national surveys. This information provides the background necessary for informed decisions regarding the applicability of project findings to other populations of interest. Such a comparison offers a means of locating this study within the broader national discourse that addresses informal long-term care for older adults by identifying areas of convergence and divergence between the characteristics of study participants and those of caregivers represented by randomly selected national survey participants. Chambers (2000) has noted that this practice "...seems particularly relevant to applied research...." (p. 858). Finally, responses obtained during participant interviews will be presented, utilizing the framework for inquiry described above.

Chapter 4

Results

Participant Survey

Description of Care Recipient Characteristics

A self-selected representative from each of the twenty-two families participating in the study completed the participant survey. The results of the survey were as follows. The average age of care recipients participating in the project was 77 (N=22). Ages ranged from 62 to 93 years. Most (70%) of the care recipients were women. This is not unusual given the longer life expectancy of women. Since they live longer and experience more chronic illness in late life, older women are frequently in need of long-term care. These demographic facts are also reflected in the higher proportion of women residing in long-term care facilities (Arendell and Estes, 1994).

Caregivers were asked to indicate whether the care recipient's disabilities included physical limitations only, cognitive limitations only, or a combination of physical and cognitive limitations. Their responses indicated that 50% (11) of the care recipients had physical limitations only, approximately 12% (3) had cognitive limitations only, such as Alzheimer's disease, and 38% (8) had a combination of physical and cognitive limitations, resulting primarily from strokes.

Caregivers also were asked to rate the care recipients' level of disability. The following guidelines were provided to assist caregivers with this rating. Maximum disability indicates that the care recipient is essentially bedridden and may need assistance to turn in bed. Moderate disability indicates that the care recipient is able to transfer from bed to chair with assistance and needs substantial assistance with activities of daily living (ADL). Minimal disability indicates that the care recipient primarily requires supervision as well as some assistance with ADL. Of the twenty-two care recipients, approximately 30% (7) were rated by caregivers as having a maximum level of disability, 50% (11) were rated as having a moderate level of disability, and 20% (4) were rated as having a minimal level of disability.

Caregivers also were asked to rate the economic status of care recipients, based on the following scale: lower (less than $12,000 annual income), middle (between $12,000 and $24,000 annual income), upper (more than $24,000 annual income). The majority (14) of care recipients in the sample were in the lower economic group, according to caregiver ratings. Approximately 20% (5) were in the middle economic group and only one was in the upper economic group. This distribution is not surprising given that programs provided by both recruitment sites target low-income populations.

Finally, the ethnic identity of each caregiving system was documented. Based on caregivers' ratings, 77% (17) of the participating families were Caucasian, 14% (3) were African American, and 9% (2) were Native American. Unfortunately, no Hispanic families were represented in this study although an attempt was made to access this population by including Intercare Community Health Network as a participant recruitment site.

Data resulting from the participant survey are comparable to data drawn from a national survey sponsored by the National Alliance for Caregiving and the American Association of Retired Persons (NAC/AARP, 1997). That study was based on telephone surveys with a nationwide randomly selected sample of caregivers. A total of 1,509 English-speaking family caregivers participated. To be included in the study, caregivers had to be at least 18 years old. In addition, they had to be either currently providing informal care or having done so within the previous twelve months. There were, however, no stipulations regarding where the care recipient lived nor the amount, duration, or frequency of care provided. The following table (Table 1) provides a comparison of the age and gender of care recipients participating in this study to data drawn from NAC/AARP survey.

Table 1: Comparison of Study Sample to National Survey Data*
Regarding Age and Gender of Care Recipients

Variable	Study Sample	National Survey
Average age of care recipient	77 (range:62-93)	77
Gender of care recipient	70% Female	"Typically female": 31% mothers, 9% mother-in-laws, 12% grandmothers

*National Alliance for Caregiving and American Association of Retired Persons (1997)

Table 2 provides a comparison of the level of disability of care recipients participating in this study, as reported by their caregivers, and the level of care provided to respondents of the NAC/AARP (1997) survey. That survey utilized the Level of Care Index, which is based on hours of care per week and types of care provided. For purposes of this comparison, a "level of care" based on the types of care provided and the hours of care per week, as reported by caregivers, was assigned to each care recipient participating in this study. Generally, a higher level of care indicates a higher level of disability.

Table 2: Comparison of Study Sample to National Survey Data
Regarding Level of Disability/Level of Care

Level of Disability: Participant Survey	Level of Care : Study Sample	Level of Care: National Data
Minimal 20% (n=4)	23%	40%
Moderate 50% (n=11)	14%	19%
Maximum 30% (n=7)	63%	36% *

* Total less than 100% indicates missing data

This comparison suggests that the care recipients participating in this study are more disabled and therefore require a higher level of care than the care recipients represented in the national survey. This is likely due to the sampling pool since the Care Management Program, one of the recruitment sites, is targeted to individuals at risk for nursing home placement. It should be noted, however, that many caregivers had difficulty estimating the number of hours they spent providing care each week. For many, the number of hours varied from day to day based on changes in the care recipient's level of functioning and the availability of formal support services. Most primary caregivers perceived themselves to be "on-call" twenty-four hours a day, seven days per week. The implications of this perception of constant responsibility for the well being of care recipients will be discussed in the following chapter.

Description of Caregiver Characteristics

In addition to documenting the demographic characteristics of care recipients, information regarding caregivers also was collected via the Participant Survey. This information can also be compared to national survey data (NAC/AARP, 1997). For example, Table 3 compares the age, gender, and duration of caregiving for caregivers participating in this study with caregivers represented by the NAC/AARP survey.

In addition, a second study, the National Survey of Families and Households (1992) provides additional perspective regarding the average number of caregivers per care recipient, a topic not addressed by the previously mentioned survey. This data suggests that it is not uncommon for more than one person to be involved in the provision of care within a caregiving system.

Table 3: Comparison of Study Caregivers with Caregivers Represented by National Survey Data (NAC/AARP, 1997)

Variable	**Study Sample**	**National Survey**
Age of Caregiver	57 (range: 30-86)	46
Gender of Caregiver	68% Female; 32% Male	73% Female; 27% Male
Average Duration of Caregiving	4% < 1 mo.; 18% 7 mos. to 1 yr.; 77% > 1 yr.	4.5 years
Average No. Of Caregivers per Care Recipient	1.9	1.7 *

* From National Survey of Families and Households (1992)

This comparison suggests that caregivers participating in this study are considerably older than caregivers represented by the national survey. In addition, the proportion of male caregivers in this study is larger. Both groups, however, include long term caregivers. That is, 77% of the caregivers participating in this study have been providing care for more than one year while national survey data reflect the average duration of caregiving to be 4.5 years. It should be noted, however, that some caregivers provide care to multiple care recipients, either simultaneously or sequentially, resulting in extensive caregiving *careers*. At least three study participants reported that they had been providing care for more than five years.

The larger proportion of male caregivers may again be an artifact of the sampling pool since all of the participating families had some level of contact with the formal service delivery system (i.e. Area Agency on Aging, Care Management program). The literature (Horowitz, 1985a; Kaye, and Applegate, 1990) indicates that male caregivers tend to utilize formal services at a higher rate than female caregivers. In addition, the distribution of male caregivers participating in this study suggests that they are more likely to be members of caregiving teams rather than primary caregivers. For example, twelve (86%) male caregivers were identified as "team members" and two (14%) as "primary caregivers". Among the female caregivers, however, eighteen (64%) were identified as "team members" and ten (36%) as "primary caregivers". This is consistent with the findings of Pyke and Bengtson (1996). Of the twenty-two families participating in the study, twelve (55%) used the primary caregiving approach and ten (45%) used a team approach to caregiving. The caregiving teams ranged in size from two members to six members.

The caregiving approach utilized by participating families was compared to the ethnic identity of the caregiving system. The results of this comparison are presented in Table 4.

Table 4: Comparison of caregiving approach and ethnic identity

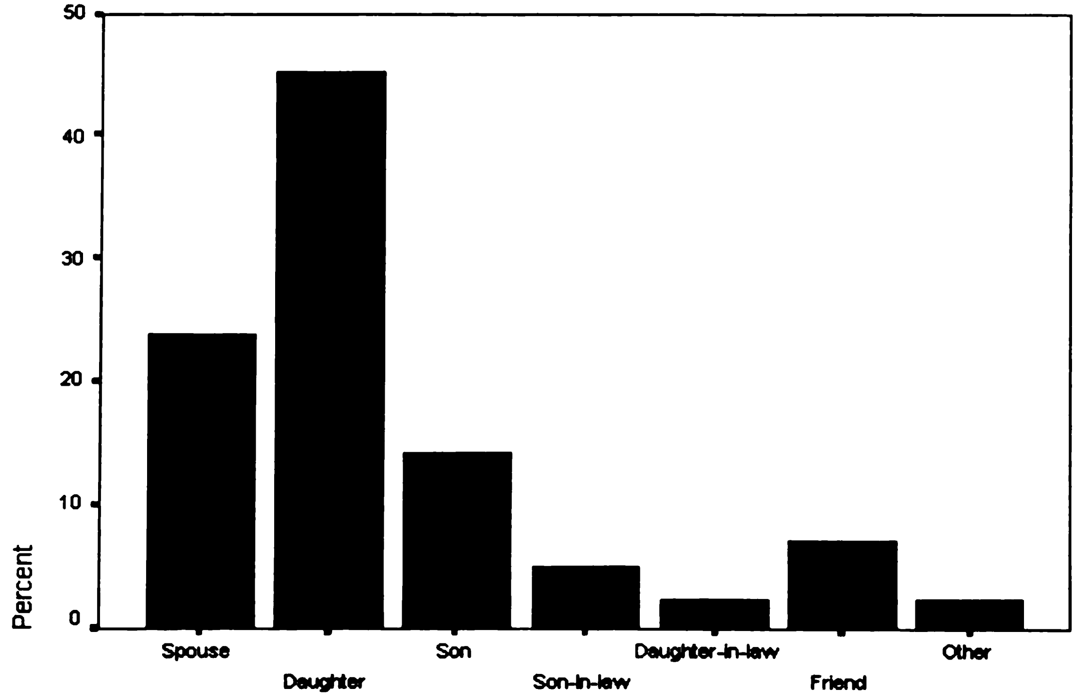
Ethnicity	**Primary Care Approach**	**Team Care Approach**
Caucasian (N=17)	10 (59 %)	7 (41%)
African American (N=3)	2 (67%)	1 (33%)
Native American (N=2)	0	2 (100%)

These findings seem to suggest that Native American families are more likely to use a team approach than either Caucasian or African American families. However, this interpretation should be viewed with caution due to the limited number of cases involved. Also, the participant survey requested information regarding the ethnic identity of the care recipient rather than caregivers. In both cases involving Native American care recipients, the caregivers were Caucasian. This may reflect a level of assimilation and integration among ethnic groups in this geographic area not found in other regions.

Other scholars (Pyke and Bengston, 1996) have suggested a linkage between ethnicity and the structure of caregiving systems utilized. For example, in their analysis of individualist and collectivist caregiving systems, Pyke and Bengston (1996) suggested that collectivism is associated with working class, ethnic minority families. These findings lend some support to that observation.

Finally, the relationship of caregivers to care recipients was documented. Figure 1 illustrates the relationships identified by participants. Caregiving spouses were equally distributed between males and females. Approximately 45% of the caregivers were daughters of care recipients, while sons constituted 14% of the caregivers. The remaining caregivers were identified as sons-in-law, daughters-in-law, friends, and a niece.

Figure 1: Caregiver relationship to care recipient



In addition to situating the current project within the national discourse regarding long-term elder care by families, this description of the sample has been provided in order to enable readers to make informed decisions regarding the application of study findings to other populations of interest.

Participant Interviews

The organization of the following section is based on participant responses to the questions constituting the "framework for inquiry", which was introduced in Chapter 3.

1. What factors influence the selection of caregiving approaches?

In order to verify the data collected via the Participant Survey, care recipients were asked to identify the people who usually provide assistance when needed. In addition, they were asked how long each person had been providing assistance and whether others had been involved in the past (see Appendix 3.A for specific wording of interview questions). Care recipients generally identified their spouses and adult children when responding to these questions. A few also mentioned formal service providers such as home health aids.

When exploring changes in the caregiving system over time, care recipients often referred to changes in the work schedules of their adult children to explain why they were less involved than in the past. For example, one elderly mother explained, "we have a daughter that was working 12 hours a night. When she was working that shift, she didn't work on Friday nights and then she would come up on Friday and take me out for a while. But when she's working 12 hours a day, she can't do that."

In a few cases, alterations in the health status of a caregiver resulted in changes to the caregiving system. For example, one daughter who was assisting her mother with providing care for her demented father was diagnosed with cancer and needed considerable assistance herself while undergoing chemotherapy. Her sister, who had been living in Florida, moved to Michigan in order to assist with the care of both her father and sister. This case also illustrates that geographic distance is not necessarily a barrier to caregiving, depending on the circumstances and motivations of the individuals involved. In this particular case, the woman and her spouse had lived in the area previously and had moved to Florida in order to pursue educational opportunities. They had already considered moving back to Michigan and care needs within the family simply prompted their decision to do so.

In another case, a woman moved from California to Michigan in order to care for her father and his elderly sisters. She explained her decision as follows:

> My father was their brother, and my father and I had always been very, very close, and he lived in California with me for many years. And he had said to me, "I want to go to Michigan to live with my sisters. There's just the three of us left, and one's been sick for a long time." Wherever my father was, I was always there. In eighty-seven, I came back here to visit with him during my vacation, and recognized the need. Before then, I don't think I ever had. I went back to California, and shared that need with my husband. I had been offered a couple of retirement plans – early retirements that had penalties associated with them because of my age. I wasn't fifty-five at the time. I had refused those. So it was August of that year, eighty-seven, when I went back and told my husband about it. Two months later I was off with full retirement.
>
> Then my dad passed away in ninety-three, so this young lady is the last one here, and she is quite a lady...I always accepted responsibility for my father. My mother died when I was two years old, and I was so close to my father, so I

> always recognized that as a responsibility, but never realized that the sisters also needed the help. So when he was back here…as soon as I got time and vacation in eighty-seven, I came. I remember sitting right here watching her in there. My dad had emphysema for many years before he passed away, so he wasn't in the best of health. She was taking care of my dad, basically. She was taking care of her sister that was bedridden, and she was taking care of a lady down the street. I sat here and I thought – she needs help! I tell her all the time that actually I came here to help her, because my dad and the other sister had her.

On the other hand, one caregiver expressed the belief that her siblings had moved away at least partially in order to avoid caregiving responsibilities. She stated, "...both of my brothers have been gone –one probably 20 years and the one for 10. My sister just left here maybe three or four years ago. They give me their best [regards] and tell me they wish they could help with mom."

In order to better understand how caregiving systems are formed, caregivers were asked whether they had anticipated their caregiving role and how they became involved in providing care (see Appendix 3.B, questions 2 and 3). Only five caregivers indicated that they had expected to be involved in caregiving. In most of these cases, there had been another family member who needed care, e.g. a mother-in-law. This seemed to precipitate planning or at least some consideration of the potential needs of the current care recipient. A few caregivers had medical training or other work-related experiences that had increased their awareness of the care needs of older adults. All of these caregivers were adult children rather than spouses. Spousal caregivers frequently mentioned plans they had made for retirement but denied that they had anticipated caregiving needs or responsibilities.

For some of the caregivers, their involvement was very rapid, often resulting from a stroke or some other acute medical problem. For others, their involvement increased gradually over time and may have evolved out of other responsibilities, such as in the case of the niece/caregiver previously described. In another case, a daughter provided the following history of caregiving:

> I was involved with my mom's care... I took her to the doctor, took care of whatever I needed to take care of for her. And then when she passed away, Dad just started not feeling good. So I started taking him to the doctor then to find out what was wrong with him and that was six years ago. It has just been an up and down thing the whole six years. We just keep an eye on him ... when you are right here it is just very easy. And also when you are the youngest child, they seem to have a tendency to depend on you more.

It is interesting to note that this caregiver attributed her caregiving role to her position as the "youngest child" in the family. As discussed in chapter two, the eldest sibling is often the preferred caregiver; however, younger siblings occasionally fill this role due to situational factors, such as early widowhood or the premature disability of a parent.

Other caregivers indicated that the onset of their caregiving role was very rapid. For example, a wife stated it this way:

> For me it was sudden, because it had been coming on for a while, but I guess I just refused to see it. Then when we were down to my daughter's in Florida

> visiting, he became lost when he went out for a walk and he became incontinent... So, of course, as soon as we got home we started taking him to the doctor and seeing what his problems were and as it turned out there were many.

In order to assess the extent of caregivers' involvement, participants were asked to estimate the number of hours of care provided per week and whether the hours had increased or decreased over time. Most caregivers had difficulty estimating the hours of care provided, as previously mentioned, since it varied on almost a daily basis. Five caregivers expressed a perception of continuous responsibility for the well being of a family member. They were unable to estimate the number of hours of care provided per week because they felt they were always on call or monitoring the care recipient. Two of these individuals indicated that they were the sole family caregiver while three indicated that other family members assisted with caregiving tasks, yet they perceived this assistance to be secondary to their role and felt the need to monitor or "back-up" other care providers. This perception of continuous responsibility appeared to be associated with higher levels of stress and a diminished sense of general well being.

Most caregivers indicated that the time they spent increased as the care recipient's condition deteriorated and they were less able to do things for themselves. This was very apparent in the cases that involved dementia or progressive conditions such as multiple sclerosis. However, in several cases caregivers felt the time they spent with care recipients had "leveled off" or decreased, usually because other services or supports became available to assist with care. In some cases, the amount of time devoted to caregiving had decreased because of outside circumstances. For example, a spouse lost their job, so the caregiver needed to work fulltime. In another case, a caregiver diagnosed with cancer needed to spend more time on self-care. In each of these cases, other family members stepped in to meet the care recipients needs.

To summarize, it appears that these informal family caregiving systems, composed of the care recipient and at least one family caregiver, are dynamic. That is, they evolve over time in response to both the changing needs of the care recipient and the changing circumstances of caregivers. Rather than being implemented as the result of a deliberate decision-making process, they are usually formed and transformed in response to changing needs and circumstances. They expand or contract over time in response to internal or external conditions. This is consistent with Hareven's (1995) argument that family relations in late life are molded by individual members' cumulative life histories as well as by specific historical circumstances, such as wars, migrations, and economic conditions. Factors influencing the caregiving approaches used by families also include awareness of need, ability (physical, financial, and emotional) to respond to the need, and willingness to act on behalf of the care recipient. The latter appears to be linked to the quality of both past and present relationship between the care recipient and potential caregivers. This will be explored more fully in the following section.

2. Is there a relationship between caregiving approach utilized and the subjective well being of the caregiver(s)?

In order to explore the connection between the caregiving approach utilized and the subjective well being of the caregiver(s), caregiver interviews included questions addressing the history of their relationships with both the care recipient and other caregivers, when appropriate, as well as other important relationships. (See Appendix 3.B, questions 21-24).

Effects of Caregiving on Relationship between Caregivers and Care Recipients

Eight caregivers acknowledged negative effects of caregiving on their relationships with care recipients. They described feelings of frustration, anxiety, fear and anger that related to alterations in the care recipients' level of functioning or to their own limitations. One caregiver also acknowledged guilt feelings in relation to her impatience with the care recipient. Another caregiver reported that she and her spouse had been estranged for a number of years prior to the onset of caregiving. However, she allowed him to move into her home when he became ill because "someone had to do it," but there appeared to be little, if any, affection between the two. Despite the potential distortion of responses due to joint interviews as discussed in Chapter 3, these reports of negative effects were distributed equally between caregivers interviewed in the presence of care recipients and those interviewed separately.

Six caregivers expressed the belief that their relationships with care recipients had improved as a result of caregiving. Two described emotionally distant relationships with their parents prior to the onset of caregiving. Both felt that they have gotten to know their parents better and as a result felt "closer" to them now than in the past. This may represent one of the benefits of caregiving that is often overshadowed by the burdens (Horowitz, 1985a). It may also reflect the last-ditch efforts of adult children to correct problematic relationships with their aging parents.

A few caregivers reported "no change" in their relationships with care recipients. Most clarified this by stating "we have always been close". Such closeness may motivate the initial commitment to caregiving and help to reduce the stress involved. However, it also would appear that the lack of such emotional "closeness" does not necessarily preclude involvement in caregiving as demonstrated by the caregivers that described distant relationships prior to the onset of caregiving.

Effects of Caregiving on Relationships between Caregivers

During caregiver interviews, participants again were asked to identify other informal caregivers and to describe how shared caregiving responsibilities had affected their relationships with those people. It was interesting to note that several participants who had identified themselves as "sole" caregivers when completing the participant survey were able at this point to identify other family members who shared the responsibility for providing care and who were therefore part of the caregiving system. These individuals have been labeled "hidden caregivers" because their work is often invisible or obscured. In a very real sense, they stand behind the "sole" or primary caregiver. Their work is, nevertheless, important to the stability of the caregiving system. They provide support to the primary caregiver and are available to step in when emergencies arise. Consequently, they help to ease the burden of care in small, but essential ways. For example, one caregiver said, "Oh my son once in a while, just to help me, you know, but not on a regular basis at all." Another stated,

> I'm basically alone as far as commitment. I should say, there are people that I do call. She has a dear friend that will sometimes come over on Sunday and spend a couple of nights with her. There's another gentleman down the street that checks to see if she needs anything. I have a daughter that is very busy raising a teenager, but sometimes she stops by. So all of them stop by and check on her.

These comments suggest that caregiving behaviors within families are not always recognized and defined as such. This may contribute to the perceived dominance of the primary caregiving approach, which obscures the contributions of those who play supporting rather than central roles within caregiving systems. It could be useful to identify these hidden caregivers and work toward amplifying their roles to create a sense of partnership or teamwork where it does not already exist. This will be explored more fully in Chapter 5.

Members of caregiving teams also were asked to reflect on changes affecting their relationships with other team members. Three caregivers explained that the effects of caregiving on family relationships have been mixed. That is, they noted improvement in some areas, like communication, as well as deterioration or tension in other areas. For example, in one family dealing with dementia, family members had different perceptions of the level of impairment of their father. One brother believed the care recipient was more able while the others saw him as more disabled. This resulted in differences in how family members approached and responded to the care recipient, which in turn generated friction among the caregivers. The son acknowledged that he frequently felt annoyed at siblings and his mother for showing "disrespect" to his demented father by treating him like a child. The mother, on the other hand, believed this son did not accept, or "refused to see", his father's limitations.

In this family, old issues of "who did what for whom and when" seem to contribute to the tension. There was an underlying theme of old scores to be settled. Hargrave and Anderson (1992) refer to this as the "intergenerational family ledger" (p.170), which contains an unwritten record of obligations and entitlements. Furthermore, these scholars suggest that helping families to achieve a balance in the intergenerational ledger is an important focus when working with aging families.

Although difficult at times, the family mentioned above was willing to work together to ease the burden of care that would otherwise fall on their mother. They expressed concern regarding her well being and the potentially negative effects of caregiving. For example, one sibling stated, "she has gotten short-tempered and she just seems to be so much more worried about things than she used to be. I think it has got to be because she must have depended on Dad so much more than we realized."

Five caregivers denied that sharing caregiving responsibilities had any effect on their relationships with other members of the caregiving system. Most explained this by saying something like "we have always been close" or " we have always worked together as a family". Three caregivers reported improved relationships with other family members as a result of shared caregiving. For example, one sister who moved from another state to assist with the care of her father expressed that she feels emotionally closer now that she is geographically closer to her family.

Several caregivers acknowledged that sharing caregiving responsibilities had a negative effect on family relationships. For example, an adult daughter, temporarily living in the home of her parents while helping to care for her father, acknowledged that she and her mother "get on each other's nerves" more than in the past. She characterized their relationship as "more like friends" than parent/child and believed that living under the same roof with her parents – along with her own young children – had strained this relationship. The tension appeared to be secondary to their shared caregiving responsibilities.

Another caregiver complained that she and her spouse, who helped care for her mother, rarely are able to spend time away from home together. She states, "either he goes and I stay, or I stay and he goes. We seldom go out together anymore". Finally two sisters who share caregiving responsibility for a neighbor acknowledged that they occasionally experience friction when negotiating caregiving tasks.

Other Effects of Caregiving

Caregivers also were asked to describe how their caregiving role had affected their work or other important relationships. Several of the caregivers were retired, and one worked part-time as a volunteer. Among those caregivers who were employed, two acknowledged that they had left work on occasion due to emergencies involving the care recipient. Both denied that this was a problem and stated that their employers were "understanding" and "flexible" because they were aware of their situations.

One woman, whose spouse was apparently in the early stages of dementia, described a feeling of perpetual stress due to worrying about him while she was working. He denies his disability and refuses supervision during the day. Consequently, she is anxious regarding his safety. Another caregiver said that co-workers as well as her spouse have expressed concern about the amount of time she spends providing care. For example, they express concern when she uses her personal leave days from work to transport the care recipient to medical appointments. She states that she has made a decision that "this has to stop" but is sure that the care recipient will resist using alternative transportation. One caregiver stated that she had quit her job to care for her mother. This woman, one of the younger caregivers, also mentioned that she had hoped to continue her education, but deferred her plans in order to care for her mother.

Other caregivers mentioned that fatigue related to caregiving chores had affected their lives in a negative manner. This seemed to be an issue for younger caregivers with school-aged children as well as older caregivers, who had trouble sleeping at night due to anxiety. For example, one elderly man reported "sleeping with one eye open" and being "tuned in" to his wife's breathing.

Several caregivers mentioned that their personal leisure time has been drastically reduced due to caregiving chores. An elderly couple mentioned that their support system has diminished since her health now precludes their annual trips to Florida with friends. They also noted that many of their friends are experiencing similar health problems and that several have died, further constricting their social support system. Two male caregivers mentioned that caregiving chores had resulted in less time for leisure activities such as hunting and fishing. One also mentioned a loss of interest in previous hobbies, suggesting reasons beyond caregiving for the decrease in activities. He said, "as far as recreation and hobbies, and that sort of thing, I think at the age I am now, I've lost interest in those things anyhow, because I can't physically do them anyway." This statement could be an indication of depression. In addition, it may serve to reduce feelings of guilt experienced by the care recipient or it may simply represent a statement of fact.

Many caregivers report that activities now require more planning and are therefore less spontaneous. One caregiver stated, "I wouldn't say we really spend any less time. It is a little more difficult if I want to go do something because I need to have somebody here. It is coming up more so now than it has (in the past) because she is getting worse." Another stated, "We have a son who plays basketball. Caregiving duties often interfere with my ability to attend his games if they are away. Also, when we are invited out, for example to a birthday party, I have to arrange to put my mother-in-law to bed a little earlier than usual."

A total of nine caregivers indicated that they have reduced or eliminated social activities that they had previously enjoyed. These activities ranged from church attendance and service club involvement to informal visits with friends. One caregiver specifically mentioned feeling isolated by her caregiving responsibilities and another admitted feeling lonely due to lack of contact with friends.

Three of the caregivers acknowledged that their caregiving responsibilities reduced the amount of time they spend with their children or grandchildren. One woman said that her spouse, the care recipient, was reluctant to leave home, even for family gatherings. She was frequently confronted with the choice of leaving him alone or missing opportunities to see her grandchildren. She identified herself as the sole caregiver. Another elderly male caregiver described a constant feeling of "pressure". He seemed very concerned about the quality of care his wife received and may experience performance anxiety in relation to his role as caregiver.

Self-Assessment of Caregiver Well Being

Finally, caregivers were asked to compare their current overall sense of well being (i.e. physical health, emotional status, and important relationships; see Appendix 3.B, question 10) with their status prior to the onset of caregiving. Six caregivers believed that they were "about the same", that is, they denied that caregiving had affected their well being in any way. Some caregivers seemed uncomfortable or unaccustomed to consideration of their own well being, perhaps due to preoccupation with the needs of the care recipient and/or the presence of the care recipient during the interview. This may have prompted ambiguous responses as illustrated by the following:

> Well, I'm a diabetic, and I give myself two shots, and sometimes I get off balance because I forget. I get so busy that I just forget, but then I figure, well, I'm all right, you know. But I do get tired. That I will say. I do get tired.

Of the responses coded *ambiguous*, five occurred during joint interviews while only one occurred during a separate interview.

Seven caregivers felt their overall well being was "better" as a result of their caregiving experience. One male caregiver said that he had made a decision to live a healthier lifestyle after observing the deterioration of his father's health. Others felt they were more "understanding" or communicated more effectively with other family members. One woman stated that caregiving had given her a sense of purpose, "I feel very committed to this, very comfortable, and very peaceful. I had not found that peace in my life before."

Ten caregivers, however, acknowledged that they were "worse" off as a result of caregiving. Most cited health problems such as high blood pressure and/or heart disease. Others described chronic fatigue and emotional distress. Two caregivers mentioned that they were taking prescription medications, such as antidepressants, to alleviate emotional problems. Several acknowledged the importance of self-care, but stated they sometimes had trouble finding time for activities such as exercise or medical appointments.

These responses were further analyzed regarding the presence or absence of the care recipient during the interview. There did not appear to be substantial differences between the responses of caregivers interviewed separately as compared to those interviewed jointly. This suggests that the presence of the care recipient during the interview may not have been as influential as previously assumed.

Difficult Aspects of Caregiving

Caregivers also were asked to discuss the difficult aspects of the caregiving role as well as the positive aspects, based on their own experience (see Appendix 3.B, questions 11 and 12). Seven caregivers denied that they considered any aspect of caregiving "difficult". These responses were frequently qualified by comments such as "it's not that bad" or "... it is not that difficult. This is what I do". One man stated, "I don't feel it is because I'll tell you what, when she first got down in bed, I just started a routine, getting up in the morning, doing certain things and then I do it every day the same way."

Three caregivers indicated that overcoming the resistance of the care recipient was a difficult aspect of providing care. For example, one daughter caring for her demented mother found it necessary to move the care recipient into her home despite her mother's objections:

> ...so I had to bring her here and it was very, very – that was very difficult – because she was very paranoid, very difficult, physically difficult. She kept threatening to leave and to walk and to go back home and this type of thing. It was very difficult taking care of her.

While such resistance may have made caregiving more difficult, it did not appear to diminish the determination of this caregiver to provide for the needs of her elderly mother. In another case, pride seemed to be the basis for the care recipient's resistance. For example, the caregiver stated:

> It's a pride thing. She said that she doesn't need anybody to cook for her. She can eat. She was eating because I was cooking meals five days a week, and then a couple of frozen dinners on the weekend. That went on, I cooked for probably two and a half, or three months, before I got her to accept the meals on wheels. That was really hard. She said, 'I'm not going to take charity. I'm not going to take meals without paying for it.'

Two caregivers mentioned that dealing with delusional ideas and related behaviors was very difficult for them. For example, one female caregiver commented, "...mainly the most disturbing thing is whenever he has a delusion, that upsets me. Like Sunday he didn't know I was his wife...but he's not like that, hardly ever. I mean, you know, this just happens once in a while. But, it is scary when it happens."

One caregiver mentioned that bathing and dressing her elderly father has been difficult for her, although she had training and work experience as a certified nurse's aid. Her discomfort seemed to be related to the intimate physical contact more than the actual labor involved, as illustrated by this comment:

> ...I did it at the hospital and I did it to other people, but it is – I don't know – it is different when you do it for your family. I mean I know it has to be done, so I just do it.

Her discomfort may be related to societal taboos that preclude intimate physical contact between parents and children of the opposite sex (Horowitz, 1985b; Montgomery, 1992).

Four caregivers mentioned that arranging to "get away" or take a break from caregiving duties was the most difficult aspect of their situations. This was more frequently the response of sole caregivers, but also was reported by one team caregiver. The following illustrates this type of response:

> Sometimes it is hard when you say, 'no I can't do something because I have to take care of him' – like going camping or out to dinner. Sometimes you get mad at yourself because ...I'm human. Like I said, we've been doing it for almost a year and there are times when I don't want to do this – then you feel really bad when you feel that way. It only lasts a short time and then you are over it. You know that this is what you have to do.

Two caregivers, both of whom were male, mentioned that sleep deprivation and the resulting fatigue were very difficult for them. For example, one caregiver attributed his own health problems to lack of sleep, "See this is why I think I had the breakdown. I had to get up every night. Sometimes I couldn't sleep before or after I couldn't sleep, I didn't get much sleep." Subsequent to his "breakdown" (apparent CVA), another family member took over the task of periodically repositioning the care recipient during the night so that this elderly man could get uninterrupted rest. However, the residual effects of his CVA continue to diminish his general sense of well being.

One caregiver stated that coping with her anger is the most difficult aspect of caregiving. She saw herself as the sole caregiver, although she reported that her adult children do help out occasionally by providing respite care for their father. In this case, she was separated from her spouse, the care recipient, prior to the onset of caregiving but allowed him to move into her home rather than see him admitted to a nursing facility. She attributed his illness to alcoholism and stated,

> To see somebody do that to themselves – the first time he was sick, the doctor told him he would have to stop drinking, because the first time he went in the hospital he was in for acute alcohol poisoning. I said, 'You almost died.' When I took him back to the doctor, the doctor said, 'You're not drinking, are you?' and he said, 'Well, sort of.' The doctor told him there's no such thing as 'sort of dead'.

An adult daughter, who provides care for her mother who is afflicted with Alzheimer's Disease, stated that she is fearful regarding her own future. She said,

> I think the difficult part is seeing her lose her everyday things – I mean her short-term memory. It is just frightening. She gets mad and frustrated because there are times when she can see (her own limitations). I think that's probably the most difficult and to think – well maybe in twenty years, I'll be the same way.

Only one caregiver mentioned that finding time to do necessary tasks was the most difficult aspect of providing care. Ironically, this woman was part of the largest caregiving team to participate in the study. She was, however, a key member of that team, taking responsibility for medication and money management. In addition, she had recently resumed full-time employment.

Another woman, who assists with the care of her mother-in-law, noted difficulties related to differences in styles of communication. She explained the situation this way,

> They don't ever complain – it is the way they were brought up – so I feel that I shouldn't either. Sometimes that is a problem. Like when I went to the hospital last week, they were shocked because they didn't realize that I wasn't well.

Occasionally, such differences can result in misperceptions regarding the needs and limitations of both caregivers and care recipients.

The perception of caregiving "difficulties" seemed to be influenced by gender. Responses from male caregivers ranged from denial of any difficulty to acknowledging chronic fatigue due to sleep deprivation. Some mentioned that being confined to the house was difficult for them. For example, one elderly male spouse stated,

> Just having to be here all the time. You know, I'd like to wander off somewhere. I got a small blueberry patch I need to cut back, but I can't go out there, you know, if she hasn't got help in here...

Another man stated that helping his wife cope with chronic pain was difficult for him, "...the pain that she had – what hurts her, hurts me. I would say everything else is all right, but that gets to me."

Finally, an adult son who helped to care for his father states that watching the progression of dementia has been difficult for him, "Well the most difficult for me is just the basic simple fact of seeing Dad, but not seeing *Dad*." In another case, a daughter caring for her demented mother said that her siblings used similar difficulties to justify their lack of involvement, stating, "Mom just isn't *Mom* anymore." Female caregivers were more likely to mention the difficulty of managing emotions such as fear, anger, and anxiety as well as coping with social isolation.

Positive Aspects of Caregiving

On the other hand, many caregivers were also able to identify benefits, or positive aspects, of their caregiving role. Four caregivers indicated that the "best thing" about caregiving was that it allowed them to feel closer to or get better acquainted with the care recipient. One woman expressed it this way:

> Getting to know her, and spending time with her. I feel as I work with her – she's like a mom to me. Since my mother passed away when I was two years old, I think that spending the time with her is just priceless. It's my family roots, and I'm able to come over and talk to her about anything. We can laugh and share secrets. It's just wonderful.

Six caregivers indicated that being able to meet the needs of the care recipient and/or to make their life better in some respect was the "best thing" about their work. One caregiver stated, "the best is the look on her face – the look of relief, of satisfaction and comfort." Another stated, "I feel good that I'm just able to help her."

Five caregivers indicated that having the companionship of the care recipient was the "best thing" about the work of caregiving. One son stated this very succinctly, "...a chance to spend time with Dad" and a daughter stated, "I'm glad that I did it, because I've had five years with her that I probably would have missed."

Four caregivers (all daughters) indicated that being able to fulfill family obligations or keep commitments was the "best thing" about doing the work of caregiving. Deep feelings of affection or love for the care recipient appeared to motivate their actions. Two of these caregivers perceived themselves to be solely responsible for caregiving while the other two were members of caregiving teams. However, their perspectives seemed to be very similar. One daughter stated, "I learned a long time ago that your family is everything and even though I moved away, when I needed to come back, I came back." Another daughter stated, "I'm adopted, and so I feel I'm giving back some of what they did for me – I love them, you know." Finally, a daughter stated, "I just love my father – I don't think of it as a chore, I don't think of it as a burden or anything. It is just a part of my life." In many cases, these feelings of affection appeared to be reciprocated, as illustrated by this caregiver's comment, "when she tells me at night, 'thank you', and that she appreciates it, and that she loves me."

Two caregivers viewed their work as an investment in their own future. One summarized her perspective this way:

> My grandmother took care of me a lot when I was a little child. One of the things she taught me was 'God is going to pay you back when you care for others.' One day, I will need someone to take care of me...

Another stated, "Oh I don't know other than my children having an opportunity to see some of the responsibilities that I feel toward my parents. I think my children have a learning experience in that." He also indicated his belief that this would influence their caregiving behavior when it was his "turn" to receive care. Such role modeling was also identified by Horowitz (1985a) as one of the benefits of caregiving.

Three caregivers mentioned that their caregiving had resulted in increased faith or spiritual awareness, or had made them, "a better person". For example, one woman stated, "I've been a Christian a long time, but this has made me realize that I have stronger faith than I did before." Another said, "I have never been overly religious. Now, I practice my faith, and it's brought me back into my faith more. Sometimes it is, 'God, give me the strength.' Sometimes that's all that gets me through."

Of the twenty-two families represented in the study, twelve used a primary caregiving approach while the remaining ten families used a team approach to caregiving.

The responses of primary caregivers seem to indicate that they have more difficulty arranging time away from their caregiving tasks, they may neglect their own needs and, consequently, may suffer more from fatigue and chronic health problems. Team caregivers, on the other hand, were more likely to indicate that their overall well being was "better", or "about the same". Improvement was most often attributed to improved communications and feeling emotionally closer to other family members.

Although team caregivers reported experiencing difficult emotions similar to those experienced by primary, or sole, caregivers, they also had more immediate access to support from other team members. Such support may help to mitigate some of the negative effects of caregiving (Horowitz, 1985b, Kahana, Biegel, and Wykle, 1994). Families with a history of "working together" seemed to adapt more easily to shared caregiving functions. For at least one family, however, conflict did not preclude collaborative caregiving, as illustrated by the son who was frequently in conflict with other family members as a result of his perception of "disrespect" shown toward their demented father.

3. Is there a relationship between the caregiving approach utilized and the quality of care provided to older adults?

In order to explore the relationship between the caregiving approach utilized by family caregivers and the quality of care provided to older adults, several questions addressing this issue were included in both care recipient and caregiver interviews (see Appendix 3.A, questions 8-12, and Appendix 3.B, questions 11-13).

Care Recipients' Perspectives Regarding Quality of Care

First, care recipients were asked whether they felt they were getting enough assistance to meet their needs. Responses to this question generally were positive; that is, respondents indicated they were getting enough assistance to meet their needs. Only two respondents indicated they were not getting enough assistance. Both of these individuals had complaints related to agency staff rather than family caregivers.

Care recipients were then asked whether they were ever without help when they needed it. Responses to this question generally were negative; that is, respondents said they were never without help when they needed it. However, in five cases respondents indicated that they were occasionally without help. Four of these complaints were in relation to the scheduling of agency personnel. In the fifth case, the care recipient was a male with dementia who was very preoccupied with his tractor and frustrated that his sons were not always available to help when he had problems with it. This man was very concerned with lawn and garden chores but seemed unaware of household tasks performed by his spouse and daughters. This suggests the possibility of gendered differences in the perception of "quality" care.

Next, care recipients were asked to identify some aspect of their care that they considered "good" or "important". Only one respondent was unable to identify something about their care that was "important" to them or that they considered a "good thing". Most respondents identified concrete tasks that address basic needs such as food preparation or assistance with bathing and toileting. For two respondents, the consistent presence and companionship of caregivers were very important.

A list titled "Elements of Quality Care" was then shared with care recipients (see Attachment, Appendix 3.A). This list was generated by focus group participants in a previous study conducted by the researcher (Brewer, 2000). It contained items such as safety, respect, love, consistency of care, and effective communication. Respondents were encouraged to delete items or add items to the list based on their own experience. All respondents agreed that the items listed as "elements of quality care" were important to them and no items were deleted. However, one respondent added two items. These were "a clean living area" and "trust". This person reported that she had experienced theft by a former caregiver and that the experience made the ability to trust caregivers very important to her.

Finally, care recipients were asked to rate their level of satisfaction with the care they receive. Eight care recipients indicated that they were "very satisfied" with their care and six indicated that they were "satisfied". None indicated that they were "not so satisfied". There appeared to be some blurring of the boundary between family and formal caregivers when addressing the issue of quality of care. That is, respondents sometimes referred to paid caregivers rather than family caregivers to provide rationales for their responses. However, all responses were generally positive.

Respondents' feelings of vulnerability may have influenced their responses or they may have been reluctant to disclose less than satisfactory care due to fear of repercussions. Also, there was some indication that care recipients were "satisfied" if they believed their caregivers were doing the best they could, even though their situations were less than ideal. For these individuals "quality of care" seemed to be measured in terms of effort expended on their behalf and the good intentions of their caregivers.

Caregivers' Perspectives Regarding Quality of Care

Caregivers also were asked to rank their level of satisfaction with the care provided by themselves and other family members. Most of the caregivers interviewed said they would rate the quality of the care provided as "high quality". Eight caregivers rated the quality of care provided as "average". Some commented that they could do a better job if they didn't have other responsibilities. For example, one caregiver stated, "If I didn't have to work I could do better." Only one caregiver rated the quality of care provided as "low". In this case it was clear that the caregiver was referring to care provided by agency staff rather than the care provided by family, although the researcher attempted to clarify this distinction. For example, she stated "The help takes advantage of me – they don't do simple things like emptying the trash or running the vacuum unless I ask them to and when I do ask, they get an attitude. They want to sit and talk and they often leave early." It seemed that there was a need to ventilate pent up frustrations and this caregiver used the interview to do so.

There was no evidence of substantial differences in the quality of care provided by families using a team approach as compared to those using the primary caregiving approach. This could be due to a general reluctance to disclose dissatisfaction or problems associated with care provided by family members. When complaints were expressed, these always were directed toward formal service providers rather than family members. It is important to remember that this discussion of quality of care is based on the perspectives and subjective opinions of the participants. The observations and impressions of the researcher revealed that the quality of care provided by families ranged from excellent to barely adequate. For example, in one home the strong odor of stale urine suggested that personal care needs were not being adequately addressed. The care recipient, however, indicated that she was "satisfied" with the quality of care received. This suggests that if "objective" measures were used to evaluate quality of care, the results could be considerably different than those reported by the participants.

4. What type of interventions or supports do family caregivers believe they need in order to strengthen their caregiving capacity?

The final question of the framework for inquiry addresses the perceived needs of families for additional interventions or supports in order to strengthen their caregiving capacity. This question was included in both care recipient and caregiver interviews (see Appendix 3.A, question 13 and Appendix 3.B, question 14). Many of the care recipients were unable to identify anything they thought would improve their situation and most reiterated that they were satisfied with the care they were currently receiving. Two indicated that their situation would improve if only they were able to do more for themselves. However, they also indicated that this was unlikely to occur. One care recipient mentioned a specific piece of medical equipment that was needed, and another said that she would like to go out more often.

Caregivers, on the other hand, usually were able to identify unmet needs, although seven were unable or unwilling to do so at the time of the interview. Several mentioned that they were currently satisfied with the assistance they were receiving since the Care Management program had arranged for them to obtain needed services. One caregiver said that getting her mother to the doctor's office for routine checkups was a real challenge and she wished that this could be done at home. She said, "I just dread taking her to the doctor. I got to take her now to get ...a flu shot. Why can't somebody come to the home and give it to her and check her out because that's about all they do when I take her in. They could do all that every so often..."

Six caregivers identified issues with in-home care. A few identified the need for more personal care hours. Some had issues with the reliability or quality of available in-home workers. For example, one caregiver stated:

> Okay, getting somebody that I could trust. I had a girl come in, which Medicaid would pay for. I was not comfortable with this person at all. I guess I would want somebody that I could meet a few times and be around and see them work. How do you know if they are going to beat her – I mean, talk about paranoia – I'm paranoid! Just like it's imbedded into me. Maybe not somebody doing my housework...more so just making sure that she's got her shower in the morning and she's got her breakfast and she's got clean clothes on and, you know, if I could get somebody to do that, it would be wonderful.

Another caregiver stated, "I could use more hours and help that will do the work that they are paid to do. I end up doing what they are paid to do and that isn't fair." Other caregivers expressed concern regarding the level of training available to personal care workers, such as the ability to use a *Hoyer* lift or skills in assisting with wheelchairs, bedpans, etc.

Three caregivers identified needs related to adult day care services (ADC). One family was currently using the service but wished that it could start earlier in the day so that the care recipient need not be left alone in the morning after the caregiver went to work. Another caregiver expressed a need for ADC for her father, which she believed would also benefit her mother. She said "...probably what would make things better is for my mom and my dad to have a break from each other. I know at one time they had talked about getting my dad to...like a daycare for elderly."

In still another case, the caregiver mentioned that ADC was available, however the care recipient chose not to use it. She stated:

> I would love to be able to take her to daycare, which is available today, ... but she chooses not to do that, and that's all right... If I could take her to a facility, and know that she's going to be okay there while I'm gone, and know that she's going to be fed, and taken care of medically, and that type of thing... She just chooses not to do that. She's just so independent.

In addition, three caregivers identified specific equipment needs, such as a larger shower, covered wheelchair ramp, or an electric cart. Three caregivers identified a need for "more money" to cover general expenses associated with caregiving. Other needs identified by at least one caregiver include evening respite hours, assistance with the cost of prescription medications, better medical transportation, housing repair, and assistance with meal preparation.

The final question, "Is there anything else you would like to add?" was designed to give participants an opportunity to expand on any of their previous responses as well as to bring closure to the interview process. Many care recipients did not have anything to add to the interview at this point. However, a few did express gratitude toward their caregivers and one expressed dissatisfaction with care received previously in a rehabilitation facility. Another respondent stated that "dependence" was the hardest part of her situation and another described her struggle with intractable pain.

When asked if there was anything else they would like to add, eight caregivers indicated that they had nothing further to say. Three caregivers described feelings of guilt or other uncomfortable emotions associated with caregiving. For example, one woman stated, "...just the feelings that you have. Sometimes you get the guilt feeling. You get frustrated and then wish you hadn't gotten frustrated. You realize it is not their fault and you know – just more the emotional, I think than anything else."

In addition, three caregivers described positive emotions associated with caregiving. For example, one woman stated, " To me, its just family. It's commitment. I do it gladly, and it's an honor."

One caregiver expressed gratitude for being able to work with her sister to provide care for their father. She said:

> I just think my sister and I are very fortunate that we are in a position that we can work together. You know, my folks did a great job with developing relationships. She and I have a great relationship and I hear so many families that don't. We just work very well together keeping him home. I just – I feel very thankful for that.

However, in other cases, caregiving strained relationships and added to tension within the family. In one family, using a team approach to care for their father who suffers from a combination of physical and cognitive limitations, a son stated:

> I think the relationship with everybody – with all of us – probably has changed. I guess what I'm referring to is attitude. One of my sisters and my brother, they just don't treat Dad with the respect that the man deserves all the time. They don't consider his difficulties when they are dealing with him. I'm kind of upset about

> that at times. I don't know if they don't understand or they don't have patience but it just makes me mad.

Another woman discussed the dilemma of deciding to place her mother, an Alzheimer's patient, in a nursing facility to ensure the well being of her elderly father. She stated:

> I was told by the social worker, it was either put my mom in a home, or my dad would die...he's eighty-seven. It was very hard for me – with my mother – because I'd come over here, and my dad would be in the back bedroom trying to take a nap. That was when I worked. I got off at one o'clock in the afternoon. I'd be here about one-thirty, and my dad would be taking a nap, and my mother would be sitting on the couch screaming because my dad was sleeping. Well, he'd probably been up all night, see?

Other topics mentioned by at least one caregiver include problems with paid help, concerns regarding the cost and quality of medical care, and frustrations regarding the lack of individualized medical information. In addition, one caregiver described the difficulty of helping the care recipient cope with unpleasant emotions. She said, "She might have five visitors in one day, and be upset because she couldn't rest, and the next day she'll be sad because she didn't hear from anybody, or nobody stopped by."

Finally, one caregiver addressed the issue of "keeping the promise". This woman had cared for her mother prior to her recent death and continues to provide care for her spouse, who has suffered a severe stroke. She said:

> I don't think it's as bad as what some people think it is – caring for your own. I know that I'd rather do it here, than to have him in a home (i.e. nursing facility). I

> promised Mom I'd never put her in a home...I was able to keep that promise. I promised him that I will take care of him just as long as I can...

It is interesting to note the change in the promises made by this woman to her mother as compared to her spouse. Perhaps she learned from her first caregiving experience that "never" can be a very long time. Although she remains committed to caring for her spouse, she also has given some consideration to her own needs and limitations – to what she can and cannot do.

The following is a summary of the major findings of this project, based on the framework for inquiry outlined in Chapter 3.

1. What factors influenced the selection of the caregiving approach?

The caregiving approach selected by families appears to be influenced by a variety of factors. These include, but are not necessarily limited to, awareness of the need for care, ability to respond to the identified need, and willingness to act on behalf of care recipients, sometimes despite their resistance. It was also apparent that informal caregiving systems are usually formed and transformed in response to the changing needs and circumstances of family members. Rather than being implemented as the result of a deliberate decision-making process, they seem to evolve over time as families adapt to both internal and external forces, such as aging and/or ill health or job requirements.

2. Is there a relationship between the caregiving approach utilized and the subjective well being of the caregiver(s)?

Participants utilizing either a primary caregiving approach or a team caregiving approach were able to identify both positive and negative effects of caregiving on their personal sense of well being. However, team caregivers were more likely to indicate that their overall well being was "better" or "about the same". The responses of primary caregivers seemed to indicate that they have more difficulty arranging time away from caregiving responsibilities, that they may neglect their own needs, and that they suffer more from fatigue and chronic health problems. While team caregivers reported experiencing difficult emotions similar to those reported by primary caregivers, they also had more immediate access to support from other family members. This support seemed to moderate the negative effects of these emotions. It was also noted that families with a history of "working together" seemed to adapt more easily to caregiving functions. However, conflict did not necessarily preclude collaborative caregiving.

3. Is there a relationship between the caregiving approach utilized and the quality of care provided to older adults?

The issue of quality was addressed in interviews with both care recipients and caregivers. All of the care recipients agreed that the "elements of quality care", such as safety, respect, love, consistency, effective communications, were important to them. In addition, the majority reported that they were either "satisfied" or "very satisfied" with the quality of care they were currently receiving. If dissatisfaction was expressed, it was always directed outside the family caregiving system and toward formal caregivers. Furthermore, their "satisfaction" appeared to be associated with the efforts of family members on their behalf. In other words, if they believed the family was "doing the best they can", they were satisfied regardless of the actual quality of care received.

The majority of caregivers rated the quality of care provided by the informal system as "high" or "average". Again, comments regarding "low" quality were directed outside the informal system. There was no evidence of substantial differences in the quality of care provided by families using a team approach as compared to those using a primary caregiving approach. It was noted, however, that the use of an objective measure of "quality" could yield considerably different results.

4. What type of interventions or supports do family caregivers believe they need in order to strengthen their caregiving capacity?

This question also was addressed in interviews with both care recipients and caregivers. Care recipients, for the most part, did not identify anything they thought would improve their situation but reiterated their satisfaction with the care they were currently receiving. Caregivers, on the other hand, were usually able to identify unmet needs. Many of these needs were associated with in-home care. These included a need for house calls by physicians, more personal care hours, better training for in-home workers, extended adult day care hours, and evening respite services. In addition, caregivers mentioned needs for specific medical equipment and "more money" to cover general expenses associated with caregiving.

The issue of monetary compensation for family caregivers highlights another area of blurred boundaries between informal and formal caregiving systems. While this practice does bring additional financial resources into the caregiving system, it also can have unintended negative effects. For example, two caregivers (daughters) in the sample were being paid through home health agencies for some of the time spent caring for their elderly parents. In one family, this seemed to work very well as it enabled the daughter to devote more time to caregiving in lieu of full-time employment. In the second family, however, it seemed to contribute to conflict between siblings since the uncompensated sister felt it was not her "job" to assist with care, as reported by the primary caregiver. In another case, a grandmother occasionally paid her grandchildren to provide respite care for her mother, who suffered from Alzheimer's Disease. If payment for services is used as a criterion to distinguish formal from informal caregivers, these individuals stand at the boundary between systems.

Another occurrence of blurred boundaries was observed between the roles of caregiver and care recipient. For example, a daughter who was part of a caregiving team, became a care recipient due to changes in her health status. In another case, a woman who served as a primary caregiver to her spouse now needs assistance from their daughter because of deterioration in her own physical condition. This observation illustrates the evolution of roles that occurs within such systems over time.

When considering these findings in relation to the general hypothesis that families utilizing a team approach to caregiving experience more positive outcomes than those utilizing a primary caregiving approach, the results are mixed. In relation to the outcome of quality of care provided, there is no evidence of substantial differences among families utilizing either approach. However, in relation to the outcome of caregiver well being, there is evidence that team members report a better sense of over-all well being when compared to primary caregivers. Although the hypothesis cannot be rejected, more research is needed in order to support it fully.

This chapter has described the results obtained from the participant survey and participant interviews. Survey results were compared to national caregiving data in order to situate this project within the broader national discourse addressing informal, long-term care for older adults. In addition, the results of participant interviews were presented and summarized utilizing the "framework for inquiry." The implications of these observations as well as conclusions drawn from study findings and directions for further research will be discussed in the following chapter.

Chapter 5

Summary, Conclusions and Implications

As stated in Chapter one, this project utilized ethnographic methods to explore the culture of caregiving, situated within the context of families that are actively engaged in the provision of elder care. The project was designed to investigate the general hypothesis that families using a team approach to caregiving experience more positive outcomes than those using the primary caregiving approach. Semi-structured interviews were conducted with twenty-two families. Of those families, twelve represent the primary caregiving approach and ten represent the team approach. Interviews included care recipients, when feasible, as well as all available family caregivers. In addition to the interviews, a written participant survey was used to collect pertinent demographic data. The intent of the project was to develop a better understanding of how caregiving systems are constituted, how roles within such systems are defined, the meanings that participants ascribe to caregiving responsibilities, and the effects of caregiving on individual and family well being.

The Evolution of Caregiving Systems

The findings reported in Chapter four suggest that caregiving systems are constituted, or formed, in response to changing needs and circumstances within families. Factors influencing the caregiving approach utilized by families include awareness of need, ability to respond to the need, and willingness to act on behalf of those in need. Geographic proximity may facilitate awareness and identification of need, but does not necessarily guarantee it. This was demonstrated by family members who "failed to see" or "refused to see" the need for care although living in close geographic proximity to their older relative. In addition, one participant suggested that several of her siblings had left the area in order to avoid caregiving responsibilities. On the other hand, two participant families had members who relocated from other geographic areas in order to assist with caregiving. Nevertheless, it appears that females living near the care recipient are more likely to be actively involved with caregiving than are family members living at greater geographic distance.

Keith (1995) suggested that the gender composition of families might be a factor in the formation of caregiving teams; that is, when several daughters are present, they are more likely to share caregiving responsibilities. This was not substantiated, however, in the current study. In fact, in one family of three sisters, the primary caregiver expressed intense anger that her sisters had virtually abandoned their caregiving responsibilities. It should be noted that this caregiver was receiving payment for at least part of the hours of care that she provided for her parents. It is possible that this practice may have contributed to the perception by her siblings that caregiving was her "job", not theirs. Unfortunately, it was not possible to verify this speculation since the other sisters were not interviewed. It was observed, however, that among the ten caregiving teams represented in the study, only two were composed entirely of female siblings. The other eight teams included male spouses, sons, sons-in-law, or friends. This also demonstrates that the role of male caregivers may be obscured when the primary caregiver is the focus of investigation.

Furthermore, these findings suggest that, while specific caregiving approaches are rarely the result of a deliberate decision-making process, they do appear to evolve over time as families adapt to alterations in both internal and external conditions. Such adaptation is an important theme of family ecology theory, as described by Bubolz and Sontag (1993).

The definition of roles within caregiving systems also appears to be a dynamic process. That is, role definitions changed over time as caregivers became care recipients and as family members who had been only tangentially involved with caregiving assumed more central roles. This was demonstrated in interviews with caregivers who initially identified themselves as the "primary" or sole caregiver but were later able to identify other family members who also provided valuable assistance. The role of these "hidden" caregivers was obscured because their work was not originally defined as *caregiving*. This information regarding the formation of caregiving systems is important because it could contribute to strategies for expanding participation in caregiving systems as well as for improving their performance. For example, providing support and information to families during the formation of caregiving systems may help to prevent problems that would otherwise disrupt the functioning of these systems.

There was considerable variation within the sample in relation to the meanings that participants ascribed to their caregiving responsibilities. Many participants felt that caregiving was simply a reasonable response to the strong affection, or love, they felt for the care recipient. Other participants indicated that caregiving was the fulfillment of a deeply felt obligation or reciprocation for assistance previously provided to them, as in the case of an adopted daughter who provided care for her father. Still others saw caregiving as a means of protecting vulnerable family members, such as an elderly mother. For example, one daughter stated "if we don't do it, she will have to". The meanings ascribed to caregiving were highly individualized and were based on the unique history of each family.

Outcomes of Team and Primary Caregiving

This project has examined the outcomes experienced by families utilizing either a team or primary caregiving approach to elder care. Although the primary caregiving approach has dominated research on the topic of family caregiving, a range of caregiving strategies can be identified when observing the actual practices of families. These strategies include partnership and team approaches to caregiving as well as the sole, or primary, caregiving approach. It is not possible, based on the findings reported here, to say whether one approach is superior to the others in terms of the quality of care provided. It would seem, rather, that in this context *quality* is not an issue of better or worse care, but whether a particular approach seems to work for a particular family. That is, are the needs of the care recipient consistently met and are caregivers reasonably satisfied with their roles? If not, families may benefit from interventions designed to help them find a better fit between their caregiving capacity and the needs of their elder members.

Based on participant responses, it also was clear that caregivers using either a primary care or team approach struggle with painful emotions such as anxiety, anger, and guilt that affect their sense of personal well being. However, the negative effects of these emotions appeared to be meliorated by the use of a team approach, possibly due to the support provided by other team members. To summarize, there appears to be little if any difference in the quality of care provided by caregiving teams when compared to primary caregivers. Furthermore, the team caregiving approach appears to have some benefit in terms of caregiver well being. Therefore, it may be useful to assist families in developing their capacity for team caregiving where it does not already exist.

An Ecological Analysis of Caregiving Systems

Using family ecology theory as a conceptual framework, it is important to consider the influences of natural and human-built environments as well as social cultural environments in the analysis of family caregiving systems. While natural and human-built environments influence both the form and functioning of such systems, it is clear that the influence of the social cultural environment is much greater. For example, the quality of air and water as well as the climate in certain geographic areas may influence life styles and physical health, such as hip fractures resulting from falls on icy sidewalks. This in turn may precipitate the need for care among older adults as well as affect the capacity of families to respond to that need.

Furthermore, human-built environments can facilitate or impede the caregiving functions of families. For example, the design and flexibility of housing can affect the activities of families who are striving to respond to the care needs of elder members (Kahana, Biegel, and Wykle, 1994). Renovation of older homes to accommodate wheelchairs and other necessary equipment may be very costly. Furthermore, elders living in apartments may not have sufficient space to accommodate live-in caregivers or restrictive policies may preclude their doing so. Finally, inadequate public transportation systems may increase the dependency of older adults on family members for transportation to medical appointments and other activities. For example, several care recipients participating in this study indicated that they were reluctant to use available medical transportation services because of the perception that such services were unreliable.

While these influences are important, they are overshadowed by the influence of the social cultural environment. Tylor (1871) provided the classic definition of culture – that complex whole that includes knowledge, belief, art, law, morals, custom, and any other capabilities and habits *acquired by a human being as a member of society* (emphasis added). Society consists of people while culture consists of their practices and patterns of interaction. Culture provides a blueprint for the socialization of individuals into the roles they will assume as members of society (Bubolz and Sontag, 1993), including the roles of caregiver and care recipient.

Culture also provides a template for seeing, feeling, thinking, and responding to the world, including the care needs of family members. Through microdevelopmental processes (Ortner, 1994), culture affects individual responses to changes within the family. In addition, through macrohistorical processes (Ortner, 1994), culture affects the political and economic context of caregiving and, subsequently, the resources available to assist families in fulfilling their caregiving functions. The social cultural environment includes both the institutional structures that give form to society and the shared lifestyles, customs, beliefs and practices that add substance to a particular group of people at a particular historical time and place (Germain and Bloom, 1999).

Anderson and Carter (1999) have suggested several analytic dimensions of culture, including technology, language, and systems of social relations, or *caring*. Caring, they state, "involves both an emotional disposition and caring labor...a practice in which both thought and action are integrated around central aims or goals" (p. 64). Such integration was observed in families utilizing either the primary caregiving approach or a team caregiving approach, although the team approach required a higher level of integration and coordination of efforts among multiple caregivers. Caregiving requires the intellectual awareness of a need and sufficient motivation to respond to that need, as well as the physical ability required to perform the necessary labor. Furthermore, each of these areas--awareness, motivation, ability--represents internal resources necessary for the optimal functioning of caregiving systems. There is tremendous diversity among and within families regarding the capacity to integrate awareness and action to produce caring behaviors.

Levine (1999) developed a matrix that outlines the intersection between family capacity and care recipient need. The matrix is based on indicators of high, moderate, and low family caregiving capacity. These indicators include intangibles such as family dynamics and culture as well as the number of people available to provide care, economic resources, and other family responsibilities. Caregiving capacity can then be compared to the level of identified need. Furthermore, Levine suggested that the gap between need and capacity should serve as a guide for targeting services and supports to families.

Implications for Practice

As stated in Chapter 1, the findings reported here hold implications for every level of social work intervention with aging families, including the micro, mezzo, and macro levels of practice. At the micro level, it is essential that medical social workers, case managers, and others responsible for developing care plans with elders remain sensitive to both the strengths and limitations of family caregivers. Placing unreasonable demands on families may jeopardize the well being of caregivers and care recipients alike. At the mezzo level, identification and mobilization of caregiving networks within families and communities may help to decrease the burden experienced by primary caregivers. This in turn could result in more positive outcomes for both caregivers and care recipients. For example, female caregivers may be able to maintain a higher level of community involvement, including labor force participation, if they are viewed as part of a caregiving team rather than as primary caregivers. This also could help to improve the economic status of middle aged and older women (Wood, 1994).

At the macro level, policy analysts and program developers must consider the needs of family caregiving systems rather than focusing exclusively on either primary caregivers or care recipients. As mentioned in Chapter 2, much of the research addressing family caregiving has focused on the negative effects experienced by primary caregivers of dementia patients. While this is a legitimate area of concern, the time has come to broaden the focus to include alternatives to primary caregiving and to consider the potential for positive as well as negative outcomes. In addition, the care needs of individuals with physical as well as cognitive limitations are deserving of consideration.

It has also been noted that many scholars have called for additional qualitative investigation of elder care issues. Although large-scale, quantitative studies have added immeasurably to our knowledge of trends that occur within the population of those providing care for older adults, they have also obscured the diversity of caregiving experiences. Also, those experiences are often decontextualized by the standardized measures necessary for quantifying information. Qualitative methods, including ethnography, can help to restore the context of caregiving and to record the struggles of families as well as the strengths gained through the process of providing care.

Furthermore, giving consideration to the effects of policies and programs on informal caregiving systems may help to reduce the fragmentation found within the current service delivery network and, subsequently, to reduce the frustrations experienced by many caregivers as they interact with that network. In particular, there appears to be a pressing need for systematic evaluation and improvement in the delivery of in-home services for older adults.

Finally, this project has tested the compatibility of family ecology theory with ethnographic methods of data collection and a hermeneutic, or interpretive, approach to data analysis. Also, it has explored theoretical constructs such as "quality of care" and "personal well being" from the subjective perspectives of participants, based on their unique experiences. This has resulted in a deeper understanding of the functioning caregiving systems as well as a better understanding of potential outcomes for caregivers and care recipients alike. Two observations are of particular theoretical interest. First, the evolution of roles within caregiving systems highlights the capacity of families to adapt to the changing needs and capabilities of their members over time. Next, the blurring of boundaries between formal and informal systems demonstrates dynamic interaction between family caregiving systems and their environments as well as the creative utilization of resources as families struggle to fulfill their caregiving functions.

Future Research Agenda

This project could be expanded by longitudinal follow-up with these same families at two or three year intervals in order to gain a better understanding of the evolution of informal caregiving systems. In addition, the study could be replicated in other geographic areas to see whether similar patterns emerge. Furthermore, it could be useful to expand the sampling pool to include families that are not actively utilizing formal services to determine how their experiences may differ from those reported here. Subsequent studies also could be strengthened by expanding the focus of inquiry to include components of the ecosystem not yet addressed, such as the role of formal service providers within caregiving systems and specific effects of the physical environment. Finally, the special challenges confronted by members of ethnic minority groups merit further exploration. Topics of inquiry should include the strengths often demonstrated by such families as well as the problems they encounter, such as limited access to formal support services. Health disparities experienced by various ethnic groups, such as the high incidence of diabetes among Native Americans, should also be explored in relation to the implications such disparities hold for informal caregiving systems. In the future, caregiving research must focus on caregiving *systems* rather than primary caregivers. Only then can we begin to build caregiving networks that not only provide quality care to those in need, but also enhance the well being of those who care.

APPENDICES

Appendix 1

Memorandum of Introduction

From: Loretta Brewer

To: Whom it may concern

Re: Family Caregiving Research Project

The purpose of this memorandum is to provide you with information regarding a research project being conducted by Loretta Brewer, a doctoral candidate at Michigan State University. The project focuses on family caregiving relationships.

Mrs. Brewer is interested in talking with families who are currently providing care to their elderly members. The recipients of such care should be at least sixty (60) years old and living in the community rather than a nursing home. Separate in-home interviews will be conducted with the care recipient as well as with all available family caregivers. A cash payment of $10.00 will be provided for each completed interview. In addition, information regarding services for older adults will be provided to each participant.

All responses will be treated with extreme confidence and the identity of individual participants will not be disclosed in any report resulting from the project. If you are interested participating, or if you need additional information, please contact the person who gave you this memorandum. He or she will then put you in touch with Mrs. Brewer.

Thank you for your time and consideration.

Appendix 2

CONSENT FORM

Loretta Brewer, a doctoral candidate at Michigan State University, is conducting a research project concerning family caregiving arrangements for older adults. The project will involve conversations regarding your experience with caregiving within your family. Participation in this project is likely to require one to two hours of your time.

Participation is voluntary. You may choose not to participate at all, or not to answer certain questions, or to discontinue the conversation at any time without explanation, penalty or loss of benefits to which you are otherwise entitled. If you choose to participate, all responses will be treated with extreme confidence and your identity will not be disclosed in any report resulting from the project. Your privacy will be protected to the maximum extent allowable by law.

Potential risks of participation are minimal and may include mild emotional distress. On the other hand, potential benefits include a better understanding of family caregiving relationships. In addition, each participant will receive information regarding services available to older adults as well as a cash payment of $10.00 per completed interview.

If you have questions about this project, you may contact either Loretta Brewer, 299 W. Parson Ave., Watervliet, MI 49098, 616-463-6063 or Professor Diane Levande, 254 Baker Hall, MSU, E. Lansing, MI 48824-1046, 517-432-3724. If you have questions about the role or rights of research participants, you may also contact David Wright, Ph.D., University Committee on Research Involving Human Subjects, at 517-355-2180.

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

____

Participant's Name (please print)

____________________________________ ______________________

Participant Signature Date

Appendix 3.A

CARE RECIPIENT
INTERVIEW GUIDE

1. As people grow older, many find that they need some assistance to get through the day. Is that the case with you?
2. What kinds of assistance do you usually need? (use prompts as needed to identify ADL and IADL needs)
3. Who usually provides that assistance? (identify by name and nature of relationship, if possible—cross check with Participant Survey)
4. Does anyone else help out sometimes?
5. How long have each of these people been providing assistance? (estimated duration of care)
6. Have others been involved in the past? (identify changes in caregiving system over time) If "yes", go to #7; if "no", go to #8
7. Do you have any idea why these changes occurred?
8. Do you feel you are getting enough assistance to meet your needs? (If "yes", go to #10; if "no", go to #9)
9. Are you ever without help when you need it?
10. What are some of the good things (or things that are important to you) about the care you receive?
11. What things are most important to you? (If necessary, use attached list to prompt identification of elements of "quality care")
12. In general, when you think about the assistance that you receive, would you say you are "very satisfied", "satisfied", or "not so satisfied"?
13. What do you think would help to improve your situation?
14. Is there anything else you would like to add?

ATTACHMENT

Elements of "Quality Care"

- Safety (feeling physically secure with caregiver)
- Respect (feeling that patient's dignity and self-worth are valued by caregiver)
- Love (strong feelings of affection between caregiver and care recipient)
- Consistency of care (feeling you can count on assistance from caregiver over time)
- Individualized care (care is modified when needed to meet changing needs of care recipient)
- Effective communications (able to openly discuss issues related to care)
- Minimum stress (caregiving arrangements help to reduce daily stress for recipient)
- Providing "extras" (caregiver goes beyond basic necessities when providing care)

Appendix 3.B

CAREGIVER
INTERVIEW GUIDE

1. I understand that you routinely provide assistance for (care recipient). I am interested in hearing about what you have learned from that experience. How are you related to (care recipient)? Would you describe the type of assistance you provide—the kinds of chores or tasks you do?

2. Did you ever expect to be doing this kind of work?

3. How did you become involved?

4. About how many hours per week do you spend providing care for (care recipient)?

5. About how long have you been doing this work?

6. Has the amount of time you spend increased or decreased over time?

7. How has this affected your relationship with (care recipient)?

8. Who else is involved in caregiving? How has this affected your relationship with them?

9. How has your commitment to caregiving affected the rest of your life, for example, your relationships with friends or family members or your work?

10. When you think of your overall well being—your physical health, emotional status, and important relationships—would you say things are better, worse, or about the same as they were before you started doing this work?

11. What part of this work has been the most difficult for you?

12. What is the best thing about doing this work?

13. When you think about the care provided to (care recipient) by yourself (and others), would you say it is high, average, or low quality? How satisfied are you with what you are doing?

14. What kinds of services and/or supports do you think would help to improve things for you and (care recipient)?

15. Is there anything else you would like to add?

Appendix 4

PARTICIPANT SURVEY

Participant code #: ________________________ Date:__________________

Care Recipient: Age__________________ Gender__________________

Please circle one response for each of the following items:

Nature of disability: 1. Physical 2. Cognitive 3. Combination

Severity of disability: 1. Minimal 2. Moderate 3. Maximum

Economic status:
1. Lower (less than $12,000 annual income)
2. Middle (between $12,000 and $24,000 annual income)
3. Upper (more than $24,000 annual income)

Ethnic identity: 1. African American 2. Hispanic 3. Native American
4. Caucasian 5. Other__________________________

Comments:

____

____

Caregiver(s)

Name/phone #	Relationship	Age	Gender	Tasks *	Hrs. of care/wk.

*1. Medication management 2. Assistance with transfers or in-home mobility
3. Transportation 4. Housekeeping and/or laundry 5. Grocery shopping
6. Meal preparation 7. Feeding 8. Toileting 9. Dressing 10. Bathing 11. Money Management 12. Other (please specify):_____________________________

Duration of current caregiving system:

Duration of current caregiving system:
1. less than one month 2. one to six months 3. Seven months to one year 4. More than one year

Are any formal services or programs being used in addition to family caregivers?____ If yes, please specify the service or programs:

____

Comments:

____

BIBLIOGRAPHY

BIBLIOGRAPHY

Albert, S. 1990. "Caregiving as a cultural system: conceptions of filial obligation and parental dependency in urban America." *American Anthropologist,* 92, 319-331.

Ames, B. 11/1/98. Course notes.

Anderson, R. and Carter, I. 1999. *Human Behavior in the Social Environment.* New York: Aldine DeGruyter.

Arendell, T., and Estes, C. 1994. "Older Women in the Post-Regan Era." in *Women's Health, Politics, and Power,* edited by Fee, E., and Krieger, N. Amityville, NY: Baywood Publishing.

Atchley, Robert. 1994. *Social Forces and* Aging. Belmont, CA: Wadsworth Publishing Co.

Berg-Weger, M., Rubio, D., Tebb, S. 2000a. "Depression as a Mediator: viewing caregiver well-being and strain in a different light." *Families in Society: the journal of contemporary human services,* 81 (2) 162-173.

Berg-Weger, M., Rubio, D., Tebb, S. 2000b. "Living with and Caring for Older Family Members: issues related to caregiver well-being." *Journal of Gerontological Social Work.* 33 (2) 47-62.

Berg-Weger, M., Rubio, D., Tebb, S. 2001. "Strengths-Based Practice with Family Caregivers of the Chronically Ill: qualitative insights." *Families in Society: the journal of contemporary human services,* 82 (3) 263-274.

Berger, P. and Luckman, T. 1966. *The Social Construction of Reality,* NY: Doubleday.

Bergeron, L. 2001. "An Elder Abuse Case Study: caregiver stress or domestic violence? You decide." *Journal of Gerontological Social Work,* 34 (4) 47-63.

Boulding, K. E. 1985. *Human Betterment.* Beverly Hills, CA: Sage.

Brewer, L. 2000. "A Qualitative Study of Family Care Models for Older Adults," Unpublished manuscript. Michigan State University at East Lansing.

Brody, E. 1981. "Women in the Middle and Family Help to Older People." *The Gerontologist,* 21, 471-450.

Brody, E. 1985. "Parent Care as a Normative Family Stress." *The Gerontologist,* 25:19-29.

Bubolz, M. and Sontag, M. 1993. "Human Ecology Theory," in *Sourcebook of Family Theories and Methods,* Edited by Boss, P., Doherty, W., LaRossa, R., Schumm, W., and Steinmetz, S. New York: Plenum, 419-448.

Cantor, M. 1980. "The Informal Support System: it's relevance in the lives of the elderly." in *Aging and Society: research and policy perspectives*, edited by McClusky, N. and Borgatta, E. Beverly Hills, CA: Sage.

Chambers, E. 2000. "Applied Ethnography." In *The Handbook Qualitative Research,* edited by Denzin, N. and Lincoln, Y. Thousand Oaks, CA: Sage Publications. 851-869.

Cicirelli, V. 2000. "An Examination of the Trajectory of the Adult Child's Caregiving for an Elderly Parent." *Family Relations,* 49 (2), 169-175.

Climo, Jacob. 2000. "Eldercare as 'Woman's Work' in Poor Countries." *Special Issue of The Journal of Family Issues, Aging and Eldercare In Less Developed Countries,* edited by Johnson, N. and Climo, J.

Coward, R., Horne, C., and Dwyer, J. 1992. "Demographic Perspectives on Gender and Family Caregiving." in *Gender, Families, and Elder Care,* edited by Dwyer, J. and Coward, R. Newbury Park, CA: Sage.

Denzin, N. and Lincoln, Y. 1994. *Handbook of Qualitative Research.* Thousand Oaks, CA: Sage.

Geertz, Clifford. 1973. *The Interpretation of Cultures*. Princeton, NJ: HarperCollins.

Germain, C., and Bloom, M. 1999. *Human Behavior in the Social Environment.* New York: Columbia University Press.

Gubrium, J. 1991. *The Mosaic of Care: frail elderly and their families in the real world.* New York: Springer.

Haley, W. 1997. "The Family Caregiver's Role in Alzheimer's Disease." *The American Academy of Neurology*, Tampa, FL.

Hareven, T. 1995. "Historical Perspectives on the Family and Aging." In *Handbook of Aging and the Family,* edited by Blieszner, R. and Bedford, V. Westport CT: Greenwood Press. 13-31.

Hargrave, T. and Anderson, W. 1992. *Finishing Well,* New York: Brunner/Mazel.

Ho, C., Weitzman, P., Cui, X., and Levkoff, S. 2000. "Stress and Service Use Among Minority Caregivers to Elders with Dementia." *Journal of Gerontological Social Work*, 33 (1) 67-86.

Hooyman, N. 1992. "Social Policy and Gender Inequities in Caregiving." in *Gender, Families, and Elder Care,* edited by Dwyer J. and Coward, R. Newbury Park, CA: Sage.

Horowitz, A. 1985a. "Family Caregiving to the Frail Elderly." in *Annual Review of Gerontology and Geriatrics,* edited by Eisdorfer, C. New York: Springer. 194-246.

Horowitz, A. 1985b. "Sons and Daughters as Caregivers to Older Parents: differences in role performance and consequences." *The Gerontologist,* 25, 6: 612-617.

Ikels, C. 1983. "The Process of Care-giver Selection." *Research on Aging*, 5 (*4*): 491-509.

Kahana, E., Biegel, D., and Wykle, M. 1994. *Family Caregiving Across the Lifespan.* Thousand Oaks, CA: Sage.

Kain, E. 1990. *The Myth of Family Decline.* Lexington, MA: Lexington Books.

Kaye, L., and Applegate, J. 1990. *Men as Caregivers to the Elderly: understanding and aiding an unrecognized family support.* Lexington, MA: Lexington Books.

Keith, C. 1995. "Family Caregiving Systems: Models, Resources and Values." *Journal of Marriage and the Family*, 57, 179-189.

Kramer, B. and Lambert, J. 1999. "Caregiving as a Life Course Transition among Older Husbands: a prospective study." *The Gerontologist,* 39 (6) 658-667.

Levande, D., Herrick, J., and Sung, K. 2000. "Eldercare in the United States and South Korea." *Journal of Family Issues,* 21:5, 632-651.

Levine, C. 1999. "Home Sweet Hospital: the nature and limits of private responsibilities for home health care." *Journal of Aging and Health.* 11:3: 341-359.

Levine, S. 4/24/97. "One in Four US Families Cares for Aging Relatives." *Washington Post,* (article in reference to the National Caregivers Survey, conducted by AARP and Giaxo Wellcome Corp.)

Matthews, S. and Rosner, T. 1988. "Shared Filial Responsibility: the family as the primary caregiver," *Journal of Marriage and the Family,* 50: 185-195.

McAuley, W., Jacobs, M., and Carr, C. 1984. "Older Couples: patterns of assistance and support." *Journal of Gerontological Social Work*, 6: 34-48.

McFadden, E. 1999. "Social Work Perspectives on Aging." *Connections*, 23: 11.

Meloy, J. 1994. *Writing the Qualitative Dissertation,* Hillsdale, NJ: Lawrence Erlbaum Associates, Inc.

Meshefedjian, G., McCusker, J., Bellavance, F., and Baumgarten, M. 1998. "Factors Associated with Symptoms of Depression Among Informal Caregivers of Demented Elders in the Community." *The Gerontologist,* 38-2: 247-253.

Montgomery, R. 1992. "Gender Differences in Patterns of Child-Parent Caregiving Relationships." in *Gender, Families, and Elder Care,* edited by Dwyer, J. and Coward, R. Newbury Park, CA: Sage.

National Alliance for Caregiving and American Association of Retired Persons. 1997. *Family Caregiving in the U.S.: findings from a national survey.* Washington, D.C.: Author.

National Association of Social Workers. 1996. *Code of Ethics.* Washington, DC: Author.

National Survey of Families and Households. 1992. *Informal Caregiving: compassion in action.* Washington, D.C.: Administration on Aging.

Ortner, S. 1994. "Theory in Anthropology since the Sixties," in Dirks, N., Eley, G., and Ortner, S. (eds.), *Culture/Power/History*, Princeton, NJ: Princeton University Press. 372-411.

Phillips, L. and Rempucheski, V. 1986. "Caring for the Frail Elderly at Home: toward a theoretical explanation for the dynamics of poor family caregiving. *Advances in Nursing Science,* 8 (4) 62-84.

Pearlin, L., Mullan, J., Semple, S. And Skaff, M. 1990. "Caregiving and the Stress Process: an overview of concepts and their measures." *The Gerontologist,* 30, 583-594.

Piercy, K. 1998. "Theorizing About Family Caregiving: the role of responsibility." *Journal of Marriage and the Family,* 60, 109-118.

Pillemer, K. 1986. "Risk Factors in Elder Abuse: results from a case-control study". In K. Pillemer and R. Wolf (eds.) *Elder Abuse: conflict in the Family.* Dover, MA: Auburn House Publishing Co.

Pillemer, K. and Finkelhor, D. 1988. "Prevalence of Elderly Abuse: a random sample survey. *The Gerontologist*, 28, 51-57.

Pyke, K.D. and Bengtson, V.L. 1996. "Caring More or Less: individualistic and collectivist systems of family eldercare." *Journal of Marriage and the Family,* 58, 379-392.

Sherrell, K., Buckwalter, K., and Morhardt, D. 2001. "Negotiating Family Relationships: dementia care as a midlife developmental task." *Families in Society: the journal of contemporary human services,* 82 (4) 383-393.

Silverstein, M., Parrott, T., and Bengtson, V. 1995. "Factors that Predispose Middle-Aged Sons and Daughters to Provide Social Support to Older Parents," *Journal of Marriage and the Family,* 57: 465-475.

Stanford, E. and Schoenrock, S. 1992. *Delivery of Health Promotion Programs: outreach to minority elders.* Washington, DC: AARP National Eldercare Institute on Health Promotions.

Tebb, S. 1995. "An Aid to Empowerment: a caregiver well-being scale." *Health and Social Work,* 20 (2) 87-92.

Tebb, S. And Jivanjee, P. 2000. "Caregiver Isolation: an ecological model." *Journal of Gerontological Social Work,* 34 (2) 51-71.

Toseland, R. and McCallion, P. 1997. "Trends in Caregiving Intervention Research," *Social Work Research,* 21 (3) 154-164.

Toseland, R. and Rossiter, C. 1989. "Group Interventions to Support Family Caregivers: a review and analysis." *The Gerontologist.* 29: 438-48.

Tutty, L., Rothery, M., and Grinnell, R, Jr. 1996. *Qualitative Research for Social Workers*, Needham Heights, MA: Allyn and Bacon.

Tylor, E. 1871. "Primitive Culture." In *High Points in Anthropology,* edited by Bohannan, P. And Glazer, M. New York, McGraw-Hill, Inc. 1988.

U.S. General Accounting Office. 1996, *Long-Term Care: diverse population includes millions of Americans of all ages.* (GAO/HEHS-95-26). Washington

Wolf, R. 1999. "The Criminalization of Elder Abuse." *A paper presented at the Pan-American Congress 1999,* 2/22/99, San Antonio, TX.

Wood, J. 1994. *Who Cares? Women, Care, and Culture.* Carbondale, IL: Southern Illinois University Press.

Zarit, S. 1992. “Measures in Family Caregiving Research.” *Conceptual and Methodological Issues in Family Caregiving Research* (proceedings of the Invitational Conference on Family Caregiving Research), the Gerontology Center, Pennsylvania State University.

Zarit, S. and Toseland, R. 1989. “Current Future Direction in Family Caregiving Research.” *The Gerontologist.* 29, 481-483.

General References

Abel, E. 1997. "Adult Daughters and Care for the Elderly." in *The Other Within Us,* edited by Pearsall, M. Boulder, CO: Westview Press.

Abel, E. and Nelson, M. 1990. "Circles of Care: an introductory essay." in *Circles of Care: work and identity in women's lives,* edited by Abel, E. and Nelson, M. Albany: State University of New York Press.

Atkinson, M., Kivett, V., and Campbell, R. 1986. "Intergenerational Solidarity: an examination of a theoretical model," *Journal of Gerontology,* 41 (3) 408-416.

Brody, E., Hoffman, C., Kleban, M., and Schoonover, C. 1989. "Caregiving Daughters and Their Local Siblings: perceptions, strain, and interactions." *The Gerontologist,* 29, 529-538.

Calasanti, T. 1999. "Feminism and Gerontology: not just for women." *Hallym International Journal of Aging,* 1 (1), 44-55.

Cantor, M. 1983. "Strain Among Caregivers: a study of experience in the US." *The Gerontologist,* 23: 597-604.

Cattell, M. 1996. "Gender, Aging, and Health: a comparative approach." in *Gender and Health: an international perspective,* edited by Sargent, C. and Bretell, C. Upper Saddle River, NJ: Prentice-Hall.

Chandler, B., Marlow, C., and Rosa, M. 1997. "Family Preservation and Elders," *Journal of Gerontological Social Work,* 29 (1) 57-75.

Chodorow, N. 1971. "Being and Doing: a cross-cultural examination of the socialization of males and females." in *Woman in Sexist Society,* edited by Gornick, V., and Moran, B. New York: Basic Books, Inc.

Cicirelli, V. 1992. "Siblings as Caregivers in Middle and Old Age." in *Gender, Families, and Elder Care,* edited by Dwyer, J. and Coward, R. Newbury Park, CA: Sage.

Doyle, L. 1994. "Women, Health, and the Sexual Division of Labor," in *Women's Health, Politics, and Power,* edited by Fee, E. and Krieger, N. Amityville, NY: Baywood Publishing.

Emerson, R., Fretz, R., and Shaw, L. 1995. *Writing Ethnographic Fieldnotes,* Chicago: University of Chicago Press.

England, S., Keigher, S., Miller, B., and Linsk, N. 1994. "Community Care Policies and Gender Justice." in *Women's Health, Politics, and Power,* edited by Fee, E. and Krieger, N. Amityville, NY: Baywood Publishing.

Evandrou, M., Arber, S., Dale, A. and Gilbert, G. 1986. "Who Cares for the Elderly? Family care provision and receipt of statutory services." in *Dependency and Interdependency in Old Age,* edited by Phillipson, C., Bernard, M., and Strang, P. London: British Society of Gerontology.

Fee, E. and Krieger, N. 1994. "Man-Made Medicine and Women's Health: the biopolitics of sex/gender and race/ethnicity." in *Women's Health, Politics, and Power,* edited by Fee, E. and Krieger, N. Amityville, NY: Baywood Publishing.

Finch, J. 1989. *Family Obligations and Social Change.* Southampton, England: Camelot Publishing.

Gilligan, C. 1982. *In a Different Voice.* Cambridge, MA: Harvard University Press.

Glass, L., and Hendricks, J. 1992. *Gender and Aging,* (Generations and Aging Series), Amityville, NY. Baywood Publishing Co.

Gutmann, D. 1987 "The Virile Older Woman." in *Reclaimed Powers: a New Psychology of Men and Women in Later Life.* New York: Basic Books, Inc.

Gutmann, D. 1992. "Developmental Perspectives on the Vital Older Woman." in *In Her Prime*, edited by Kerns, V. and Brown, J. Chicago, IL: University of Illinois Press.

Hazan, H. 1994. *Old Age: constructions and deconstructions.* Cambridge, UK: Cambridge University Press.

Hareven, T. 1996. *Aging and Generational Relations over the Life Course*, Berlin: Walter de Gruyter & Co.

Hooyman, N. and Kiyak, H. 1999. *Social Gerontology: a multidisciplinary perspective.* Needham Heights, MA: Allyn and Bacon.

Johnson, R. 1981. "The Black Family and Black Community Development." *Journal of Black Psychology*, 8: 35-52.

Kao, H. and Stuifbergen, A. 1999. "Family experiences related to the decision to institutionalize an elderly member in Taiwan: an exploratory study." *Social Science and Medicine,* 49: 1115-1123.

Kaufman, G. and Uhlenberg, P. 1998. "Effects of Life Course Transitions on the Quality of Relationships between Adult Children and their Parents," *Journal of Marriage and Family,* 60, 924-938.

Keller, E. 1993. "*Making* Gender Visible in the Pursuit of Nature's Secrets." in *Feminist Theory: a reader*, edited by Kolmer, W. and Bartkowski, F. Mountain View, CA: Mayfield Publishing Co.

Kirp, D., Yudof, M., and Frank, S. 1986. *Gender Justice.* Chicago, IL: University of Chicago Press

Laws, G. 1995. "UnderstandingAgeism: lessons from feminism and postmodernism." *The Gerontologist*, 35: 112-118.

Litwin, H. 1999. "Support Network Type and Patterns of Help Giving and Receiving Among Older People," *Journal of Social Services Research*, 24 (3/4) 83-101.

Lustbader, W. and Hooyman, N. 1994. *Taking Care of Aging Family Members: a practical guide.* NY: The Free Press.

Marks, N. 1996. "Caregiving Across the Lifespan: national prevalence and predictors," *Family Relations*, 15: 27-36.

Mishler, E. 1986. *Research Interviewing: context and narrative,* Cambridge, MA: Harvard University Press.

Montgomery, R., and Datwyler, M. 1992. "Women and Men in Caregiving Roles." in *Gender and Aging,* edited by Glass, L. and Hendricks, J. Amityville, NY: Baywood Publishing Co.

Morrow-Howell, N., Proctor, E. and Dore, P. 1998. "Adequacy of Care: the concept and its measurement," *Research on Social Work Practice,* 8 (1) 86-102.

Orthner, D. 1990. "The Family in Transition," in Blankenhorn, D., et al. (eds.) *Rebuilding the Nest: a new commitment to the American family*, Milwaukee, WI: Family Service American, Inc.

Rawls, J. 1971. *A Theory of Justice.* Cambridge, MA: The Belknap Press of Harvard University Press.

Ray, Ruth. 1996. "A Postmodern Perspective on Feminist Gerontology." *The Gerontologist,* 36, 5: 674-680.

Richardson, R. and Sistler, A. 1999. "The Well-Being of Elderly Black Caregivers and Noncaregivers: a preliminary study," *Journal of Gerontological Social Work,* 31 (1/2) 109-117.

Rosenberg, H. 1990. "Complaint Discourse, Aging, and Caregiving among the !Kung San of Botswana." in *The Cultural Context of Aging: worldwide perspectives,* edited by Sokolovsky, J. NY: Bergin & Garvey.

Rossi, Alice. 1985. "Gender and Parenthood." in *Gender and the Lifecourse.* Hawthorne, NY: Aldine Publishing Co.

Scheper-Hughes, N. 1979. *Saints, Scholars, and Schizophrenics: mental illness in rural Ireland.* Berkely, CA: University of California Press.

Smith, G. (ed.). 1995. *Strengthening Aging Families: diversity in practice and policy,* Thousand Oaks, CA: Sage.

Steiner, A, Raube, K., Stuck, A., Aronow, H., Draper, D., Rubenstein, L., Beck, J. 1996 "Measuring Psychosocial Aspects of Well-Being in Older Community Residents: performance of four short scales," *The Gerontologist,* 36 (1) 54-62.

Stoller, E. 1993. "Gender and the Organization of Lay Health Care: a socialist-feminist perspective." *Journal of Aging Studies* 7: 151-170.

Tyson, K. 1995. *New Foundations for Scientific Social and Behavioral Research: the heuristic paradigm.* Needham Heights, MA: Allyn and Bacon.

Walker, A. 1992. "Conceptual Perspectives on Gender and Family Caregiving." in *Gender, Families, and Elder Care,* edited by Dwyer, J. and Coward, R. Newbury Park, CA: Sage.

Woodward, K. 1991. *Aging and Its Discontents.* Bloomington, IN: Indiana University Press.