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The experience and meaning of caring for urban family caregivers of persons with strokes

Linda L. Pierce

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THE EXPERIENCE AND MEANING OF CARING
FOR URBAN FAMILY CAREGIVERS OF PERSONS WITH STROKE

By

LINDA L. PIERCE

DISSERTATION

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Co-Advisor Date

Marie-L. Friedemann 6/4

Co-Advisor Date

Carolyn L. Lindgren

Ruby L. Wesley

Mary C. Sengstock

DEDICATION

To the memory of my parents, Fairland and Alice Brown, who always gave me encouragement and support throughout my educational undertakings; to my husband and best friend, Mark, and children, Julie, Ken, Scott, and Heather, whose unending love, patience, faith, and support have made this dream a reality, I dedicate this dissertation.

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STATEMENT OF THE PROBLEM

Two to 4 million people in this country live with the aftereffects of stroke (Bronstein, Popovich, & Stewart-Amidei, 1991; Dawson, 1987; Lyden, 1997). Stroke can result in cognitive, emotional, social, behavioral, and functional impairments (Galarneau, 1993; Payne, 1988). The profound changes that can accompany stroke may create considerable problems for those families caring for the affected person. For low-income, urban family caregivers (UFCs), these problems with caring may be magnified due to meager or depleted resources, as cities have experienced erosion and decay that accompany deteriorating infrastructures and compound social problems (Wacquant & Wilson, 1989). Urban cultural patterns are basic assumptions, shared values, and behaviors that families develop to survive these problems and that work well enough to be taught to the next generation (Friedemann, 1995; Schein, 1985). UFCs of persons with stroke, as members of family subsystems, may deal with daily problems with caring that outweigh anything the average suburban family has known (Friedemann & Musgrove, 1994). This is of particular significance as there are 500,000 new persons with stroke each year who have an average duration of life after stroke that exceeds 5 to 10 years (Bronstein et al.). However, these statistics, based on previous research, were conducted primarily with all white populations. Broderick and associates (1998) placed the incidence of strokes at 700,000 per year in a new study that included 14% African American participants. This was approximately 200,000 more strokes than previously cited in the literature with the same expected life duration after stroke. The incidence of stroke is greater for some populations. African Americans have approximately two to four times more strokes per 100,000 persons than European Americans (American Heart Association, 1990; Broderick et al.). African Americans present a unique public health problem as they suffer epidemic stroke rates, and like other minorities and women, they are underrepresented in the research. One way nursing can address these problems is by conducting research focused on UFCs of persons with stroke within an African American family system context in community settings.

Over a 3-year period, this researcher cofacilitated a support group in northeastern Ohio for persons dealing with stroke. In this support group setting, UFCs came together and explored experiences, providing each other with individual support. These individuals discovered that emotions of anger, guilt, grief, loss of control, helplessness, anxiety, vulnerability, and fear of the future were feelings also experienced by others in the group. In describing their interpersonal caring experiences, most family caregivers reported some role change. Over time and within the group setting, UFCs were encouraged by other group members to deal with the reality of their situation, including role conflicts and changes. There was an atmosphere of hope in the group, as UFCs of persons with stroke discovered that their experiences and problems were not unique (Pierce & Salter, 1988).

While their experiences may not be truly unique, in that it may be similar to caring for others with chronic illness, caring by UFCs of persons with stroke may result in difficult situations for the family. Little is known about how the family contributes to the problem or prevents crisis in these situations. Understanding the caring experience and what caring means to UFCs of persons with stroke and to their family system is of the essence.

DOMAIN OF INQUIRY AND ORIENTATIONAL DEFINITIONS

This study investigated the UFCs' experience and meaning of caring as they influence their capacity to care for persons with stroke and to interact with others in their family. The researcher's interest in this domain is based on the fact that millions of persons, as members of families, must deal with the daily reality of stroke and on personal interactions with UFCs. The following orientational definitions for urban culture, family, and UFCs; human caring distinguished from caregiving; the experience of caring; and the meaning of caring guided this study.

Culture can be thought of as the total life process of systems, persons, and families who have adapted to the same environment (Friedemann, 1995). **Urban culture** for this inquiry is adaptation by persons living in inner-city environments, an environment created by similar living conditions, such as poverty, that results in common and reasonable responses to a given structuring of total life process (Devine & Wright, 1993; Friedemann). Family is a structural and organizational unit interacting with this environment and is composed of a system of interpersonal subsystems: people with relationships who interact with other family members, the total family, and other systems in the environment (Friedemann). According to Friedemann and for this study, **family** is all those people the person defines as family, such as relatives or friends and people living with the person or far away. Therefore, **UFCs** may be thought of as kin, friends, or neighbors who reside in similar inner-city environments and deal with caring processes.

There must be a common experience for caring to occur, namely that of humanness (Friedemann, 1991). According to Leininger (1988), human caring is composed of subjective feelings and interactional behaviors between at least two people in which assistive or enabling acts are performed. While humanistic caring is an interpersonal process, caregiving, as described in the literature, implies a one-way relationship in which psychomotor tasks based on cognitive knowledge and support actions are given to another. Writers on caregiving, such as Montgomery, Gonyea, and Hooyman (1980), Montgomery, Stull, and Borgatta (1985), Poulshock and Deimling (1984), and Robinson (1983), have mainly addressed the roles, tasks, and consequences related to caregiving. Clearly, human caring is a much broader term. According to Pepin (1992), the literature on caring has been developed by nurses, feminists of various disciplines, and philosophers to describe caring in the nurse-client relationship, caring as women's way of expression, and caring from a more general perspective. Pepin stated that the literature on caring that was developed on a conceptual level brings philosophical perspectives of human caring to a common understanding of the caring process for women and men in nursing. Using primarily qualitative research methodologies, caring has been studied from the perspective of those who are living the experience (U.S. Department of Health and Human Services, 1994). The literature on caregiving, on the other hand, has been furnished by gerontologists, nurses, sociologists, and social workers to describe the care given by family members to elders or others with chronic illnesses with the physical and emotional consequences for primary caregivers. This literature has grown differently than the literature on caring, mainly through quantitative research using correlational and structural modeling designs based on stress and coping frameworks (Pepin). Simple correlational projects are not sufficient to explain the multicausal or nonrecursive relationships that truly reflect the complexity of caring (U.S. Department of Health and Human Services). For this study, **human caring** is a total life process involving self and then others in which the results, at times, may be successful and/or problematic. Specifically, human caring includes cognitive, psychomotor, and affective interactions between UFCs and the person with stroke occurring within the common experience of their family system.

The **experience of caring**, based on cognitive knowledge and without regard to successful or problematic outcomes, is defined for this inquiry as assistive or enabling actions that occur between the UFC and the person with stroke within the context of their family system. The UFCs' experience of caring incorporates their perceptions of the following: (a) how caring actions are incorporated into their family's functioning and (b) how personal change occurs as a result of caring actions and influences their family's functioning.

The **meaning of caring** in this inquiry is based on how the UFCs and the person with stroke interpret or explain their situation, specifically how they adjust to individual changes and respect each other's opinions and how they maintain effective emotional relationships among family members. A positive meaning of caring is evidenced through the exploration of the family life process that results in satisfaction with the role of UFC and the quality of family relationships. UFCs who have found meaning within caring maintain their identity and self-worth, promote a sense of wholeness, and are likely to have a healing effect on the family system as a whole (Friedemann, 1995). The UFCs' meaning of caring pertains to their perception of how personal growth and enrichment occurs; how mutual support is given; and how emotional, spiritual, and cultural aspects of caring affect their own well-being and their family's functioning.

SIGNIFICANCE OF THE STUDY

The Hastings Center Report ("What Do We Owe the Elderly?" 1994) presented the reflections of an international research group that focused its attention on the moral problems of the elderly in the years ahead. Two of the key recommendations from this report have bearing on this study. First, there is the need for a social dialogue and refinement related to maintaining a firm sense of moral solidarity between the generations. Second, this report warned that the full brunt of caring done by women in the past cannot and should not be sustained. New strategies in the division of responsibility for caring must be developed. This report also indicated that older persons will continue to depend upon young persons both for financial resources conveyed by the government through taxation or directly through the family. These international researchers believe that within families, the encouragement of an ongoing investment of time and personal commitment to caring, such as that done by many UFCs of persons with stroke, may be of a higher priority in the future than financial assistance.

Nurse researchers are just beginning to describe the processes involved in family caring and the way these processes affect the family caregiver, the care recipient, and the caregiver-care recipient dyad. Additionally, the relationships between the caregiver, the care recipient, and the community are starting to be investigated by nurse researchers (U.S. Department of Health and Human Services, 1994). Recently, the focus on tasks to represent caregiving was questioned by Bowers (1987). Using a grounded theory approach, Bowers reconceptualized caregiving activities by purpose rather than by tasks. Analysis of the data reveals five distinct, but overlapping, categories of caregiving: anticipatory, preventive, supervisory, protective, and instrumental (more commonly recognized as caregiving). The first four categories are not observable behaviors but processes critical to caregiving and to understanding the caregiving experience. Data from Bowers' study introduce what is recognized as caring into the caregiving literature. Bowers redefined the term caregiving to refer to the purpose a caregiver attributes to a behavior rather than the nature of the demands of the behavior itself. This affective component of caring is evidenced primarily within Bowers' categories of anticipatory, supervisory, and protective caregiving.

Individuals with stroke increasingly depend upon their family caregivers' resources for continuing care, particularly when they are experiencing advanced deterioration of health and accompanying challenges of aging. As these demands become more extensive, problems associated with caring can reach overwhelming proportions. This is of particular importance to date, as the ultimate caring responsibilities usually fall on women caregivers who are adult offspring or the person's spouse (Lindgren, 1990, 1993; Musolf, 1991; "What Do We Owe the Elderly?" 1994). Often this family caregiver is unable to meet the interpersonal demands of the situation because of age or other responsibilities. Although the physical healthcare needs of the family caregiver may be addressed by professional providers, their emotional and support needs are usually not met. According to Bunting (1989) and Lindgren (1990, 1993), these personal needs may be neglected due to the increasing constraints of the caring situation. For instance, Bunting hypothesized that as the care recipient's need for care increases, the caregiver fails to engage in personal self-care activities. Lindgren (1993) agreed with Bunting, in that as family caregivers become enmeshed in the dependency demands of the person who needs care, little time, if any, is left to pursue their own needs and interests.

As family members deal with the experience of caring, the demand for commitment and support actions to assist the individual with stroke in carrying out the rehabilitative regimen and tasks of daily living is considerable. Additionally, like the person with stroke, UFCs need to be supported and guided by others(family members and professional healthcare workers(in trying appropriate strategies and in dealing with their feelings about the stroke and the accompanying disability (Payne, 1988).

Outside support is not always welcome; UFCs often refuse help and resources, as they may feel that professionals are prying into their private lives. However, if the functioning of the family system is understood, effective caring by professionals involves the ability to suggest the kind of help that is in tune with the family's life process. Family caregivers' acceptance of nursing care comes from the congruence of such care with the personal subjective meaning they have attached to the caring situation (Friedemann, 1995). Many UFCs will be better able to adapt to the long-term consequences of stroke if they receive meaningful help to successfully adjust to the realities of caring (Pierce & Salter, 1988).

Caring by family members is similar to caring by nurses (U.S. Department of Health and Human Services, 1994). However, the need for family caring often arises from a difficult situation in the family, and caring, at a time of crisis, may cause problems for the family. There is a lack of understanding by nurses about how family dynamics contribute to incongruence, tension, and anxiety, and about how nurses can offer relief. To gain awareness, nurses need to view the situation from a family perspective, asking questions about the family system and examining the impact of culture on this system. This is an especially critical component in viewing UFCs where urban culture and an environment created by living conditions, such as poverty, play a significant role in defining the caring situation. While each family develops its own unique culture, which depends upon how the family system interacts with the urban environment, and applies information according to its daily pattern, differences and similarities occur between and among ethnic groups. Thus, the significance of this research to nursing is that the findings have the potential to (a) aid in understanding the concept of caring as an interpersonal process between UFCs, the persons with stroke, and the remaining family members; (b) place the concept of caring in a family system and culture context in that both UFCs and persons with stroke are members of and actors within a family system; (c) examine diversity as well as common trends among families of the urban environment; (d) test explications based on assumptions underlying Friedemann's (1995) Framework of Systemic Organization; and (e) extend the findings, with caution, to caregivers of persons with other illnesses and disabilities.

THEORETICAL FRAMEWORK AND ASSUMPTIONS

The Framework of Systemic Organization by Friedemann (1995) was chosen as the basis for this inquiry. According to Friedemann's Framework of Systemic Organization, which is based upon open systems principles, the person is a system that is surrounded by an environment and that is in continuous motion, exchanging information, energy, and matter with its subsystems and the environment. The person is defined by

Friedemann as an open system that interacts with others such as persons, social systems, nature, and the universe.

Systems strive toward **congruence**, defined as harmony and compatibility of patterns and rhythms of subsystems, systems of contact in the environment, and the universal order. Incongruence or disharmony and incompatibility among systems evokes tension and prevents the free flow of energy. Well-being is the affective indicator of congruence, whereas tension is evidenced as anxiety (Friedemann, 1995). A UFC's personal system reflects subjectively the level of congruence based on what is learned from the caring situation and in interaction with the family system and the environment. This study examined health, which is the subjective experience of congruence. According to Friedemann, indicators of health are well-being and satisfaction with the situation and the family. In UFCs of persons with stroke, health is expected to be intimately related to the meaning of caring within the family context.

Definition of Family

In addition to the definition presented earlier, Friedemann (1995) specified that family is (a) a unit with structure and organization that interacts with the environment; (b) a system with interpersonal subsystems defined by emotional bonds and common responsibilities; and (c) composed of persons with distinct relationships with other members of the family, the total family, and contact systems in the environment. For this study, the concept of caring is viewed from a family system context in that both persons with stroke and UFCs are members of a family subsystem with defined roles and functions.

Characteristics of Family Systems

Several assumptions about families can be derived from systems theory to support Friedemann's (1995) Framework of Systemic Organization. First, the system of the family is greater than and different from the sum of its parts. Second, family systems are constantly changing within their environment in response to long-term problems, such as the demands of caring. Third, change in one part of the family system can affect the total family system. Finally, a family system is an organized whole. Therefore, persons within the family are each a part of the system and interdependent (Mercer, 1989; Minuchin, 1985). The interpersonal caring relationship between the UFC and the person with stroke is one such example of this interdependency.

Systemic Targets

Friedemann (1995) described **health** as the freedom from debilitating anxiety derived from successfully balancing four systemic targets so that a satisfactory level of congruence with and within the environment is gained. **Family health** is the outcome of an interpersonal process in which the four targets of stability, growth, control, and spirituality are dynamically balanced in accordance with the changing situation of the family (see Figure 1). (Permission to use this diagram is displayed in Appendix A.) The target of **stability** in the family refers to the maintenance of identity in tradition, values, and cultural beliefs. The **growth** target refers to the ability to change through new understanding and examination of beliefs, whereas the target of **control** focuses on the organizational and regulatory functions of the family with the aim of minimizing or regulating the effect of change. **Spirituality** targets connectedness and belonging and results in acceptance of change through adjustment of the system's own patterns and rhythms to those of other systems. Spirituality is based on values concerning commitment, love, and affection. **Congruence** occurs through balancing and reconciling the four targets in many areas of daily living. While congruence is continually attempted, it is never fully realized because changes and conflict continuously threaten the system's operation.

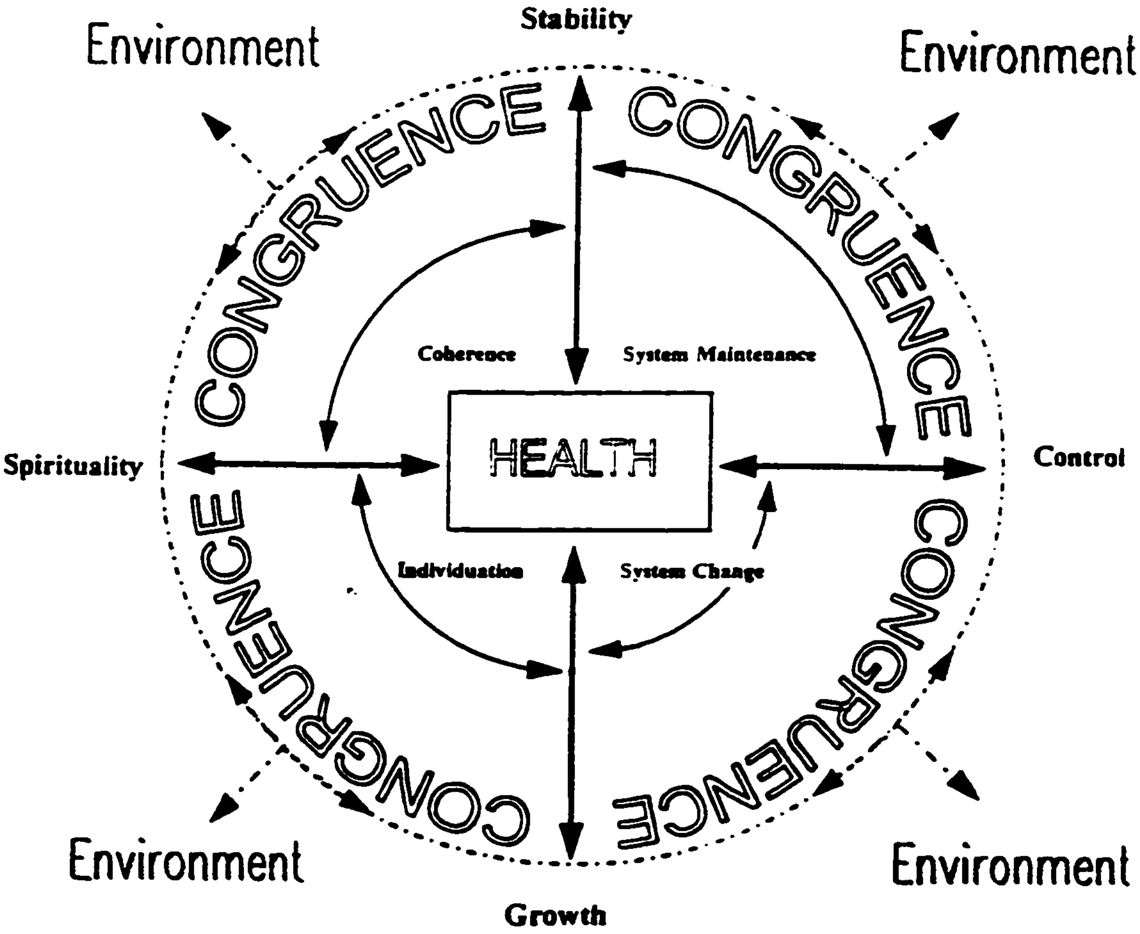


Figure 1. The Framework of Systemic Organization by Friedemann (1995) depicting the major concepts of health; environment; systemic targets of stability, control, growth, and spirituality; process dimensions of system maintenance and change, coherence, and individuation; and congruence.

Note. From The framework of systemic organization: A conceptual approach to practice and research with families and family members, by M-L. Friedemann, 1995. Copyright 1995 by Sage Publications. Reprinted with permission of Sage Publications.

Process Dimensions

In trying to achieve a dynamic state of equilibrium (i.e., congruence), family behaviors may take on very diverse patterns (Friedemann, 1995). For example, some UFCs of persons with stroke have been observed to deny the resultant changes in the family system and deal with the caring situation by disengaging from the person with stroke. Other UFCs of persons with stroke choose more adaptive ways, using problem solving skills, such as holding family meetings to talk over problems. Friedemann noted that such reactions are based on the family's overall style or basic pattern of functioning. The family's style is defined by the family's emphasis on the four process dimensions (i.e., system maintenance, system change, coherence, and individuation) and the behavior patterns within them (Friedemann). These process dimensions are depicted in Figure 1.

System maintenance consists of behaviors that are grounded in tradition, refer to the structure and process of the family, and pertain to organizing and operating the family business (Friedemann, 1989b, 1995). According to Friedemann (1995), system maintenance comprises roles, rules, organizational patterns, rituals, decision making, power structure, and division of labor and targets control and stability. The capacity for change is also anchored in system maintenance, as readiness for change is a stable pattern rooted in the family's value system. In contrast, **system change** refers to major alterations of system operations that result in shifts within the traditional family value system, requiring the cooperation and agreement of all family members. System change targets growth and control in that new information is incorporated and channeled; values and adjustment of beliefs are tested; behavior patterns to concur with new values are adjusted; and new patterns are incorporated into system maintenance by changing or eliminating old ones. **Coherence** refers to emotional bonding and caring relationships among family members and targets the spirituality and stability of the family. For example, the family may share concerns, participate in joint activities, and provide mutual support for one another. **Individuation** refers to the family's promotion of individual learning and changing attitudes, taking in and incorporating information, and sharing opinions and beliefs. Individuation targets spirituality and growth, because through communication, the family encourages examination of the new values suggested by its members and initiates system change (Friedemann, 1995).

The process dimensions are actions or behaviors rooted in values and beliefs used to pursue the systemic targets. Each target is attempted by enacting two process dimensions, as indicated in Figure 1. A multitude of different behavior patterns pertain to each process dimension. In order to maintain congruence within the family, caring behaviors for the member who is ill or disabled relate to the family style and pertain to all four process dimensions (Friedemann, 1995). For example, in one family that attended the support group, the researcher observed that the family system had been economically maintained by the husband. Following this man's stroke, the family discussed and concluded that the wife would become responsible for the income of the family. This decision was made by the family as a whole and promoted coherence in the family system. As the family learned other ways of producing income, individuation and system change occurred.

The Theoretical Tenets for the Study

In addition to examining the perceived and observed congruence of UFCs of persons with stroke, this researcher also investigated Friedemann's (1995) constructs of system maintenance, system change, coherence, and individuation as they pertained to these caregivers. For example, the researcher observed the experience of caring as described by the UFCs of persons with stroke; these observations were gleaned from the family's assistive or enabling caring action patterns as they fall within Friedemann's process dimensions.

First, system maintenance behaviors of caregivers focus on and involve all members of the family and are directed at stability and control. A set of values and cultural beliefs concerning physical and mental health and the commitment to assist the helpless form the basis of system maintenance. Such caring behaviors represent patterns or strategies that maintain the family's sense of security and autonomy. While system maintenance operations are fairly persistent, changes in behaviors are not precluded. Family members may adopt new compensatory or more efficient caring actions that lead to the same targets of control and stability (Friedemann, 1995). For instance, in one family in the support group, the husband believed that the wife's work was caring for the family by preparing the meals. Following an initial stroke, the wife was able to maintain the current family system by continuing meal preparation with the use of adaptive equipment.

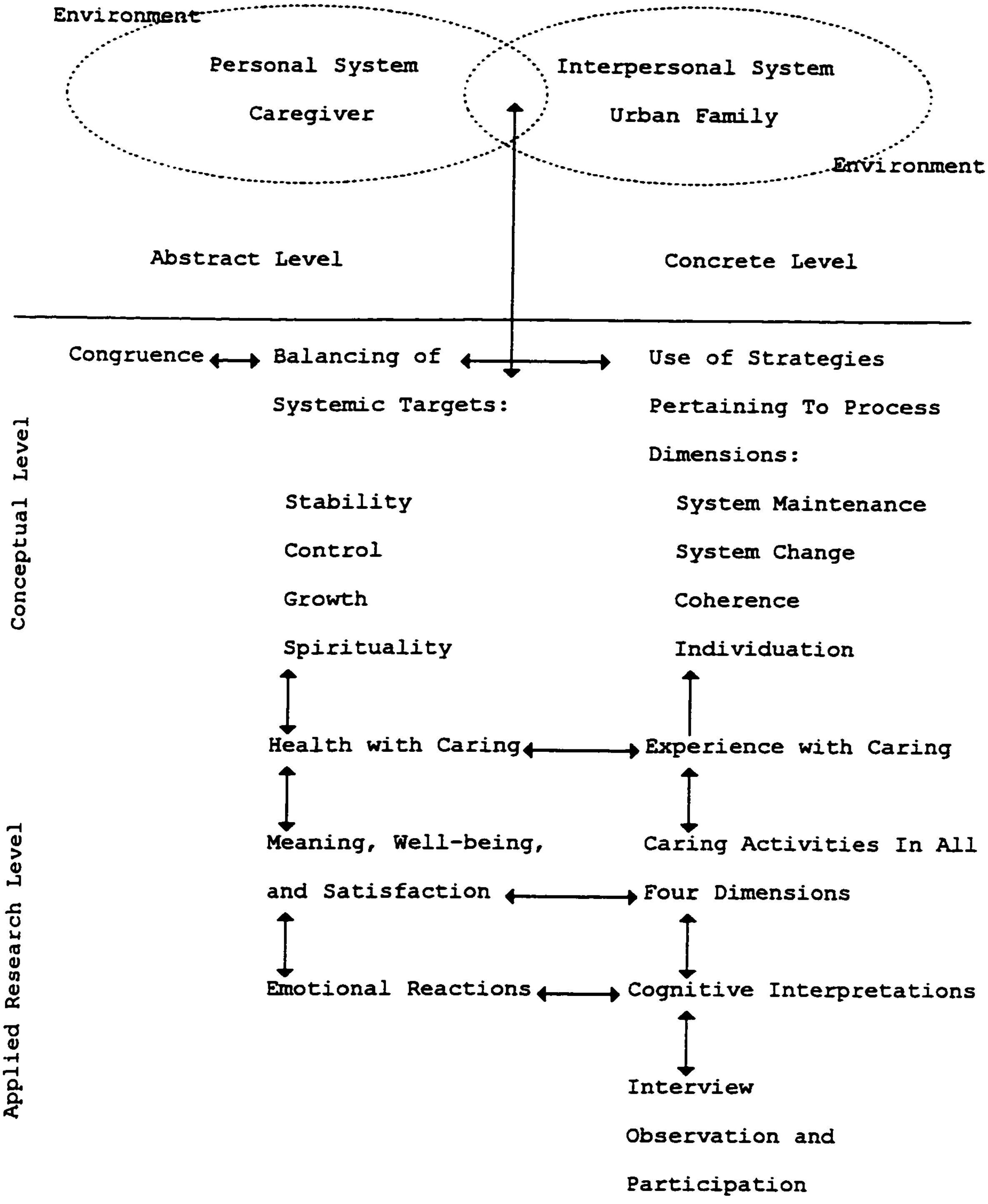
Second, by being flexible, caregivers within a family setting may respond to the need to change both attitudes and beliefs in order to allow the introduction of new roles and patterns. Such shifts lead to growth and system change (Friedemann, 1995). To continue the above example, as the wife's condition worsened, she was no longer able to continue caring for the family with meal preparation. The husband was able to alter his belief about the woman's role in the family and learned to prepare the meals. This was a change for the family system.

Third, coherence patterns include those that express and promote emotional bonding along with the commitment of time and energy to the family and each other. Values underlying coherence concern the self and the human purpose of life (Friedemann, 1995). The emotional support that UFCs display for the person with stroke or the family is an example of coherence. Caring is a spiritual process in that caregivers will adjust their own rhythm and patterns and feel connected to the family member who is the care recipient.

Fourth, individuation, identified as caring actions, is the pursuit of interests and meaning for all family members and the family's accommodation to it, leading to growth through an interpersonal and interactive process with other systems (Friedemann, 1995). Through such connections, UFCs develop talents and ideas, absorb new knowledge, and gain an understanding from an individual and a family perspective. This is part of the caring process in that UFCs individuate by learning from the person with stroke and with other family members. Families adapt to changes brought on by the stroke. According to Friedemann, having an understanding of individuation on the family level can reveal why some family members are more committed to caring than others.

The Framework of Systemic Organization by Friedemann (1995) provides a broad theoretical foundation, and yet, specific processes can be explicated to study the experience and meaning of caring for UFCs of persons with stroke from a family perspective. The framework guided the structure and topics of the interview as well as the data analysis procedure. The main concepts for this study are presented in Figure 2. This diagram pictures the UFCs' experience and meaning of caring from abstract and concrete levels to conceptual and applied research levels using Friedemann's Framework of Systemic Organization.

Congruence is key to understanding the UFCs' subjective meaning of caring. By examining the process that leads to congruence, individuation, and coherence on the personal system level, connections can be made to the family process in that the individual who is coherent is likely to have a healing effect on the family system as a whole. Family health is evidenced in the well-being of its members. Family health may be measured by determining if the balance of the systemic targets is satisfactorily achieved by all family members; if the family system and the environmental systems are reasonably congruent; and if the family members experience low anxiety (Friedemann, 1995).



<u>Figure 2.</u> Concepts of caring by urban family caregivers related to Friedemann's (1995) Framework of Systemic Organization.

RESEARCH QUESTIONS

The first major research question for this study was: **What is the experience of caring for UFCs of persons with stroke within their family system?** That is, (a) What are the perceived and observed caring actions of UFCs of persons with stroke within their family setting in regard to Friedemann's (1995) four process dimensions of system maintenance, system change, coherence, and individuation? (b) What are UFCs' perceptions of how caring actions are incorporated into family functioning? and (c) What are UFCs' perceptions of how changes in themselves and in their families occur with these caring actions?

The second major research question for this study was: **What is the meaning of caring for UFCs of persons with stroke within the family system?** That is, What are the perceived and observed personal and family congruence in regard to caring: (a) pain and disappointment versus personal growth and enrichment, (b) conflicts versus mutual support, and (c) meaning concerned with the spiritual and cultural aspects of life for UFCs and the family?

The third major research question for this study was: **What expressed caring actions (i.e., the experience of caring) and what expressions of congruence (i.e., the meaning of caring) are universal or cultural bound for UFCs?** That is, (a) What are the components of cultural maintenance for UFCs and the family? and (b) What are the components of cultural transformation for UFCs and family?

SUMMARY OF CHAPTER

In this chapter, the domain of inquiry was identified: the UFCs' experience and meaning of caring, as it influences their capacity to care for persons with stroke and to interact with others in their family. Orientational definitions for urban culture, family, and UFCs; human caring distinguished from caregiving; the experience of caring; and the meaning of caring were presented. The significance of this study is that the findings have the potential to help nurses understand the concept of caring as an interpersonal process between UFCs, persons with stroke, and family members. It also may help place the concept of caring in a family system context, while examining diversity and common trends among families of the urban environment. This research was developed and executed within Friedemann's (1995) Framework of Systemic Organization. The main concepts of health; environment; systemic targets of stability, control, growth, and spirituality; process dimensions of system maintenance, system change, coherence, and individuation; and congruence were discussed and related to UFCs of persons with stroke. Two major research questions were generated that deal with the experience and meaning of caring for UFCs as it influences their capacity to care for persons with stroke and to interact with others within their family system. A third major research question focused on expressed caring actions (i.e., the experience of caring) and expressions of congruence (i.e., the meaning of caring) that were universal or cultural bound for UFCs.

CHAPTER 2

REVIEW OF THE LITERATURE

Humanistic caring is defined as "subjective feelings, experience, and interactional behaviors between two or more persons in which assistive or enabling acts are performed" (Leininger, 1988, p. 101). A search of the general and nursing literature focused on the following topics: caring related to families of the urban poor; human caring as culture maintenance and transformation; and caring related to Friedemann's (1995) process dimensions of system maintenance, system change, coherence, and individuation. In other selected research literature, the topic that was searched was caring by caregivers that leads to incongruence or negative consequences and that maintains congruence or positive consequences.

General and Nursing Literature

Caring Related to Families of the Urban Poor

In 1990, 13.5% of the American population were poor (U.S. Bureau of the Census, 1991) and, of these, 42% lived in urban communities (U.S. Bureau of the Census, 1990). This government report also identified that 15% of the U.S. population over the age of 65 are officially poor (U.S. Bureau of the Census, 1990). Hidden in these figures are rather dramatic racial disparities. In urban cities, approximately 27% of impoverished European Americans live in poverty areas versus 62% of the nation's African Americans (U.S. Bureau of the Census, 1990).

With regard to health care, many African American families feel that receiving care is a degrading and humiliating experience. In many settings, African Americans continue to be viewed as persons beneath the healthcare worker. Often, insults are subtle and not seen but rather felt or experienced by African American individuals and families (Devine & Wright, 1993; Spector, 1991).

Without regard to race, it is not a secret that African American and European American families living in poor urban settings receive their care in public clinics and hospitals. They are viewed as the people on whom students practice and on whom medical research is done. Some poor families fear or resent the healthcare system. For example, when they have clinic appointments, individuals usually lose work time, as they have to be at the clinic at an early hour and may then have to spend hours waiting to be seen by a physician. In addition, they often receive inadequate care, are unable to understand their problem, especially when it is described to them with medical jargon, and are not given an identity and instead, are viewed as a body segment (Spector, 1991). In light of this treatment, it is small wonder that these families prefer to use home remedies rather than be exposed to the humiliating experiences of clinics and hospitals. Another reason for using home remedies is poverty. These families cannot afford the high cost of health care. Often, even with financial assistance, the hidden costs of care, such as transportation and child care, make acquiring health services impossible (Spector).

With regard to caring, low-income African American and European American families that are unable to purchase services, even when they are available, usually turn to family members for help (Adams, 1980; Kinshef & Yeolin, 1981; Ward & Carney, 1994). While family involvement in caring is sometimes difficult for young persons, for older adults who may be ill and disabled, providing care for another elderly person can be overwhelming. Nevertheless, older adults in need of long-term care receive the majority of their care from family members who are, themselves, elderly (Baines & Oglesby, 1992). According to Stack (1974), without the help of relatives or kin, the African American family's ability to survive decreases. Kin relationships that include networks of friends, underlaid by feelings of obligation to one another, make survival possible. Stack concluded that kin are expected to help one another. Similarly, Boaz and Hu (1997) found that the most important resources in providing and maintaining home caring are a combination of family helpers who join forces with elderly people with disability.

Caring responsibilities among the poor, predominately done by family caregivers who are women, are well documented in the literature (Lindgren, 1990, 1993; Musolf, 1991; Stack, 1996; Ward & Carney, 1994; "What Do We Owe the Elderly?" 1994). Older women are disproportionately poor, especially if they are unmarried, live alone, belong to an ethnic minority, or live in an urban community (Christensen, 1991; Stone, 1987). However, the population as a group has not been studied sufficiently. When low-income women were included in studies of caregivers, they usually were part of a larger sample and the effects of income were not a focus (Stone, Cafferata, & Sangl, 1987). In one report specifically directed at elder kin care by low-income women, Ward and Carney described caring as a transitional process beginning with the inevitability of the caregiving role and ending with acquiescence to it. For many women, the experience required little assistance; for others, the need for assistance was extensive. Ward and Carney concluded that beyond gender issues, low-income families have economic constraints that limit their ability to envision and use alternatives to their own time and labor.

Poverty, or the family's adaptation to their economic reality, is a unifying factor that affects UFCs. While its exact share has not been determined, its influence seems considerable. The kinship systems of ethnic minority families in urban settings resemble each other, as they are characterized by intimate involvement and a set of unwritten obligations to the family (Wilkinson, 1993). In several studies with an urban focus, UFCs described their initiation into caring for family members as a learned experience, the result of circumstances in which the choice not to provide care was largely absent. It seems likely that patterns and quality of caring are different if they are based on obligation and lack of options rather than voluntary decision making (Stone et al., 1987).

Caring As Culture Maintenance and Transformation

Helman (1984) viewed culture as an inherited lens of shared concepts and rules of meaning through which society's members perceive the world, guide their behavior, and determine their emotional reactions in daily living. According to Leininger (1991b), culture "refers to the learned, shared, and transmitted values, beliefs, norms, and lifeways of a particular group that guides their members' thinking, decisions, and actions in patterned ways" (p. 47). Similar to Helman, Leininger (1991b, 1993) further contended that culture has a pervasive and lasting influence on the beliefs, values, and lifeways of individuals. In sum, culture has been identified as a major concept, structural feature, and dominant influence of care related to health or well-being by Leininger (1991b, 1993).

While culture has implicit rules that individuals may not consciously recognize (Leininger, 1978), it is also a universal experience that determines how individuals interact with each other (Lea, 1994). Ethnicity involves a person's identity that is based on historical continuity (Giordano & Giordano, 1977). Variations may occur within each ethnic group due to factors such as age, sex, education, socioeconomic status, birthplace, and religious affiliation (Bauwens & Anderson, 1992; Helman, 1984). Cultural diversity is a reality that exists between ethnic groups, and cultural variations may prevail among different generations and subgroups (Lea).

A somewhat different view of culture was presented by Friedemann (1995). For Friedemann, culture is the total life process of systems, persons, and families, who have adapted to the same environment. Culture maintenance of ethnic patterns occurs through system maintenance and coherence at the family system level in that values and beliefs are mutually guarded against conflicting environmental trends and ideals (Friedemann, 1989a, 1995; Friedemann & Musgrove, 1994). If environmental patterns and ideologies conflict with the patterns grounded in system maintenance, families may incorporate through individuation some new knowledge and compromise many of their usual behaviors. This process inevitably leads the family to system change and culture transformation. Each family will develop its own distinct culture that is dependent upon how the family system interacts with the environment and applies the information to its daily pattern. Thus, ethnic groups have common characteristics based on tradition and history, but individual families differ according to the environment in which they live and to the extent by which they adhere to tradition or allow change over time. The rate of change depends on the flexibility built into their system maintenance. With time, distinct ethnic identification may become blurred due to the cultural transformation process influenced by adaptation to a variety of environments. Consequently, created by similar living conditions, such as urban poverty, there are inter-ethnic similarities and intra-ethnic differences.

Such complexity points to the need to define culture on the level of each family (Friedemann, 1995). Culture as a process inherent in the family was examined with UFCs of persons with stroke in this study, as UFCs are confronting similar situations based on the urban setting in regard to the problems of caring on a daily basis.

Caring practices as part of family culture and of the peculiarities of caring in different cultural groups have been described by numerous authors (Aamodt, 1977; Horn, 1978; Kelly, 1994a, 1994b; Leininger, 1970, 1984; Price, 1994; Ragucci, 1977; Tripp-Reimer, 1980; Wykle & Segal, 1991). Friedemann (1991) noted that "ethnicity represents those stable cultural patterns that are shared by a group of families who have the same historical roots" (p. 173). People of several races and many different ethnicities compose the urban setting. While diverse, these lower-income families are combined by the force of poverty, and many have assumed certain typical urban cultural patterns (Friedemann; Ward & Carney, 1994). Studies cited in the literature allude to commonalities in caring related to basic human needs true for all, as even caring patterns among the races show more similarities than differences (Kelly, 1994a, 1994b; Wykle & Segal). For example, both African Americans and European Americans not only believe that the home, rather than a nursing home, is the best place for their family members who are ill or disabled but also that they need and expect more help in caring for their family member (Kelly, 1994a; Wykle & Segal).

Conversely, there are differences between African American and European American family caregivers regarding cultural patterns related to caring for others. For instance, African American family caregivers draw upon more family members for help with caring (Chatters, Taylor, & Jackson, 1985; Hines-Martin, 1992; Martin & Martin, 1978; Mitchell & Register, 1984; Price, 1994; Taylor, 1985; Taylor & Chatters, 1986; Wykle & Segal, 1991) and provide proportionally more home caring for individuals with impairments than do European Americans (Markson, 1979). Additionally, African Americans generally disapprove of placing a family member in a nursing home when family members are available to provide care (Picot, 1995). According to Stack (1996), when timing is a problem, when substantial sacrifice is required, when a family is too poor to purchase services that might lighten the burden, when no person seems well suited to a particular task, family ingenuity and commitment can be tested. Families may devise new patterns of assigning work among kin and write new scripts for old family values. No one is ever ready when their parents and grandparents can no longer take care of themselves, even if preparations have been made. Stack stated that poverty limits choices and cultural values fashion expectations, until caring for an aging relative may seem like the only thing to do in African American families. Also, African Americans place more emphasis on spirituality as a way of dealing with the caring situation (Smerglia, Deimling, & Baresi, 1988; Wykle & Segal). Gonzalez (1997) reported that religiosity among African American caregivers may serve as a means to explain how they are able to score higher in resourcefulness than European Americans. Spirituality reduces the perceived stressful behavior problems of care recipients, which leads these African American caregivers to report benign appraisals of disruptive behavior in their care recipients. In addition, Nkongho and Archbold (1995) noted that spirituality, which is composed of formal Christian beliefs and the secular value of caring for one's own, is an important reason for African American family members to assume the caring role.

In summary, cultural patterns seem to be a product of tradition, historical development, and adaptation to a common living environment (cultural transformation). They rest on shared assumptions and values, and are evidenced as behaviors (cultural maintenance) that the family develops to survive. These include tasks, such as caring for others, that are shown to be useful enough to be taught to the younger generation (Friedemann, 1995; Schein, 1985).

UFCs who suddenly find themselves in caring situations suffer difficulties related to decreased health and altered economic and social status that force them to change their patterns rapidly to avoid problems. Ideally, urban cultural caring patterns will evolve through the integration of new knowledge offered by the healthcare system into the family's way of life. Some old patterns are maintained and some less useful ones are replaced, leading to new values and an understanding of the caring situation that is then built into system maintenance and passed on to the next generation (Friedemann, 1995). This shows that culture is a dynamic process within which individuals, interacting with others, are continually engaged (Baumgart & Larsen, 1988; Benner & Wrubel, 1989).

While it is clear from the previously reviewed literature that differences do exist in caring behaviors based on ethnicity, it is not clear how much ethnocultural or economic influences contribute to patterns of caring and to what degree ethnicity, culture, and poverty affect perceptions of caring or the quality of care being provided. Very little research has been conducted in these areas (Stone et al., 1987; U.S. Department of Health and Human Services, 1994).

Caring Related to Process Dimensions

By examining the literature as it relates to Friedemann's (1995) process dimensions of system maintenance, system change, coherence, and individuation, an understanding of caring can be gained. This review of literature is subdivided into perspectives of the personal and interpersonal systems. The person, as an individual or personal system, is defined as one who interacts with others (Friedemann, 1995) and internalizes subjective experiences; only the individual, not the family, is directly affected by the experiences. Friedemann (1989c) defines the interpersonal system as two or more individual systems, subsystems of the total family, that have a common purpose of interacting with each other. The caring process by UFCs of persons with stroke is affecting both the personal and interpersonal systems.

Selected authors, for example, Roach (1992) and Gaylin (1976), are included along with seminal work related to caring by Buber (1965), Mayeroff (1971), Noddings (1984), and Watson (1979, 1988). These authors were selected for review as their thinking supports the domain of inquiry and the underlying theoretical assumptions of the Framework of Systemic Organization by Friedemann (1995). All speak in support of the process dimensions. A synopsis of these authors' work on caring compared to the process dimensions and the interpersonal system are presented in Appendix B. The following descriptions of caring by these seminal authors are offered as a brief orientation to their work, before further discussing and comparing their work within Friedemann's framework.

Noddings (1984), an educator, explored caring as a feminine approach to ethical and moral comprehension. She mainly addressed Friedemann's (1995) process dimensions of system maintenance, system change, and individuation. According to Noddings, caring is based on receptivity. There are two parties in the relation: the one caring and the one being cared for. The one caring feels with the other (the one being cared for) and receives the other completely. While this process is not cognitive, it is emotive, which requires a motivational shift and engrossment with the other. While the situation of caring is concrete in that it is tied to a particular context, the nature of the caring relationship depends on the strength of the felt obligation and affection and can vary in intensity and duration. Caring is seen as a way of being and does not necessarily involve action or communication. From Noddings' point of view, caring is an end in itself, complete, and not a means to an end.

Similarly, Mayeroff (1971), a philosopher and teacher, described caring as a process of relating between individuals, where growth, actualization, and transformation of the relationship occur. Mayeroff focused on Friedemann's (1995) process dimensions of system maintenance, system change, and individuation. Specifically, Mayeroff stated that caring is helping someone else grow toward self-actualization. Caring is not only grounded in the worth the one caring experiences in the other, but also in promotion of self-actualization of the one caring by serving to ground the person in the world. Although the goal of caring is to help someone else grow, Mayeroff stated that the one caring determines the direction of growth for the one cared for. Mayeroff listed eight major ingredients in his model of caring: (a) knowing (helping the other grow by using explicit and implicit knowledge), (b) alternating rhythms (moving back and forth between a narrower and wider framework), (c) patience (participating with the other and giving fully of self), (d) honesty (confronting and being open to oneself), (e) trust (appreciating the independent existence of the other; trusting self and other), (f) humility (appreciating own strengths and limitations), (g) hope (expressing of a present alive with possibilities), and (h) courage (going into the unknown). Many authors writing on caring have applied

Mayeroff's eight major components of caring in their work.

Watson (1979, 1988) presented caring from a nursing perspective. Caring is viewed as a moral ideal, an epistemic endeavor, the starting point for nursing action, and a unique transaction between the nurse and other. Watson chiefly spoke to Friedemann's (1995) process dimensions of system maintenance, system change, and coherence. For Watson, caring involves the will to care, the intent to care, and caring actions. Transpersonal caring transactions are those giving-receiving behaviors and responses between two people that allow for contact between the persons' subjective worlds through physical, mental, or spiritual routes, or some combination thereof. However, the psychological, emotional, and spiritual dimensions of caring are emphasized. Caring, in Watson's terms, is a commitment to an end, the protection, enhancement, and preservation of the dignity of the other. One can easily apply the same process to the caring relationship by a family dyad.

In contrast, Buber (1965) viewed the interactive process from a different perspective. Buber exemplified the notion of intersubjective relationships with philosophical anthropology. His ideas may essentially be related to Friedemann's (1995) process dimensions of system maintenance, system change, and individuation. In Buber's work, caring can be thought of as a form of dialogue that emerges from the readiness to be addressed by another. The meaning of the dialogue is found in neither one or the other of the partners, nor in both taken together, but in their interchange. This dialogue can be spoken or silent. The essential element is seeing the other or experiencing the other side. This dialogue requires the unreserve, or the ability to be open to the claim of the other person. Caring involves moving beyond observation and reflection into a level of awareness in which one is absorbed by the present situation. For Buber, caring is a way of being rather than action. Although Buber never used the word caring, this dialogue clearly refers to what Noddings (1984) described as receptivity and what Watson

(1979, 1988) called a transpersonal caring relationship.

Caring As System Maintenance and System Change

Caring in the sense of Friedemann's (1995) system maintenance process includes behaviors that are anchored in tradition, refer to the structure and operation of the family, and pertain to organizing and operating the day-to-day business of caring for another family member. While system maintenance caring behaviors are fairly consistent, system change denotes major alterations of caring behaviors.

Personal system. Caring is an essential human life ingredient (Bevis, 1981; Leininger, 1991b). Caring as a human trait was described by Morse, Bottorff, Neander, and Solberg (1991) as a part of human nature that is common to and inherent in all persons. For Noddings (1984), caring is based on receptivity; caring is a way of being.

The origins of caring refer to the reason why one cares (Vezeau & Schroeder, 1991). For Mayeroff (1971), caring stems from self-obligation; the one caring fulfills a basic need to be needed that may not be reciprocated. According to Noddings (1984), caring is a primary value that grows out of the natural caring experienced by the person in childhood. For example, as the person grows up within the family, the relationships become less familiar. Noddings believed that the person continues to care due to a natural imperative to care based on learned values. Like Noddings, Watson (1988) believed that caring can be fostered. For Watson, caring originated from moral responsibility for the person to meet society's mandate. From these writers' viewpoints, caring can be likened to ways in which the personal system is maintained, such as through tried and true accomplishments and social connections. However, this does not prevent system change. These changes can occur through involvement in caring for another person by learning and then applying new ideas and ways of caring (Friedemann, 1995).

Approaches to caring can be differentiated by whether caring is a means to an end or an end in itself (Vezeau & Schroeder, 1991). For

Mayeroff (1971), caring leads to growth, primarily for the care recipient. While Watson (1988) described caring as potentiating self-healing, as such, caring is a personal experience. In this way, growth and self-healing are similar to system maintenance and change using Friedemann's (1995) terms. However, as the focus shifts to caring as a means to an end, caring becomes interpersonal.

Interpersonal system. Caring is a human-to-human enterprise (Bevis, 1981; Leininger, 1991b). Buber (1965) noted that "feeling the address," full receptivity or "unreserve" is central to caring relationships (p. 11). For Buber, caring originates from unreserve or the ability to be open to the claim of another individual. This unreserve allows one to feel the claim and address of another and thus to engage in living dialogue. Through this living dialogue, systems are maintained and changed. Noddings' (1984) perspective is somewhat different than Buber's in that the caring relationship depends on the strength of the felt obligation, commitment, and affection that can vary in intensity and duration.

Basic to any approach to caring is the relationship of the caregiver to the care recipient. This relationship involves power, the balance of which may have many expressions (Vezeau & Schroeder, 1991). However, for Mayeroff (1971), caring signifies helping the other maintain dignity and grow regardless of the kind of relationship. Caring may be reciprocal or egalitarian in Mayeroff's model of caring.

Using somewhat different words, Buber (1965), Noddings (1984), Leininger (1991b), and Watson (1988) concurred with Mayeroff. Mutuality and reciprocity of awareness prevail in the caring relationship Buber described. For Noddings, a caring relationship is reciprocal; both individuals have the potential for enhancement through doing for each other. Leininger stated that caring involves coparticipation of those involved. In addition, according to Watson, the relationship of self and other is characterized by mutuality in the power relationship. Watson believed that both the caregiver and the care recipient benefit from the caring actions and that both experience rewards. For these authors, human systems are maintained and changed through mutuality and reciprocity of relationships. Caring may also be viewed as a therapeutic intervention. For example, Gaut (1986) considered caring to be an intentional human enterprise. Gaut presented caring as an action mode that can maintain and change interpersonal human systems.

Noddings (1984) and Buber (1965) stated that caring is an end in itself. Noddings noted that caring is a primary value unto itself, in which the relationship is valued over the outcome. Similarly, Buber viewed dialogue as a relationship in which life is experienced fully; the outcome of this lived dialogue is unimportant. Taken out of their total context, these authors' work on caring supports Friedemann's (1995) concepts of how maintenance and change occur through the involvement in caring for another person.

Caring As Coherence

Caring as coherence refers to the expression and promotion of emotional bonding of caring relationships among family members that target spirituality and stability of the family (Friedemann, 1995). According to Friedemann, coherence is acquired as individuals in the family adjust to each other's rhythms and patterns and feel connected with the family.

Personal system. Griffin (1980, 1983) and Roach (1992) defined caring as an essential way of being for the person. "Caring is essential not only to the development of the human being but also to the development of the caring of the human being" (Roach, p. 3). In a like manner, caring is also seen as part of the essence of humanness (Griffin, 1983; Leininger, 1991b). Similarly, Roach recognized that caring is "the most common, authentic criterion of humanness" (p. 2).

Brody (1988), Gadow (1985), and Watson (1988) considered caring to be a moral virtue. Others, such as Fanslow (1987), Forrest (1989), Gendron (1988), and McFarlane (1976), argued that caring is an affect; caring is an emotion. In order to understand caring, Watson noted that the individual is an integrated trinity of spirit, mind, and body. While many authors viewed caring as an embodiment, Watson's caring transcends the body, guiding the whole person toward enhancement. In support of these authors, according to Friedemann (1995), values underlying the human purpose of life form the base for coherence.

Interpersonal system. Caring is viewed as a mutual endeavor between caregiver and care recipient by Horner (1988), Knowlden (1988), Leininger (1991b), Orem (1995), and Weiss (1988). Watson (1988) also viewed caring not only as a moral virtue but as an interpersonal process. Friedemann (1995) denoted mutual caring under the process dimension of coherence for the family system. The family gains coherence through providing emotional support for one another.

Caring As Individuation

Caring as individuation is the pursuit of interests and meaning for all members of the family and the family's accommodation to it, targeting spirituality and growth. Individuation is personal growth through a spiritual connection but also involves the human interpersonal connection or growth in the interchange with another person. While individuation is always interactional, it may involve systems that are not human, such as the process of finding meaning (Friedemann, 1995).

Personal system. Writers have defined caring as the basic constructive phenomenon of human existence (Leininger, 1991b; May, 1969). In other words, caring is a human trait. Mayeroff (1971) described caring as necessary for growth and postulates such attributes as trust, courage, hope, and respect as being essential to care. Further, Gaylin (1976) discussed caring as a biologically innate phenomenon. Gaylin also emphasized the psychological aspects of caring, noting that caring is essential for balancing and overcoming anxiety and insecurity. The reasons why family members are willing to care for another may be based on affection or need fulfillment (Grafstrom, Norberg, & Hagberg, 1993).

For some authors, according to Vezeau and Schroeder (1991), "the relationship of self to body involves concepts of separation, or unity of mind and body in caring" (p. 11). The relationship of caring to embodiment, for Buber (1965), is the relationship with self-body that involves undifferentiated oneness of self "without form or content," which he calls the unity of life (p. 25). Similarly, caring is embodiment for Noddings (1984). Caring is a way of being, not necessarily involving specific action or verbal communication. This spiritual perspective of caring is explained by Reed (1987) as personal thoughts and behaviors that express a sense of relatedness to a transcendent dimension or something greater than one's self. Transcendence, therefore, is a level of awareness by which an individual achieves new perspectives and experiences, exceeding ordinary physical boundaries (Klass & Gordon, 1978-79; Reed, 1982; Smith, 1969). Self-transcendence and a spiritual perspective are dynamic responses to significant life experiences, such as caring. These life experiences are antecedents of self-transcendence and spirituality, and the outcomes either state or imply growth (Haase, Britt, Coward, Leidy, & Penn, 1992). In short, specific life events, such as caring for others, may widen a person's spiritual perspective (Baines, 1984; Kaye & Robinson, 1994; Rabins, Fitting, Eastham, & Fetting, 1990) or strengthen the pursuit of the target of spirituality through individuation in Friedemann's (1995) terms.

Interpersonal system. On the interpersonal level, caring leads to connectedness and belonging. According to Haase et al. (1992), connectedness is more encompassing and richer than social support. Connectedness is identified as a central theme across the concepts of transcendence and spirituality. Connectedness is a significant, shared, and meaningful personal relationship with another person that involves receiving and giving support as well as mutuality (Haase et al.).

Mutuality in caring was defined by Hirschfield (1983) as the caregiver's capacity to find gratification and a sense of connectedness and reciprocity in the caring relationship. Archbold, Stewart, Greenlick, and Harvath (1990) concurred that the concept of mutuality is important in family caring. These authors stated that if low mutuality was detected in the caring relationship, alternatives to family caring needed to be discussed and implemented. Leininger (1991b) found that caring constructs such as reciprocity and spiritual relatedness gave meaning to human interactions. Additionally, Hirschfield also identified that caregivers found meaning from the caring situation, indicating that spirituality may be a combination of both coherence and individuation. In keeping with the Framework of Systemic Organization, Archbold and associates stated that caregivers who experience a positive relationship with the care recipient have less tension or anxiety because they find caring inherently meaningful. Likewise, according to Chesla, Martinson, and Muwaswes (1994), lifelong family caring relationships are experienced as sustaining and meaningful.

In contrast, Mayeroff (1971) separated mind and body. Caring takes place in the mind and refers to the ability to know another individual intellectually and intuitively. Mayeroff emphasized a present and future orientation, as space is an absolute and time is directional and linear. For Mayeroff, caring leads to growth fundamentally for the one receiving care, although the one caring grows by enhanced self-knowledge.

In summary, the seminal authors all addressed mainly spirituality. Noddings (1984) and Watson (1979, 1988) described interpersonal coherence, whereas Mayeroff (1971) and Buber (1965) focused on personal individuation as an aspect of interpersonal coherence. These authors' works are consistent with the Framework of Systemic Organization (Friedemann, 1995); however, according to this framework, the endurance of a caring relationship depends on mutual growth or individuation, while other dimensions are touched by the caring process. These authors and the Framework of Systemic Organization differ in that the authors did not allow for anything not perfect; they felt that caring either exists or does not exist. The Framework of Systemic Organization allows for individuation and personal growth in caring, and thus spirituality, on various levels driven by coherence in addition to obligation. In fact, obligation, in terms of system maintenance and control in the absence of coherence, could destroy the process of caring. In other words, incongruence not only in the caregivers' personal system but also in their family system would be expected based on imbalance of the process dimensions and an overreliance on control at the expense of spirituality.

Selected Research Literature

Caring As Congruence

Overall, the perceived meaning the caregivers attach to the caring process signifies congruence, well-being, in caring. In a class discussion, a student suggested that metaphorically, congruence in Friedemann's (1995) Framework of Systemic Organization may be thought of as a sailboat on a lake in which congruence is sailing in the desired direction (i.e., the goal) by adjusting to the forces of nature and using the forces in such a way that they help achieve the goal. Anxiety is the sailor's response to a threat, namely that of loss of balance, the threat of succumbing to the forces, and losing the boat. In life, congruence entails many aspects of one's existence; some may be well under control, while others are in jeopardy. That is why it is too simplistic to think of congruence as a linear phenomenon (Friedemann, 1995). There is an abundance of research in the literature focusing on the tasks of caring experienced by the care providers as sources of incongruence and the negative consequences, while ways to attain congruence and the positive consequences of caring remain relatively unexplored.

Incongruence

Caregiving has been denoted mainly as a role, an activity, or a set of tasks, whereas caring has been thought of mainly as commitment, respect, and protection toward the person requiring care that accompany the activity (Pepin, 1992). Caring has also been described by Graham (1983) as consisting of love and labor, which cannot be separated: They are interdependent and nourish one another.

The following section, focusing on the personal and family systems of the care provider, refers to the literature on caregiving as it relates to conceptualizations in linear stress-coping frameworks and theory of role conflict or overload. According to a U.S. Department of Health and Human Services (1994) publication concerning long-term care for older adults, the literature base that describes the negative consequences of caregiving has expanded rapidly to include more than 1,000 studies in the last 10 years and unequivocally documents that caregiving is stressful. The literature presented in this section is representative of this government report but also includes other pertinent studies. The findings of these studies are complex and suggest the need for multidimensional models.

Recent research on caregivers indicates that the majority of care for elderly people with disabilities is provided at home by individuals in the family rather than in institutions (Montgomery et al., 1980; "What Do We Owe the Elderly?" 1994). It was also noted that this type of care was physically and psychologically better for the affected individuals (Kahan, Kemp, Staples, & Brummel-Smith, 1985). Although home care may be beneficial for the care recipient, the caregiver may experience a significantly increased stress level (Baldwin, 1988; Dellasega, 1991; Lindgren, 1993; Pierce, Ader, & Peter, 1989). In a recent study by Williams, Oberst, Bjorklund, and Hughes (1996), a family caregiver stated, "I can certainly see how [people] can get completely stressed out trying to understand and care..." (p. 129). Perceptions of stress by the individual family caregiver may be further escalated if there is no formal (i.e., professionals) or informal (i.e., family or neighbors) support system (Kahan et al., 1985).

Significant stress is experienced by families involved in a caring relationship for another (Carlson & Keller, 1992). The care recipient's state of psychological well-being may affect the caregiver, which, in turn, can affect the care recipient (Burgener & Chiverton, 1992). Based on clinical observations, Evans, Hendricks, Haselkorn, Bishop, and Baldwin (1992) suggested that stroke can be devastating to these interpersonal relationships. As of yet, however, the factors leading to incongruence are poorly understood.

A number of factors repeatedly have been implicated as contributors to and buffers of the caregiver's and family's stress. The following is representative of this body of research. These factors include the care recipient's levels of physical, cognitive, and social impairment (Deimling & Bass, 1986; Williams, 1993); the types of care provided by the caregiver (Draper, Poulos, Cole, Poulos, & Ehrlich, 1992; Montgomery et al., 1985; Noelker & Poulshock, 1982); the caregiver's gender and marital status (Cameron, 1990; Cantor, 1983; Noelker & Poulshock; Zarit, Todd, & Zarit, 1986); the extent to which the caregiver's personal and social life are disrupted by the demands of caregiving (George & Gwyther, 1986; Gwyther & Matteson, 1983; Poulshock & Deimling, 1984; Rabins, Mace, & Lucas, 1982); the quality of the relationship between caregiver and care recipient as perceived by the caregiver (Bowdoin, 1994; Robinson, 1983; Scharlach, 1987); and the lack of satisfactory assistance with caregiving perceived by the caregiver (Bowdoin; George & Gwyther; Zarit, Reever, & Bach-Peterson, 1980). For instance, caregivers and their families may experience high stress if the care recipient is severely disabled and if they perceive that needed assistance in caring is unavailable. Other caregivers may report low stress if the care recipient is only mildly disabled and if relatives and/or friends are able to help provide needed assistance (Bowdoin; Williams, 1993).

Some authors, such as Folkman and Lazarus (1980), Folkman, Lazarus, Pimley, and Novacek, (1987), and McCrae (1982), researched individuals' coping processes and found that older people's coping methods were similar to younger people's. If older people used different strategies, it appeared to be largely due to the different types of stress they faced, such as caring for loved ones with disease and disability and suffering from their own chronic impairments. Folkman and Lazarus found that individuals used problem- and emotion-focused coping in virtually every stressful encounter. Problem-focused coping is directed at decision making, while emotion-focused coping is directed toward managing feelings of anxiety, fear, dread, and toward restoring self-esteem. Men as caregivers coped by focusing on the tasks and projects of caregiving more so than on their emotions; men were found to use more problem-focused coping than women. In terms of the Framework of Systemic Organization (Friedemann, 1995), Folkman and Lazarus' study described strategies of system maintenance and change (i.e., problem-focused coping) as well as coherence and individuation (i.e., emotion-focused coping).

When authors such as Miller (1987), Stone et al. (1987), and Zarit et al. (1986) focused on gender differences in terms of individual stress and burden as a result of caregiving, male caregivers experienced either the same amount of burden as female caregivers (Stone et al.) or less burden (Zarit et al.). Zarit and associates noted that perceived stress or burden may be under-reported by men and over-reported by women. Men may be more stoic in disclosing information about their experienced stresses or burdens, or sampling biases may under-represent those who are experiencing serious stresses and burdens of caregiving (Miller).

Other studies reported the effects of caregiving on elderly wives who care for spouses who are chronically ill or physically disabled (Cameron, 1990; Ekberg, Griffith, & Foxall, 1986; Given, King, Collins, & Given, 1988; Phillips & Rempusheski, 1986; Sexton & Munro, 1985). All authors reported that these caregivers were dealing with emotional stress, burden, fatigue, and consequently, various forms of physical illness.

As caregiving continues over time, the roles of individuals in the family may change. If the socially prescribed roles are in marked conflict with the person's acquired concept of self, there is the possibility for psychological stress processes (Lazarus, 1966). Lazarus' work was a marked change in stress conception. His work was process oriented, integrating a wide range of literature that was a culmination of views that had been expressed earlier by others. Lazarus cited Haggard's (1949) work as a good representation of what the stress process would become over time: "An individual experiences stress when his overall adjustment is threatened, when his adaptive mechanisms are severely taxed and tend to collapse" (p. 458). Such stress may occur in UFCs' caring relationship, as the caregivers take on roles that were previously fulfilled by the person with stroke.

Specific research on caregivers of persons with stroke is scarce. A descriptive study by Williams (1993), however, that examined the health and well-being of caregivers for persons with stroke; a project by Segal and Schall (1996) that described differences in caregiver stress related to the functional ability of the persons with stroke; an exploratory study by Grant and Davis (1997) that explored caregivers' personal losses from caring for persons with stroke; and a study by Draper et al.(1992) of elderly co-resident caregivers of persons with stroke and dementia, all supported Lazarus' position. While Williams' predominately female sample of caregivers of persons with stroke had relatively few physical symptoms, there was considerable emotional distress reported, in terms of anxiety, depression, and anger. Segal and

Schall noted that the greater the functional impairment of the person with stroke and resultant role changes for all involved, the higher the caregiver's level of stress within the first few months after the stroke diagnosis. Grant and Davis reported strain and loss of self as the caregiver took on new roles with caring for the survivor with stroke. Draper's research team found that the psychiatric aspects of chronic disability, depression and anxiety, rather than the physical needs, were perceived as stressful by caregivers of persons with stroke. Psychological and behavioral factors represent an extensive body of literature in relation to caring for persons with Alzheimer's disease and/or dementia. They were found to be of paramount importance in maintaining the health of individual caregivers (Chenoweth & Spenser, 1986; Gwyther & Matteson, 1983; Hirschfield, 1983; Jones & Martinson, 1992; Lindgren, 1993; Neundorfer, 1991; Pierce et al., 1989; Robinson, 1989). The authors basically agreed that the caregivers' ability to cope with their own feelings and reactions was their major challenge.

Pearlin, Mullan, Semple, and Skaff (1990) stated that simply identifying factors that might be associated with stress is not enough. Rather, attention needs to be focused on knowing how certain conditions arise and how they come to be related to each other; attention on the relationships among the many variables leading to personal stress and the ways these relationships develop and change over time is needed not only for the person but also for the family. Individual caregiver stress is a mix of circumstances, experiences, responses, and resources that vary considerably among caregivers and that, consequently, vary in their impact on caregivers' health and behavior. According to Pearlin and associates, a change in one of its components may result in the change of others; this mix is not stable. The Framework of Systemic Organization (Friedemann, 1995) supports these statements in that individual and family systems' renewed congruence is interdependent.

As seen from the above discussion, leading researchers have broadened the view of stress. Caregiving is no longer viewed as a single variable with a linear effect on the care recipient. For example, in stroke research, in a study of 20 caregivers of first-time stroke survivors, Periard (1989) and Periard and Ames (1993) found that strain or stress related to caring may not be confined to direct caring activities but may be related to complex overall patterns of daily life for caregivers and their family.

There is a growing body of evidence that caregiver stress can be explained, in part, by mutuality and interconnectedness (Archbold et al., 1990; Bowdoin, 1994; Homer & Gilleard, 1990; Smith, 1994). The research of Archbold and associates (1990) and Wolf (1988) exemplify this work in that they found that caregivers who have a poor relationship with the care recipient and who do not have satisfying social contacts may experience elevated levels of stress. In turn, this increased level of stress for the caregiver may lead to neglect and/or abuse of the care recipient (Pillemer & Finkelhor, 1989). Neglect or abuse can occur in small ways, such as an impatient word (Hinrichsen & Niederehe, 1994), a smart slap on the wrist, or leaving the care recipient isolated from human company or social happenings. Ultimately, more serious instances of neglect and/or abuse may occur (Pillemer & Finkelhor).

A common theme in neglectful families is codependency among caregivers and care recipients (Williams-Burgess & Kimball, 1992). There is a persistent view in the literature on elder abuse by researchers such as Anetzberger (1987), Hwalek and Sengstock (1986), Pillemer (1985), and Wolf, Strugnell and Godkin (1982), that caregiver stress arises from the dependence of the caregiver on the care recipient. In other words, caregiver abuse results not from the increased needs of the victims, but from the deviance and dependence of the abusers. In Friedemann's (1995) terms, caregivers are unable to individuate sufficiently in their family system; these caregivers strive to control the behavior of the care recipient in order to maintain their system. Phillips and Rempusheski (1986) stated that power and control are key issues for caregivers in neglectful and/or abusive caregiving situations. Rigidity of system maintenance behaviors increases stress, and thus, creates more incongruence (Vitaliano, Young, Russo, Romano, & Magana-Amato, 1993). Incongruence builds until a crisis point is reached by the caregiver that might take the form of a sharp word of impatience or, in several cases, as physical violence, neglect, or abandonment of the care recipient (Hinrichsen & Niederehe, 1994; Pillemer & Finkelhor, 1989).

According to Friedemann (1995), individuation happens when the caregiver realizes that controlling the care recipient is not possible. As the process of getting reacquainted with the changing care recipient and realigning the caregiver's own systemic process with that of the care recipient and family occurs, the caregiver is supported by his or her own coherence, and examines and changes his or her values and attitudes. If new values are adopted, changes in caregiving behaviors will follow. These changes result from the processes of individuation and coherence and constitute a system change that produces growth of caregivers as well as their family.

In summary, all these studies reported that tensions, strains, and stresses cause feelings of anxiety and burden for caregivers and their families, which in turn lead to incongruence for the individual and family system as a whole. Research projects that examined the responses of care recipients in regard to the affective meaning of this experience were not found.

Congruence

Upon reviewing the literature on caregiving as it affects caregivers, it may be tempting to conceptualize giving care as a purely negative process that produces tension, anxiety, and stress. However, there is evidence of feelings of well-being or positive effects of caring on the caregivers. In fact, these positive outcomes are likely to be the motivations to continue the caring relationship. Nevertheless, the research base describing positive consequences is less extensive and more qualitative in design. These studies use mainly ethnographic and phenomenologic methods (U.S. Department of Health and Human Services, 1994).

Using the Framework of Systemic Organization by Friedemann (1995), a healthy personal system is viewed as freed from debilitating anxiety and successful in balancing the four systemic targets in a way that establishes harmony within and with the environment. Thus, health is evidenced as well-being. While not much has been published, the study of Farran, Keane-Hagerty, Salloway, Kupferer, and Wilken (1991) serves as an example in that it points to the need to understand the meaning of caring for another and the potentially positive outcomes for the caring person. The caregivers in this study valued their own feeling of confidence in that this motivated them to give good care. According to Davis and Grant (1994), caregivers with less than 6 months' experience in the role reported having found personal meaning and purpose in the caregiver experience. Furthermore, Nolan and Grant (1989) reported that satisfaction with caring was evident in the majority of caregivers. A basic factor leading to satisfaction was the caregivers' ability to protect their own psyche from negative self-perception and threatening emotions, such as guilt. At a higher level, this positive self-image provided a chance for personal development and an opportunity to better understand the human condition.

The study of Farran and associates (1991) also addressed interpersonal issues. Caregivers valued positive aspects of relationships and of the caring situation in a family context. For example, positive family and social relationships, the care recipient's love for the caregiver, and pleasant memories of others and accomplishments were valued by the family caregivers. These caregivers also found meaning in aspects of caring such as seeing the care appreciated by the recipient and earning positive responses to the care provided.

The maintenance of reciprocity in a relationship seems to play a major role in caregiver satisfaction (Nolan & Grant, 1989). In situations in which caregivers found some degree of satisfaction, the relationship seemed to be reciprocal to some degree in that there was an element of return for the caregivers. This element did not necessarily signify a personal gain. Instead, the main source of satisfaction seemed to result from the act of giving to the care recipients. These researchers found that satisfaction heightened for caregivers when it was clear that the care recipients enjoyed themselves or maintained their dignity and self-esteem. Many caregivers reported that caring was embedded in a relationship in which they felt needed, useful, and productive.

Three studies specifically focused on positive effects of caring by family caregivers. Evans, Bishop, and Ousley (1992) in interviewing family caregivers of persons with stroke found that family relations seemed to be a source of strength. In a study of family caregivers of institutionalized elderly persons, Smith and Bengston (1979) reported three positive effects associated with the caring experience. They were renewed closeness and strengthening of family ties, continuation of closeness, and discovery of new love and affection. Silliman, Fletcher, Earp, and Wagner (1986) stated that families of elderly persons with stroke felt good about themselves when they learned to manage the illness situation successfully. In fact, most families noted a closer relationship with the person who had a stroke because of the caring experience. No studies were found that focused directly on the meaning that UFCs of persons with stroke ascribed to caring and the influence of that meaning on the family's capacity to care.

The process of caring that leads to congruence remains somewhat of an enigma, especially from urban and family system contexts. A few published studies may have addressed congruence, in that they focused on well-being or the positive consequences of caring by caregivers, such as maintenance of the caregivers' psyche from negative self-perceptions and of reciprocity in a relationship (Farran et al., 1991; Nolan & Grant, 1989). These studies reflect the implicit influence of the seminal work by Buber (1965), Mayeroff (1971), Noddings (1984), and Watson (1979, 1988), as the authors viewed caregivers as being involved in a variety of personal and interpersonal interactions of caring and found them experiencing satisfaction with their role. In addition, the reported studies supported the processes that were theoretically explicated by the use of the Framework of Systemic Organization by Friedemann (1995).

SUMMARY OF CHAPTER

This review of literature depicts caring related to families of the urban poor, as well as caring as culture transformation and maintenance. With regard to health care, many African American families feel that receiving care is a degrading and humiliating experience. With regard to caring, low-income African American and European American families that are unable to purchase services, even when they are available, usually turn to family members for help. Poverty, or the family's adaptation to their economic reality, is a unifying factor that affects UFCs.

According to Friedemann (1995), culture is the total life process of systems, persons, and families, who have adapted to the same environment. Cultural patterns seem to be a product of tradition, historical development, and adaptation to a common living environment (cultural transformation). They rest on shared assumptions and values, and are evidenced as behaviors (cultural maintenance) that the family develops to survive. With time, distinct ethnic identification may become blurred due to the cultural transformation process influenced by adaptation to a variety of environments. Consequently, created by similar living conditions, such as urban poverty, there are inter-ethnic similarities and intra-ethnic differences. While it is clear from the previously reviewed literature that differences do exist in caring behaviors based on ethnicity, it is not clear how much ethnocultural or economic influences contribute to patterns of caring and to what degree ethnicity, culture, and poverty affect perceptions of caring or the quality of care being provided. Very little research has been conducted in these areas.

By examining the literature as it relates to Friedemann's (1995) process dimensions of system maintenance, system change, coherence, and individuation, an understanding of caring can be gained. Noddings (1984) and Watson (1979, 1988) described interpersonal coherence, whereas Mayeroff (1971) and Buber (1965) focused on personal individuation as an aspect of interpersonal coherence. These authors' works are consistent with the Framework of Systemic Organization (Friedemann); however, according to this framework, the endurance of a caring relationship depends on mutual growth or individuation, while other dimensions are touched by the caring process. These seminal authors and the Framework of Systemic Organization differ in that the authors did not allow for anything not perfect; they felt that caring either exists or does not exist. The Framework of Systemic Organization allows for individuation and personal growth in caring on various levels driven by coherence in addition to obligation. In fact, obligation, in terms of system maintenance and control in the absence of coherence, could destroy the process of caring.

Processes described by UFCs as disturbing or helpful to personal, interpersonal, or family congruence were cited in the literature. Significant stress is experienced by families involved in a caring relationship for another. There is a growing body of evidence that caregiver stress can be explained, in part, by mutuality and interconnectedness. There is a persistent view in the literature on elder abuse, that caregiver stress arises from the dependence of the caregiver on the care recipient. Researchers reported that tensions, strains, and stresses cause feelings of anxiety and burden for caregivers and their families, which in turn lead to incongruence for the individual and family system as a whole. However, there is also evidence of feelings of well-being (congruence) or positive effects of caring on the caregivers cited in the literature. In fact, these positive outcomes are likely to be the motivations to continue the caring relationship. A few published studies focused on well-being or the positive consequences of caring by caregivers, such as protection of the caregivers' psyche from negative self-perceptions and of maintenance reciprocity in a relationship. All the reported studies supported the processes that were theoretically explicated by the use of the Framework of Systemic Organization by Friedemann (1995). Caring, as understood in terms of Friedemann's process dimensions, was clearly described in the literature and lent the structure for categorizing and analyzing the experience and meaning of caring described in the next chapter.

CHAPTER 3

METHODOLOGY

Chapter 1 presented the rationale for studying the experience and meaning for UFCs of persons with stroke. Orientational definitions, significance of the study, theoretical framework and assumptions, and research questions for this study were identified. A literature review in Chapter 2 supported the rationale for the study. This chapter outlines the research methodology.

RESEARCH DESIGN

An ethnographic, descriptive design was used. The ethnographic research method was used to collect and analyze data in answering the questions in this study. According to Leininger (1985, 1991a), a general ethnographic study is the principal research means for obtaining a holistic view of persons in their environments. Ethnography means studying the unexplained and allows for identification and explanation of outcomes. In other words, ethnography is a way of learning from people (Spradley, 1979, 1980). As Malinowski (1922) put it, the goal of ethnography is to embrace the "native's point of view, his relation to life, to realize his vision of his world" (p. 25). This is the emic perspective (i.e., the way members of a cultural environment view their world) (Leininger, 1985; Polit & Hungler, 1995). Using a primarily inductive method and then speculating about unexplained facts, the researcher attempts to grasp the person's worldview. In addition, ethnographic data can be used over time for comparative purposes, sensitizing people to the consequences and contexts of behavior (Friedemann, 1995; Kaufman, 1990; Leininger, 1991a; Spradley, 1979, 1980). Ethnography is an appropriate choice for this project, since the purpose of this study is to examine the experience (i.e., the perceived and observed actions) and meaning (i.e., the perceived and observed congruence) of caring for UFCs as they influence their capacity to care for persons with stroke and interact with others in their family system.

Other reasons to support the use of this method include the following:

1. Virtually no knowledge about UFCs in the context of their family is available, which precludes a quantitative study due to the lack of established instruments.
2. A broad worldview about UFCs from their viewpoints and their modes of knowing and understanding the caring situation is of essence.
3. Meaning-in-context data and meanings-in-familiar contexts may be obtained, leading to a broad worldview.
4. Recurrent and patterned behaviors may be identified as a way to explore processes (Leininger, 1991a; Spradley, 1979, 1980).
5. These descriptions may be applied to existing theory (Burns & Grove, 1993) and used to develop new hypotheses or identify salient variables that have not been identified or that merit study (Leininger, 1991a).

Therefore, the method lent itself to theory explication and the investigation of proportional relationships among concepts of Friedemann's (1995) Framework of Systemic Organization. Specific activities used in carrying out the ethnography method for this study of UFCs of persons with stroke within a family context were the field techniques of interview and observation-participation. Field notes and personal journal documentation as identified by Leininger (1985, 1991a) and by Spradley (1979, 1980) were used.

Setting and Sample

The setting for this investigation was an urban community in northwestern Ohio. A purposive sample of 8 key and 16 general informants who were UFCs of persons with stroke was selected from the rehabilitation setting at a large, urban medical college and hospital. Key informants are most knowledgeable about the domain of inquiry; whereas, general informants provide general information about the domain (Leininger, 1985). For this study, the key and general informants were

UFCs of persons with stroke for at least a 6-month duration in African American families, as only they had the depth of experience and meaning of caring from a cultural and family perspective.

Qualitative reliability refers to identifying and documenting repetitious, accurate, and consistent or inconsistent themes or patterns (Leininger, 1985). By using the proposed sample size, data repetition occurred and saturation was achieved through recurrent descriptions of the experience and meaning of caring by these UFCs, suggesting qualitative reliability. This researcher heard duplication in the informants' intense and in-depth descriptions of caring for the person with stroke. Evidence of achievement of a saturation point of information occurred when the UFCs' words, actions, and patterns appeared and reappeared. Spradley and McCurdy (1988) stated that a total of only one informant may be used for qualitative projects as long as every attempt to control for reliability is made. Spradley and McCurdy and Bruyn (1966) noted that reliability of the data can be achieved by (a) developing a good rapport with the informant, (b) inquiring about the informant's opinions in an unbiased manner, and (c) asking the same basic question(s) in all the interviews if more than one informant is used. These strategies were used in this inquiry.

According to Leininger (1985), the goal of validity in qualitative studies focuses on knowing and understanding the phenomenon. The criterion-related approach to qualitative validity emphasizes establishing the existence and nature of this phenomenon with its meanings, attributes, and contextual features. Qualitative construct validity points to identifying and discerning the nature, essence, and underlying attributes of the phenomenon under study. Concurrent validity in qualitative studies refers to the ability to show consistency, meanings, and syntactical relationships of findings. Qualitative predictive validity rests on the ability of the researcher to differentiate abstracted experiential and empirical phenomena under study to predict human behavior. In short, Leininger stated that qualitative validity rests upon knowing and understanding the phenomenon as fully as possible as a result of the study. Qualitative validity for this study entailed knowing and understanding the experience and meaning of caring for UFCs as they influence their capacity to care for persons with stroke and to interact with others within their family system.

Informant Selection

The researcher became involved with UFCs and persons with stroke in African American families in the medical college hospital's rehabilitation unit and clinics. After receiving the approval of the university and hospital Institutional Review Boards (Appendixes C and D), initial contact of potential UFCs of persons with stroke occurred in the rehabilitation inpatient and outpatient setting. As determined by the researcher, criteria for selection of the emic key informants included (a) being a primary and current UFC of a person with stroke for at least a 6-month duration since the person's initial discharge from the rehabilitation program; (b) being responsible for coordinating and providing the caring actions and/or resources required by the person with stroke; (c) being a resident in the same home environment as the care recipient; (d) having a family income that is at or below the current poverty level, receiving federal, state, and/or county financial healthcare assistance, or having no private healthcare insurance for the care recipient; (e) having an urban residence that could be verified by zip code; (f) being a man or woman older than 18 years old; (g) being an individual in an African American family who identifies himself or herself as American with cultural origins from countries on the continent of Africa and who was born in the United States; (h) having the cognitive ability to read, write, and understand English; and (i) being willing to participate in this study.

As specified by the researcher, inclusion criteria for emic general informants included (a) being a secondary and current UFC of a person with stroke for at least a 6-month duration since the person's initial discharge from the rehabilitation program, (b) being involved in providing only some of the caring actions and/or resources required by the person with stroke, (c) being a resident in the same home environment as the care recipient or nearby, and (d) meeting criteria items (d) through (i) as listed under key informants.

The researcher conducting the study collected all data. This allowed for consistency of selecting the informants, obtaining consents, interviewing and observation-participation techniques, and documenting data. After establishing an initial rapport with the UFCs by using open and honest communication skills to bridge cultural differences, UFCs who met the inclusive criteria for this study were invited to participate. The researcher wore slacks or shorts and a shirt to the meetings in order to present a nonthreatening appearance and to reduce any resulting inhibiting influence over the informants' free descriptions of caring. All key informants were chosen from referrals by nurses and physicians who were affiliated with the rehabilitation inpatient and outpatient setting. General informants were chosen from the rehabilitation inpatient and outpatient setting as described above or from referrals made by the key informants.

Protection of Informants

Informants are human beings with problems, concerns, and interests. The researcher's primary responsibility is to those who are being studied. If there is a conflict of interest, the informants come first; the rights, interests, and sensitivities of those studied must be safeguarded. The aims of the inquiry must be communicated clearly to the informants. In addition, the informants have the right to not be exploited and to confidentiality of data (Spradley, 1979, 1980).

A consent form was signed by each informant prior to data collection. The key informants were asked for consent to audiotape interviews. Some were asked to consent to an observation-participation session. The consent forms are presented respectively in Appendixes E and F. In addition, care recipients signed a consent form, displayed in Appendix G, prior to all observation-participation sessions. The general informants signed a consent form exhibited in Appendix H before the audiotaped interview. On the days of the interviews, the audiotape recorder was turned on and consent to audiotape the interviews was obtained again, on the tape at that point, before the interview went forward. It was reinforced to all informants that all data would be coded and their names would not be used; only the code number would appear on audiotape and researcher observation-participation notebook entries. All audiotapes and notebooks remained with the researcher in a locked file and were destroyed after data transcription and analysis.

Field Techniques

The field techniques of interview and observation-participation were used for this study. Much of any culture is encoded in linguistic form. The ethnographic interview is one way for getting people to talk about what they know (Spradley, 1979). Interviews with the informants served to gather demographic data and to examine the experience and meaning of caring for UFCs of persons with stroke. The technique of observation-participation enabled the researcher to further explore these concepts. According to Spradley (1979), ethnographers combine observation-participation with interviewing to observe how "folk terms are used in ordinary settings" (p. 156). The researcher may find that by visiting the setting in which the informant carries out daily activities and by participating in those activities with the informant, data may be revealed that have not been discussed in the interviews (Spradley, 1979). Ethnographers do more than just make observations; they also participate. Participation allows researchers to experience activities directly, to get the feel of what events are like, and to record their own perceptions. By participation, the researcher is more fully able to learn the cultural rules for behavior (Spradley, 1980). While participating in an activity, it is crucial for the nurse researcher to maintain a role as a research observer and not as a practicing nurse (Leininger, 1985). For this study, the researcher observed and participated in varying degrees to learn from UFCs about caring and to feel, experience, and learn by being directly involved in caring activities within the urban family setting. According to Leininger (1985), the researcher describes and explains by documenting these activities, rather than by avoiding the situations. Leininger (1985, 1991a) contended that the researcher enters the field as a stranger using observation skills and then moves into interview and participation with the informants, ultimately leaving the field as a research friend.

Prior to entering the field, the researcher became familiar with the types of housing, shops, schools, parks, and churches in the community. Initial observation of some key and general informants occurred in the rehabilitation setting. All semistructured, audiotaped interviews for key and general informants took place in home settings. The observation-participation session started in the key informant's home and sometimes extended into the community. All interview and observation-participation sessions occurred at a time that was most comfortable for that informant. A detailed account of these activities is provided in Chapter 4.

Condensed field notes were taken by the researcher during observation times; more extensive notes were written during the interviews. These accounts, which consisted of direct quotes, specific words, and key ideas, were used to identify key phrases and identify major caring actions, as suggested by Spradley (1979, 1980). In reducing notes to paper, Spradley's (1979) and Leininger's (1985) guidelines of recording ethnographic data on one side of the note paper and the researcher's immediate reaction, questions, environmental cues, and beginning analysis on the other side of the paper were followed.

In addition, a personal journal was kept by the researcher to record personal ideas, reactions, and feelings to data-gathering periods. According to Spradley (1979), such an introspective journal facilitates the investigator's awareness of personal biases that may influence the research. The journal may also serve as a reflective tool that permits the researcher to compare the informants' data with the researcher's responses (Leininger, 1985). The journal began with efforts to obtain informant consent and continued through the process of analysis and confirmation of the experience and meaning of caring for persons with stroke by the informants.

Interviews

According to Spradley (1979), a series of interviews with key informants is needed so that rapport can be built and in-depth data can be collected. Data from the key informants were gathered via three semistructured interviews in home settings, averaging 2 hours in length and 1 week apart. A short fourth meeting took place with the key informants following the third interview to confirm the data. Less intensive interviews were needed with general informants (Leininger, 1985). One interview occurred with the general informants in a home environment, averaging 2 hours in length. The interviews continued until the informants felt they had finished or exhausted their descriptions of caring for a person with stroke. All the interviews were audiotaped.

The nature of ethnomethods uses broad general questions or statements (Leininger, 1985, 1991a; Spradley, 1979, 1980). During the first interview of all informants, statements were used to elicit demographic information. A topical interview guide is presented in Appendix I. This interview guide was used with all key informants. The interview guide was not used in a rigid way, but rather in a way that encouraged all informants to share their perceptions about the experience and meaning of caring. Other questions to elicit elaboration and contrast within the informant's frame of reference and to obtain further information were asked. Gentle and sensitive probing and reflecting allowed the researcher to remain with the informant until caring for the person with stroke could be verbalized and known in its fullest dimensions.

For each general informant, the general questions concerning the experience and meaning of caring were asked from the interview guide. Then, continuing to use the interview guide, the questions to probe for system maintenance, system change, coherence, and individuation were asked of these informants in the following manner. General informant number one was asked the probe questions only under system maintenance, while the second general informant was asked only the probe questions concerning system change, and so on. Finally, all general informants were asked the probe questions concerning congruence. At the end of the interview, the general informants were asked to add or clarify statements. For instance, one daughter clarified her response: "...And blaming her [the mother] because he [the father] had the stroke.... He was awful before he had his stroke." The researcher responded, "So he is kind of angry and not a real pleasant person to be around. Is that what I hear you saying?" The informant replied, "Uh huh...he's got days where everything will be all right, but there's them days when...ain't nothin'...none of us can do." In a second example of clarification, another general informant said, "My mother is over there 24 hours with him, you know. And like I said, everybody come in and go, but most of all of us got kids, you know, and my brothers, they all married and you know, they can't put down what they do and you know." The researcher said, "Everybody has their own lives to live. I think this is what you're saying. Is that it?" The informant clarified,

> Yeah. And they do the best they can do, but when they come over there, they ain't going to listen to him cuss them out, you know. You, yourself, you come over there, when you come to see him, it's a whole different story when you sit there with him. But when we visiting with him, we got to hear all that "mother fuck" and all of that. And I feel like this: Why should I come out of my house to help you, come and sit with you, and you want talk to me in that type of way?

Using this format, the general informants added to a more complete understanding of the experience and meaning of caring for UFCs of persons with stroke.

A second and third interview were carried out with the key informants to provide support in addition to data gathering. The topical interview guide was again used to anchor the discussions. Continuous confirmation or verification of the data occurred during these interviews as information was clarified with these informants. For example, one key informant clarified his statement of "lived happily until wife had the stroke, but doing OK now" to mean that while he did not "like the stroke, [he] accepted it." At the fourth meeting, all data were verified by reviewing a summary of the transcripts with the key informants. Finally, the key informants were asked if they would like to clarify or add information in regard to caring for the person with stroke within their family system. All informants indicated, using somewhat different words, that the researcher had heard all they had to say about caring for the person with stroke.

Observation-Participation

Observation-participation occurred to a limited extent during the interview process with all informants. In addition to and following the third interview, 4 of the key informants were purposively selected for involvement in an observation-participation session. These informants were verbally articulate and willing to spend a significant amount of time with the researcher. Each observation-participation session lasted approximately 4-6 hours, divided among day and evening times; one session was held with each family. As an observer-participant, the researcher brought two purposes to this setting: (a) to observe the actions and people involved in the caring situation from a family perspective and (b) to engage in assistive or enabling actions appropriate to the caring situation that take place within the family system. The researcher traveled to doctor's appointments, shared food, helped with personal care for the care recipient, and even attended a dog training session with one of the informants. An expanded account of field notes was compiled with as many details of the caring situation for UFCs of persons with stroke as possible. Within 24 hours, the researcher completed this account by adding reactions to the data and including detailed accounts of recurrent and contrasting patterns. Whenever possible, direct quotes of the informants that expressed a theme or pattern of caring were used. The observation-participation sessions added to the richness of the data gathered concerning the interpersonal process of caring by UFCs of persons with stroke within the family setting.

DATA ANALYSIS

Ethnography yields data about the lives of people in specific situations (Spradley, 1979, 1980), such as the emic experience and meaning of caring for UFCs of persons with stroke within the family system. With the ethnographic method, data analysis begins with data gathering and starts as the researcher enters the setting (Leininger, 1985, 1991a; Spradley, 1979, 1980). Ethnographic analysis refers to the systematic examination of phenomena or processes (Spradley, 1979, 1980). In this study the experience (i.e., the perceived and observed actions) and meaning (i.e., the perceived and observed congruence) of caring by UFCs of persons with stroke were examined in order to determine its components, the relationship among components, and their relationship to the whole and the entire process within the family system. Ethnographic analysis is a search for patterns in the data to provide detailed descriptions and to uncover the system of cultural meanings that individuals use. These descriptions may be applied to existing theories, such as Friedemann's (1995) Framework of Systemic Organization and, in some cases, may lead to future hypotheses and theory development (Leininger, 1991a). Existing theories may be used as an organizational structure for data categorization, coding, and analysis (Burns & Grove, 1993; Spradley, 1979, 1980).

For this study, all audiotaped interviews were transcribed into narrative, written form and confirmed with the key informants. Field notes and personal journal entries were also transcribed. All data were managed using Microsoft® Word 6.0/Windows™ software environment. Utilization of this software provides the opportunity for other interested researchers to trail the analysis from collecting raw data to the final full descriptions and the structure of the experience and meaning of caring for UFCs of persons with stroke. An anthropologist, a psychiatric nurse specialist in family therapy, and an African American expert in Friedemann's (1995) Framework of Systemic Organization reviewed the data and resultant themes with the researcher from the ethnographic data analysis process. Using several investigators in this way, in addition to key informant checks, enhances the credibility of the data and the conclusions, according to Burns and Grove (1993) and Polit and Hungler (1995).

The researcher made all final coding decisions. Demographic data were categorized. Narrative data were sorted via four kinds of analysis. Domain analysis (i.e., a search for larger units of cultural knowledge), taxonomic analysis (i.e., a search for the internal structure of the domain), componential analysis (i.e., a search for attributes that signal differences among symbols in a domain), and cultural theme analysis (i.e., a search for relationships among domains and how they link culture as a whole) as detailed by Spradley (1979, 1980) were used. A schematic diagram of the Ethnographic Analysis: The Experience and Meaning of Caring for UFCs of Persons with Stroke in African American Families is displayed in Figure 3. The whole process of analyzing the data was not a step-by-step process in a linear model. Rather the analysis was a matter of reflecting, intuiting, analyzing, and describing throughout the entire process. The researcher returned numerous times to the original data to ensure that the content and

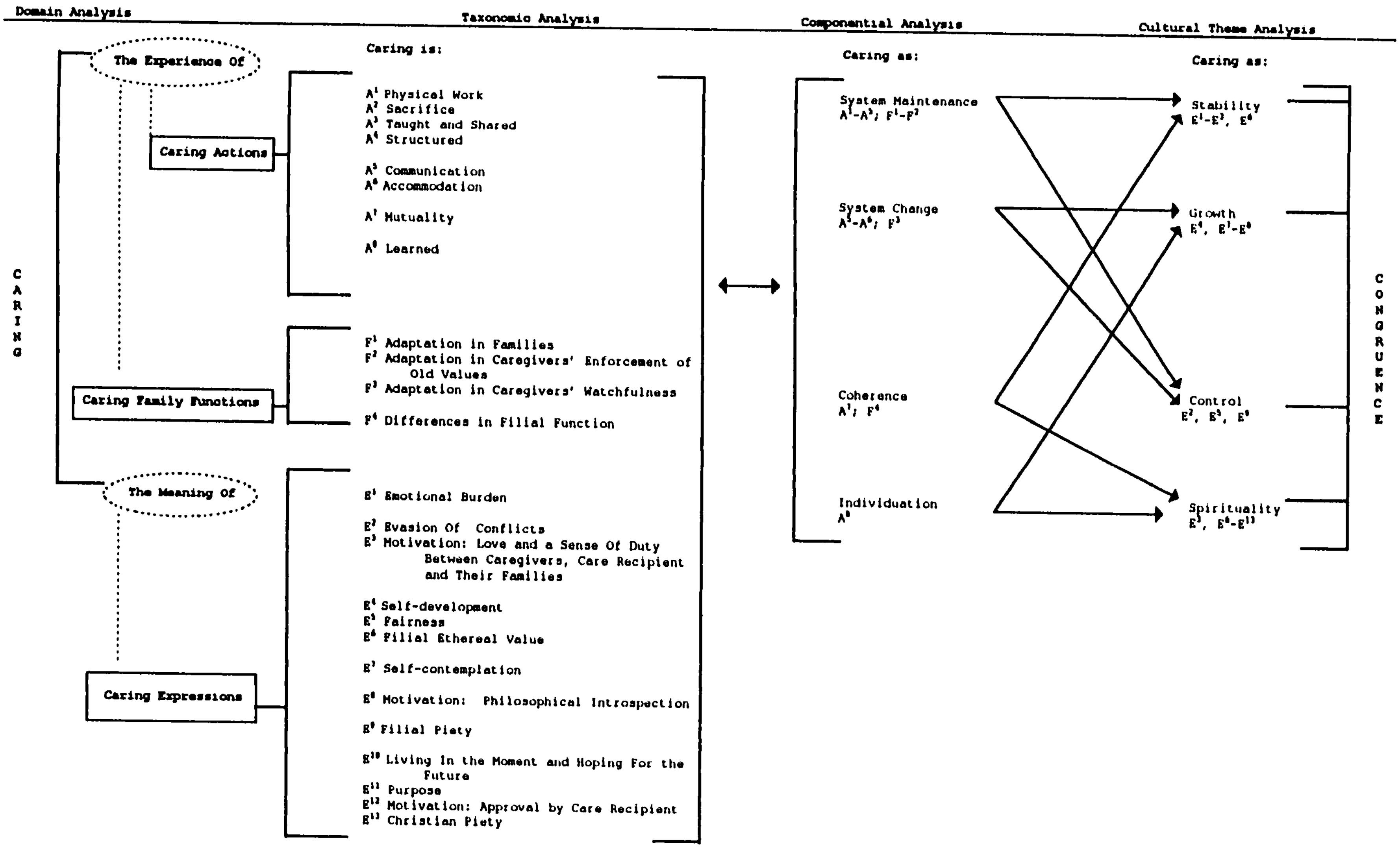


Figure 3.
The Ethnographic Analysis: The Experience and Meaning of Caring for Urban Family Caregivers of Persons with Stroke in African American Families

meanings were understood and that, in the process of moving to higher levels of abstraction, connection was not lost from the original data. In this manner, the themes continued to gradually emerge until analysis was terminated after the elaborate full descriptions of the experience and meaning of caring for persons with stroke were known. Here, the goal of the researcher was to allow the data about the experience and meaning caring to speak for itself. In this way, the data guided and directed the analysis process so that the essence and nature of the experience and meaning of caring for persons with stroke by UFCs could emerge and reveal itself.

Domain Analysis

A search for larger units of cultural knowledge called domains was done. In this context, culture referred to the patterns of behavior and knowledge that UFCs have learned in caring for persons with stroke in their African American family settings. This step in the analysis of data was going beyond the mere descriptions of behavior to discovering the cultural meaning of that behavior. The final list of domains of caring for UFCs of persons with stroke revealed that the experience of caring involved psychomotor caring actions closely intertwined with caring family functions. Together, caring actions and caring family functions for the UFCs represented the total experience of caring. The meaning of caring concerned emotional caring expressions. Caring actions, caring family functions, and caring expressions for the UFCs of persons with stroke drawn to the taxonomic findings are pictured in Figure 3.

Taxonomic Analysis

The experience and meaning of caring for UFCs of persons with stroke was culturally constituted by caring actions, caring family functions, and caring expressions in the domain analysis. The taxonomic analysis involved a search for the internal structure of these domains of caring. The analysis led to an identification of contrast sets (i.e., cultural categories). In other words, the taxonomy showed more of the relationships inside the domains, the subsets, and how caring actions, caring family functions, and caring expressions are related to the whole of the experience and meaning of caring for UFCs of persons with stroke. These relationships are diagrammed in Figure 3. Caring actions were composed of the following subsets: Caring is physical work, sacrifice, taught and shared, structured, communication, accommodation, mutuality, and learned. Subsets for caring family functions were (a) adaptation in families, in caregivers' enforcement of old values, and in caregivers' watchfulness and (b) differences in filial function. Caring expressions included the following subsets: emotional burden; evasion of conflicts; motivation from love and a sense of duty between caregivers, care recipients, and their families; self-development; fairness; filial ethereal value; self-contemplation; motivation from a philosophical introspection by caregivers; filial piety; living for the moment and hoping for the future; purpose; motivation from approval by care recipients; and Christian piety.

Componential Analysis

The componential analysis involved a search for the attributes that signaled differences among the subsets in the domains of caring for UFCs of persons with stroke. The meaning that the UFCs assigned to their cultural categories, reflected via the subsets, were drawn to the process dimensions of system maintenance, system change, coherence, and individuation identified in the Framework of Systemic Organization by Friedemann (1995). These relationships are pictured in Figure 3.

Cultural Theme Analysis

The theme analysis involved a search for the relationships among the domains and how they were linked to the culture as a whole. Cultural themes were any principle recurrent in a number of domains, tacit or explicit, and served as a relationship among subsets of cultural meaning. In this study, the cultural themes of caring identified by the

UFCs of persons with stroke were linked from the process dimensions to the systemic targets of stability, growth, control, and spirituality and then to congruence according to the Framework of Systemic Organization by Friedemann (1995). These relationships are shown in Figure 3. This step fulfilled the purpose of this ethnographic study in that it examined UFCs' experience and meaning of caring as it influenced their capacity to care for persons with stroke and to interact with others within their family system.

Final Analysis

Friedemann, who conceptualized and authored the Framework of Systemic Organization in 1995, participated in this analysis and confirmed recurrent themes and patterns of the data based on the ethnographic analysis for this study. All caring action, caring family function, and caring expression patterns, both universal or culturally bound, were reviewed case by case. Comparisons of the data were made to denote fluctuations in caring rhythms of informants based on ethnicity and gender in caring and to examine how they achieve congruence in their own way or how they fail to do so. This provided an in-depth understanding of the experience of caring for UFCs of persons with stroke and placed meaning to the entire caring process within the family system, while it served as a valid test of the explicated process of caring in accordance with the Framework of Systemic Organization.

SUMMARY OF CHAPTER

An ethnographic, descriptive design was used in this study. The setting for this investigation was an urban community in northwestern Ohio. After receiving the approval of the university and hospital Institutional Review Boards, a purposive sample of 8 key and 16 general informants who were UFCs of persons with stroke was selected from the rehabilitation setting at a large, urban medical college and hospital.

The field techniques of interview and observation-participation were used for this study. Data from the key informants were gathered via three semistructured interviews in home settings. A short fourth meeting to confirm the data took place with the key informants following the third interview. One interview occurred with the general informants in a home environment. All interviews were audiotaped. Observation-participation occurred to a limited extent during the interview process with all informants. In addition to and following the third interview, 4 of the key informants were purposively selected for involvement in an observation-participation session. Condensed field notes were taken by the researcher during observation times; more extensive notes were written during the interviews. In addition, a personal journal was kept by the researcher.

All audiotaped interviews were transcribed into narrative, written form and managed using a software environment. Several individuals and Friedemann, who conceptualized and authored the Framework of Systemic Organization in 1995, participated in this analysis and confirmed recurrent themes and patterns of the data. The researcher made all final coding decisions. Demographic data were categorized. Narrative data were sorted via four kinds of analysis.

The domain analysis revealed that the experience of caring involved psychomotor caring actions closely intertwined with caring family functions. The meaning of caring concerned emotional caring expressions.

The taxonomic analysis involved a search for the internal structure of these domains of caring. Caring actions were composed of the following subsets: Caring is physical work, sacrifice, taught and shared, structured, communication, accommodation, mutuality, and learned. Subsets for caring family functions were (a) adaptation in families, in caregivers' enforcement of old values, and in caregivers' watchfulness, and (b) differences in filial function. Caring expressions included the following subsets: emotional burden; evasion of conflicts; motivation from love and a sense of duty between caregivers, care recipients, and their families; self-development; fairness; filial ethereal value; self-contemplation; motivation from a philosophical introspection by caregivers; filial piety; living for the moment and hoping for the future; purpose; motivation from approval by care recipients; and Christian piety.

The componential analysis involved a search for the attributes that signaled differences among the subsets in the domains of caring for UFCs of persons with stroke. The meaning that the UFCs assigned to their cultural categories, reflected via the subsets, were drawn to the process dimensions of system maintenance, system change, coherence, and individuation identified in the Framework of Systemic Organization by Friedemann (1995).

The theme analysis involved a search for the relationships among the domains and how they were linked to the culture as a whole. In this study, the cultural themes of caring identified by the UFCs of persons with stroke were linked from the process dimensions to the systemic targets of stability, growth, control, and spirituality and then to congruence according to the Framework of Systemic Organization by Friedemann (1995). Text for trailing the process of analysis, selected quotations from the informants and from the observation-participation sessions, as well as the results of the analysis, are presented in the next chapter.

CHAPTER 4

RESULTS

In the previous chapter the research design, data collection procedures, and data analysis were addressed. Results of the analysis of data delineated in this chapter. Data were collected via interview and observation-participation sessions, as well as field notes and personal journal entries. First, the informants' demographic and ethnographic profiles derived from these data are given; then emergent themes are presented.

Demographic Profile of Informants

To protect the informants' anonymity, the researcher assigned each family an alphabetical surname and randomly selected first names for each family member. Nine key informants started the interview process; one woman discontinued her participation due to family issues. A total of 8 primary UFCs (the key informants) and 16 secondary UFCs (the general informants) of persons with stroke from a community in the northwestern region of Ohio participated in this study. All UFCs were either family members or family friends of the care recipients. Of these UFCs, there were a total of 4 men (2 husbands as key informants; 2 sons as general informants) and 20 women (3 wives and 3 daughters as key informants; 9 daughters, 1 granddaughter, 1 daughter-in-law, 2 sisters, and 1 friend as general informants). The age range for the key informants was 26 to 76 years of age. The general informants were slightly younger; their ages ranged from 22 to 65 years old. All of the families originated from the southern United States. The length of time spent in caring for persons with stroke by these UFCs was between 6 months and 11 years. Most of the care recipients were female and all were between 58 to 81 years of age. Most of the care recipients had right-side ischemic and/or necrotic damage of brain tissue resulting in left-side functional impairments. Table 1 presents a more detailed profile of the informants.

Table 1

Profile of Informants

Assigned Family Name	Length of Time in Caring	Primary Caregiver (n = 8)	Secondary Caregiver (n = 16)	Age of Caregiver	Relationship to Care Recipient	State of Origin for Family	Care Recipient (n = 9)	Age of Care Recipient	Care Recipient's Brain Damage Site
Adams	6 months	John		76	Husband	West Virginia	Mary	76	Left CVA+
Beck	7 years	Joan		47	Daughter	Arkansas	Joanne	70	Right CVA
			Ann	22	Granddaughter				
			Joellen	38	Daughter				
			Ellen	42	Daughter				
			Jolee	30	Daughter				
			Nancy	22	Daughter-in-law				
			Lee	40	Son				
Clark	12 months	Rose		57	Wife	Florida	Roland	58	Right CVA
			Silvia	26	Daughter				
			Mae	31	Daughter				
			Alice	29	Daughter				
			Jake	30	Son				
Dawn	12 months	Ruth		26	Daughter	Kentucky	Margaret	58	Right CVA
Erwin	6 months	Gladys		68	Wife	Arkansas	Joe	70	Right CVA
Frank	11 years	Marcus		76	Husband	Mississippi	Myrtle	75	Left CVA
			Julia	40	Daughter				
Grant	18 months	Freda		68	Common-law wife	West Virginia	Roy	70	Left CVA
			Helen	46	Friend				
Hughes	18 months		Louise	50	Daughter	Arkansas	Lillian	81	Left CVA
Ivan	8 years	Laura		29	Daughter	Tennessee	Dolly	71	Right CVA
			Maura	29	Daughter				
			Lena	57	Sister				
			Vera	65	Sister				

+CVA = Cerebrovascular Accident - the ischemic and/or necrotic damage of brain tissue

Ethnographic Profile of Informants

General Environment

All key informants lived within an approximately 1-mile radius of the community's business district. Several of the families in this study lived within blocks of each other. The general informants lived near the key informants. In the Beck family, two general informants, a daughter and a granddaughter of the care recipient, lived in the same apartment building as the daughter who was the key informant. Two general informants in the Clark family, a brother and sister, lived next door to each other. All other key and general informants lived several blocks to several miles from each other. The UFCs unanimously stated that they like living in their neighborhoods and homes. Many had grown up in these surroundings; some UFCs had lived there for more than 60 years. The UFCs said they were satisfied with the community; it was conveniently located to stores, hospitals, family, friends, and neighbors. They found people living nearby to be helpful and supportive.

Their neighborhoods were established in the late 1800s with original construction still continued in the first part of the 20th century. Many large Victorian houses built nearly a century ago were in a state of disrepair; some houses had been better maintained through the years, whereas others were in the process of being restored. On other streets, large-scale construction of new homes was observed. Nevertheless, the majority of homes in this urban area were small, worn, and in need of repair. There was continuous traffic on the main streets, but few people were seen walking outdoors. Those people who were out hurried on their way. Small grocery stores, schools and churches on corners, hospitals, and several empty parks were present, as were gas stations and old factories in various stages of abandonment. On almost every street, boarded-up buildings were covered with gang-related graffiti.

The researcher was very familiar with this setting. As a child and young adult, she often visited a relative in the neighborhood where the majority of informants resided, walked these streets, shopped in the stores, and attended church and programs at the school. On return to these surroundings nearly 30 years later, the researcher again revisited the neighborhood's streets, stores, churches, hospitals, and schools. One cold, rainy autumn day, an old man with dirty clothes huddled in the doorway of a graffiti-covered, boarded-up building. On a gray day during the winter, another man in old, torn clothes pulled a rusty wagon filled with pop cans in a plastic bag; he stopped and went through a parking lot looking for treasures left on the ground. On another day in late spring, a group of children dressed in worn clothes walked to school alongside a few disheveled men walking on the sidewalks and in the street. One hot summer evening, many people sat on their porches while a group of people gathered around a police car stopped in the middle of the street. The police officers were in a heated discussion with the people. Finally, the police car moved on down the street and turned out of the neighborhood. The researcher recorded feelings of sadness in regard to this event and relief at being able to leave the neighborhood.

No matter what season of the year, buildings, yards, and streets looked very dirty—more dirty and drab than it was thought possible. Even on golden autumn days, sparkling snowy winter days, bright and colorful spring days, or sunny summer days, these neighborhoods were predominately colored in shades of black, white, and pewter gray.

The Families and Their Homes

The UFCs' accounts of their caring for persons with stroke within their internal environment was compelling. Simply put, their stories were painted in many bright and rich colors. The journey into the world of UFCs' caring for persons with stroke in African American families began in the fall of 1996 with John Adams' statement: "I don't know what I can tell you, but if you think it will help others, then begin." These same words were echoed by Marcus Frank 7 months later in the spring of

1997. The adventure ended a short 3 months later in the summer with the words of Vera Ivan. Vera stated, "I don't know how I can help you; I don't do anything for my sister—no personal care. I almost called you to tell you not to come." The researcher responded with this question: "Is caring more than just personal care, for example, bathing and dressing?" As Vera thought about this, she replied: "I do talk to [Dolly] each morning on the phone and many times a day, too; she gives me support and I support her. I do think caring is more than just personal care." And so, the dialogue began between Vera and the researcher. At the end of this meeting, Vera hugged the researcher and stated, "Talking with you has been a good experience. Now I can go to bed and sleep really good." Each UFC and his or her family and home are presented as was recorded in the researcher's personal journal, interview transcripts, and field notes from the observation-participation and interview sessions. The stories begin with the Adams family and end with the Ivan family.

Adams Family: Fall 1996

The family.

Key informant, John Adams was a 76-year-old man with graying hair. He was overweight and wore clothes that were stained and tight. John had severe arthritis in his legs that made lifting and moving his wife very difficult. He ignored his own physical needs and continued to care for his wife. He received a small retirement income and both, he and his wife received Medicare insurance. Mary, his 76-year-old wife and care recipient, had a left cerebrovascular accident with resultant right-side hemiplegia 6 months prior to the first interview. She could move her right arm and leg to some degree. Confined to a wheelchair, she could not walk alone or move to another chair by herself. Mary's wheelchair did not fit into the kitchen or the dining room; thus, her world was the living room. Essentially, she sat and watched television during her waking hours. Mary's long-term memory had failed. She talked softly and slowly, using only a few words. John always sat where he could watch her. Mary wore jogging pants, a blouse, and socks without shoes. The Adams' had three grown children: two sons and a daughter. The oldest son, who was in his 40s, lived in the home and helped John care for Mary. However, this son was unable to speak and attended a sheltered workshop for persons with developmental disabilities. The other children lived out of town. A nurse's aid had helped with Mary's morning care, but the service had been discontinued recently. John stated that he could not afford this service, so he made other arrangements. John stated, "Friends are like family." He said that two women friends come in every day to help care for Mary's personal needs. None of the children or friends was available and/or able to participate in the study.

Their home. The Adams' small, two-story home was located on a side street near a main connecting road to the business district. Their block consisted of five other houses. The Adams' front entrance had six steps in poor repair; the storm door was broken. The inside of the home was cluttered with papers, empty pop cans, diapers and personal care products, and books in both the living and dining rooms; the sweeper was out. The furniture had plastic covers and appeared to be from the 1950s. A single bed and a bathroom commode were also in the living room for Mary's use; John slept upstairs. Mary's bed had siderails and a bell attached for Mary to call John; also, an old intercom system was attached to a siderail of the bed. Pictures of their three children, several grandsons, and friends were lying on the dining room table. Other pictures of family members were seen on tables in the living room. A Bible and other church-related papers were under the television. A framed saying on the wall read, "As for me and my house, we will serve the Lord."

Beck Family: Winter 1997

The family. In the Beck family, Joan was the oldest daughter and key informant who cared for her 70-year-old mother who had had a stroke 7 years previously. Joan was unmarried and had one child. Joan, usually dressed all in black, was 47 years old, and was the oldest of 10 children. Joan worried about the family's health; she said, "Strokes are genetic." Joan stated that one of her brothers had died and that her other siblings all lived nearby. Most of them were married and working. Joan worked 5 days a week in business. She was the person the family designated as being primarily responsible for caring for their mother.

Her mother and care recipient, Joanne, had left-side weakness (right-side brain damage). Joanne received Medicare and Medicaid insurance. Joanne lived with Joan every weekend; during the week, Joanne's daughter-in-law and a nurse's aid from a home care agency provided caring in Joanne's home. Joanne could walk with some help. She always dressed in slacks and a heavy sweater; she usually wore a hat as well. Joanne was confused at times and unsafe in her thinking ability. Occasionally during the interview process Joanne answered questions or Joan asked her opinion. Joanne moved about the home using a cane that she called "a stick" and using the walls to navigate. Joan stated, "It is important for Mom to do for herself."

There were many general informants in the Beck family, including Joan's sister-in-law Nancy, Joan's daughter Ann, and Joan's sisters Joellen, Ellen, and Jolee, and brother Lee. Each of these UFCs took turns caring for Joanne.

Nancy helped care for Joanne Beck. Nancy was married to Joan's brother, who did not participate as an informant in this study. Nancy was in her 20s and 5 months pregnant with her first child. She participated in caring for her mother-in-law and also for her 2-year-old nephew on a daily basis, usually Monday through Friday. She came to Joanne's home about 7 am and stayed until 5 pm when one of Joanne's daughters arrived to continue caring for their mother and the child was returned to the parent. Nancy stated that since she had become pregnant, a nurse's aid also helped with Joanne's morning care. All family members contributed to pay for this service. Nancy wore slacks and a sweatshirt during the visit. She was short, and her long hair was pulled away from her face. She was heavy regardless of being pregnant.

Ann lived with her 2-year-old son in the apartment next door to her mother, Joan. She was not married. Ann was a 22-year-old woman who had been involved in caring for her grandmother during the last 7 years. Ann, dressed in a black top and pants for the interview, was thin. Ann stated that she did whatever as necessary on the weekends to help her grandmother in addition to working full-time as an aid at a local hospital.

Joellen was Joan's 38-year-old sister. Joellen lived upstairs from Joan. Joellen was slightly overweight, and she dressed in black pants and a gray top during the interaction with the researcher. She was not married and had no children. She worked the night shift in a mental healthcare agency. She stayed with her mother, Joanne, several evenings each week.

Ellen was Joan's 42-year-old sister. Ellen was also involved in caring for her mother. She was the second oldest daughter in the Beck family. Ellen was thin, dressed in a black and white dress during the interview, and wore very little makeup. Employed at a local store, she had four children and several grandchildren and took care of her mother at least two evenings each week.

Jolee was the seventh child in the Beck family. She had finished technical school, was married, and had two small children. She lived about 3 miles from Joanne's home. Jolee helped in caring for Joanne on a regular basis until she had her children. At the time of the interview, she said she "participated occasionally in caring" for her mother, although she stopped by her mother's house almost every day. Jolee was in her early 30s and was slim.

Lee was Joanne's unmarried son and Joan Beck's brother. He had also been involved in caring for his mother for the past 7 years. He and his mother shared a home during the week. He worked evenings at a mental healthcare agency; other family members helped with the mother's care during the day, evening, and every weekend, as described above. Lee helped in caring for his mother through the night. Lee was 40 years old, short in stature, and dressed in jeans, a T-shirt, and tennis shoes during the interview. He was clean shaven and had very short hair.

Their home. The Beck family had lived in this community for approximately 30 years. The two main residences of Joanne, the care recipient, are specified. First, the key informant Joan Beck's home was located in an area that seemed desolate; there were no sidewalks, and no one was out walking. There were two sets of railroad tracks to cross to get to this home. Five houses were for sale within a block of the Beck home. The houses needed repair; sidewalks were cracked and fences needed mending. This street also had several empty lots. A low-cost housing apartment complex had been boarded shut a few buildings away. Joan Beck's home was located on a corner; at another corner was a Jehovah's Witness Assembly Hall and parking lot. Across the street was an old building that was being used as a veterans' meeting hall. The rest of the buildings on the block were single family homes. The Beck family home was an old, large apartment building with separate entrances for each apartment. On the outside, white paint was peeling off the building; the storm door on one apartment was hanging by a hinge. The stone gravel driveway was covered by snow and ice. Cars were parked in the back yard; no garages were available. Only few windows were present; and of those, most were broken. The four steps that led to the front door were covered with ice and snow. The front door had no storm door and was dirty. The small window in the door was covered by a dark curtain.

Joan's home had a small entrance that led to the dining room and the living room. Both rooms were cluttered with furniture, and Christmas decorations were in boxes. The dining room contained a large table and chairs with dirty seats, a buffet, and several tables. Papers, clothes, toys, and Christmas decorations were piled high on all the furniture. A broken rocking chair blocked access to one side of the dining room. The dining table was covered with a plastic cloth. The living room had several chairs and tables, a couch, and a television. A month after Christmas, the tree was still up and decorated. The white paint on the walls of the apartment was dirty and peeling in places. The remaining rooms included two bedrooms with the doors closed and a clean kitchen.

The second main home for Joanne Beck was her house; Joanne and Lee were in the process of buying the house together. This home was located on a side street several miles from Joan Beck's home. Most of the nearby houses were small and made of brick; they appeared to be well-kept. Joanne and Lee's home was a brick, 1 1/2-story house located west of the business district. Four cement steps that needed some repair led into the house. The tile by the door was broken, the carpet was worn and plastic runners covered the carpet. The living room contained a couch and two chairs, which were in good repair. The dining room contained a table and four chairs; the chairs' upholstery was dirty and torn. The walls had some black stains. There was no clutter. Pictures of Joanne's children and grandchildren were present; a Bible was open on the dining room table.

Clark Family: Winter 1997

The family. Rose, the key informant, was a heavy-set woman of 57 years. She had health problems that she described as asthma and high blood pressure. Rose did not seek medical attention for her health, as she was "too busy." The family received welfare assistance in addition to Medicaid insurance. Roland, Rose's husband and care recipient, had a large protruding abdomen and was dressed in jogging pants, no shoes, and an open shirt. He was 58 years old. Roland had a stroke about 1 year previously. Roland was unable to make safe, simple decisions and was emotionally unsteady. His left arm was paralyzed; he could walk with help. It was easy for him to hold onto furniture to move about in the home. During the interview, Roland never acknowledged the researcher nor was the researcher introduced to him. Rose said "that he is depressed and does not like white people." She clarified this to mean that her husband thought "that white people are the evil of the world." Nevertheless, Rose welcomed the researcher into their home. The Clark family had seven children and many grandchildren; most lived in the area.

Rose and Roland had been separated before Roland's stroke occurred; however, Rose moved back into the home after the stroke. Rose said, "He don't got nobody else to help him." Rose and other family members told the researcher about years of verbal and physical abuse by Roland. Rose said,

> The kids don't come around him as much as they use to cause he cusses people when he gets upset and they feel like it's wrong...they don't have to take that abuse.... He'll cry and say that it's just the stroke, he doesn't mean it...but when you say things to people it still hurts them.... [I] sometimes feel like I can't stand this man. He ruined my life. I have to take it to the altar. Do a lot of praying. I'm not over it. I have to revoke the devil in the name of Jesus...he has no power, no authority.... I pray for both of us. I find we don't fight as much (now).... Lot of pain and disappointment been going on for a lot of years.... I have adult protection agency over here, I talk to them, he [the caseworker] checks. I can talk to him and relate, although he thinks I'm handling it pretty good. He asks how am I doing. He comes to the house and sit and talk...[he is] a lot of help.

Daughter Silvia commented, "Before he had the stroke, [my father] was awful. He was a bastard...." Daughter Mae shared, "My father beat my mother years ago when she tried to leave him, cause he was with another woman. We still live with all of that. We remember it." The children stated that they loved their mother and that was why they helped in caring for their father.

Four of the seven children in the Clark family served as informants in this study. These individuals included three daughters, Silvia, Mae, and Alice, and a son, Jake. Rose said that her other children lived too far away to really help with caring for Roland.

Silvia Clark, dressed in blue pants and a sweatshirt during the interview, was Rose's 26-year-old daughter. She was involved in caring for her father. She lived in a government-subsidized, two-bedroom basement apartment in the west part of town several miles from her parents' home. She babysat for a nephew every day; she did not work outside her home. Silvia received Social Security benefits due to severe eye problems; she was legally blind. Her own 8-year-old child was in school; she was not married. Silvia had a long-standing history of anger with her father. She said, "He was never a father.... He was mean when I was growing up and now, no different." Silvia's role in caring for Roland was primarily coordinating resources for both parents.

Mae Clark lived about four blocks in the direction of the business district from her parents' house. She primarily prepared food for the Clark family and helped Rose with whatever she needed in caring for Roland. As the researcher approached Mae's house, a man in the adjacent house greeted her and asked, "Who are you looking for?" The researcher replied that she was looking for Mae. The man said, "Are you one of the kids' teachers?" The researcher answered, "No. I am a nurse." He replied that Mae was probably in the house and to just knock on either of the front doors. Later the researcher learned that this man was Mae's brother, Jake. Mae Clark looked younger than her 31 years, was unmarried, and had five school-aged children. She was a large breasted woman dressed in a revealing pink satin bodysuit. Her long dark underarm hair was visible. Jeans (unzipped) completed her outfit. She was barefoot. Mae's hair was short, dark, and colored orange in places; she wore no makeup. She volunteered at a kitchen for the homeless several blocks away from her home.

Jake, the Clarks' 30-year-old son, lived next door to Mae and within walking distance to his parents' home and to two of his other sisters' homes. He participated in caring for his father by helping Rose with home maintenance activities. Jake wore khaki pants and a beige short-sleeved shirt during the visit. He was balding, and his haircut was very short. He was slightly overweight. His wife was a short, thin woman with long hair pulled into a ponytail; she was dressed in slacks and a blouse. Jake's daughters (5 years old and 14 months old) wore jeans and sweatshirts; their hair was in braids. Jake proudly showed pictures of his four children that hung on the living room walls. Besides the two girls, he had two boys of about 9 and 10 years old. Jake admitted that he was mentally slow, but that the researcher probably couldn't tell. He said, "No one can tell, but I receives SSI [Supplemental Security Income] benefits as [I] never was able to finish high school and I has problems reading and holding a job." A deacon in his church, Jake gave the researcher "God's blessing" when she left the home.

Rose's daughter Alice was 29 years old and lived within walking distance to her parents' home as well as to brother Jake's and sister Mae's homes. Alice was a plump woman dressed in jogging pants and a dark red blouse during the interaction with the researcher. She was barefoot, had short hair, and wore no makeup. Her husband was short and dressed in dark pants and a sweatshirt. Their children were in school. The researcher noticed several different kinds of insects in her home. Family pictures hung on the walls. Alice proudly pointed out the pictures of her children. Alice also volunteered at the homeless shelter. Alice participated in caring for her father usually on weekends and supported the Clark family with daily telephone conversations to both parents.

<u>Their home.</u> The Clark family's home was the second house from the corner; it faced a school. Rose and Roland owned the home. This blue house needed paint and roof repairs, and it was very small. A chain-link fence lined the perimeter of the yard, which contained a dead tree. The fence gate was broken. A security sign was posted on the front storm door, which was also broken; the neighbors on both sides had bars on their windows. The front door was open. The house was very hot on a cold

day; Rose stated, "That is why the door is open." The living room was small with dirty white and yellow paint, filthy brown carpet, and one brown, soiled couch. There were holes in the walls and a sheet of bathroom-like tile rested against one wall. Thread-bare curtains hung at the dirty windows. A fake fireplace, or space heater, produced the heat. Pictures of the grandchildren rested on the fireplace mantle in the living room. Stereo equipment was also present, along with a radio. Miscellaneous paper and garbage covered the floor. The dining room contained another couch, which was where Roland sat. The dining room was even dirtier than the living room. More garbage was on the floor, and a plastic trash bag full of empty cans was also on the floor. Roland stayed mostly in this room; the bedroom and bath adjoined this room. The kitchen contained more garbage on the floor, table, counters, and chairs. Countless insects, including cockroaches, infested the home. Rose simply flicked them off of her dress; as they crawled across the couch during the interviews, both Rose and the researcher just brushed them away.

Dawn Family: Winter 1997

The family. Ruth, the 26-year-old key informant and primary caregiver for her mother, Margaret, was recently married. Her husband was supportive of the caring situation but did not really participate with the family in caring for Margaret. Ruth had two brothers and a sister who had their own families and homes; these individuals did not participate in the study. Ruth was overweight and wears glasses. She usually dressed in jogging pants and a soft shirt with tennis shoes. Margaret, who was 58 years old, had a series of three strokes starting in the last year. She no longer worked because of her disability. She receives government insurance for her health care. She could dress, feed, and clean herself independently; she had hemiparesis of her left arm. Margaret helped Ruth with the house cleaning; Margaret's sons helped maintain the home and yard. Margaret's cognitive thinking status was good in that she could make appropriate decisions and communicate only with minor word-finding problems; however, she often had seizures at night. Thus, the Dawn family felt that someone needed to be with her at night. Sometimes, Margaret's grandchildren or nephews stayed with her in addition to Ruth, who worked nights. Ruth's role in caring for her mother was one of supervision and companionship.

Their home. The house was about 2 miles from the business district and was located on a side street across from a school. At the end of the street was an open field filled with litter. Many houses in the neighborhood needed major repair; a few were in good condition. Dawn's white two-story house was well-cared for and sat on a lot of approximately 40 feet. It had a paved driveway and a back yard with a fence. There were four steps leading to a porch; all the steps were in good repair. Inside the home, the furniture was clean but worn; plastic runners covered the floor. There was no clutter. A picture of Jesus hung on the living room wall; pictures of children and grandchildren were also displayed.

Erwin Family: Winter 1997

The family. The Erwin family consisted of a husband, Joe, and a wife, Gladys. Joe had left-side weakness and neglect as a result of his stroke. He was a retired custodian and received a small pension in addition to Medicare benefits. His stroke occurred about 6 months previously. Joe was short and thin. Most of his physical functions had been restored with therapy; however, Joe's thinking and processing skills were unsafe. Both Joe and Gladys had no siblings. They had been married for 20 years. Both of them had children from previous marriages. One of Joe's sons died several years ago. As they all lived out of town, Joe's and Gladys' other children did not participate in caring for Joe, nor did they participate in this study. Gladys was 68 years old and had short red hair. She described herself as a survivor of breast cancer. Her surgery occurred within the past year. Gladys seemed somewhat neglectful in seeking her own follow-up care; she spent all her time with Joe. She talked almost incessantly. The Erwins had many animals, including several dogs and a cat. Gladys stated, "Animals are like kids."

Their home. The Erwin home was located in the middle of the block on a side street in the inner city. The Erwins owned their house and the lot next door. The property was surrounded by a chain-link fence; a sign at the door warned of a guard dog in the house. The house was a duplex. Four wood steps led to a wide porch, which contained a bench and a flower pot with dead flowers. Although the house could accommodate two families, only Joe and Gladys lived there. A narrow entry hall led to the living room. The living room contained a single bed where Joe slept, a dog pen, a side table, and a television. Off the living room, there was a bathroom, a bedroom with a king-size bed for Gladys, and a small room for one of their dogs. Child-proof gates separated the kitchen from the living room and another room off the kitchen in which four more dogs and a cat were kept in pens. The animals were well cared for and well groomed. Gladys bred and showed these animals. All the rooms in the home were small, uncluttered, and appeared to be clean.

Frank Family: Spring 1997

The family. Marcus was a man in his 70s who cared for his wife, 76-year-old Myrtle, who had had a stroke 11 years previously. Both Marcus and Myrtle received Medicare and Medicaid benefits. Myrtle was a heavy-set woman. The household revolved around her. She spent most of her time in bed or sitting in a chair in the dining room. Myrtle was unable to walk (even with help) and was unsafe in her critical thinking. Marcus was balding, clean shaven (except for a very small mustache), and slightly overweight. He had severe vision problems and arthritis. He had consulted a physician for his vision difficulties, but his arthritis was untreated. Marcus also was involved in caring for his brother-in-law who had had a stroke and who also lived in the Frank's home. This man was large in stature and used a walker due to left-side weakness. The Franks had five sons and a daughter. Two of their children lived only a few houses away; both of these sons were divorced and participated in caring activities with Marcus. The sons helped with cooking and whatever needed to be done in caring for their mother and uncle. While the sons refused to participate in the study, the daughter, Julia, was a general informant.

Julia Frank came to the house every day to help care for her mother. Primarily, she managed the business aspects of caring, such as paying bills. Julia was a small woman dressed in a black turtleneck shirt and pants for the interview. She was in her 40s and had short hair and glasses. She was married and had two teenaged children. Julia worked nights in a factory. She stated that working nights gave her time to help her father and mother and to care for her own family.

Their home. This neighborhood encompassed two side streets away from a main four-lane street that led directly into the business district. The Frank home was the second house from the corner. The houses on the block were only a few feet apart; one house to the right was boarded up and vacant. Four steps led to the front door and a plexiglass porch of the Frank home. The steps were cement and broken in places. Once inside the home, the rooms were small and dark. Dark green curtains were at the two windows in the living room. The living room contained a couch, a loveseat, and a chair, all in the same fabric and in good repair. The faded brown wallpaper was peeling, and the carpet was worn. Marcus proudly pointed out many family pictures of children and grandchildren. The dining room had another couch, a television, and a table and chairs. Both Myrtle and the brother-in-law sat in this room.

Grant Family: Spring 1997

The family. Freda, the key informant, had been with Roy for more than 30 years; they were not married, but Freda had power of attorney for Roy. Roy had sustained a back injury many years ago; his first stroke had occurred more than a year ago, and he had had a second stroke within the last 6 months. He received government financial assistance that included Medicaid insurance. Roy needed assistance with personal care; he could walk with difficulty with a walker or a cane. He rarely spoke. His short-term memory and decision-making skills were not good. Freda and Roy did not have children together. Freda had four children from a previous marriage. She said her children all worked and had their own lives; they did not help her in caring for Roy. None of these children participated in this study. Freda was a small woman with graying hair pulled back into a bun. She dressed in a cotton dress with her slip showing and wore house slippers. Freda had high blood pressure and asthma; she did not seek care for either conditions. Helen, a friend of Freda's for many years, supported Freda in caring for Roy.

Helen, a general informant, was a 46-year-old friend of the family who participated in caring for Roy Grant. She was overweight, her hair was pulled back from her face, she wore glasses, and she dressed in slacks and a shirt for the interview. Helen had known the Grant family for 11 years. Freda and Helen met at a nurse's aid course. Freda took the course to learn how to care for Roy; Helen took the course to obtain employment. Helen lived several blocks from the Grants' apartment. Helen had two grown boys and one grandchild. Helen came by the Grant home at least weekly and more often if Freda called her.

Their home. The Grant family lived in a government-subsidized apartment building on the south side of town on a busy, four-lane street. The two-story yellow and green building was in ill repair and needed fresh paint. The apartment was on the first floor and was easy to enter and leave. The home had a living and dining room, a kitchen, two bedrooms, and a bathroom. The floors were carpeted; the carpets were worn and dirty. The living room was small and crammed with furniture: two couches, two chairs, several tables, and a television set. Roy sat in the little remaining space in his wheelchair. Roy used a cardboard box, which he kept by his wheelchair, as a table for the telephone and a glass of water. Clutter was everywhere, including the dining room. The home looked clean on the surface; there was a strong odor of disinfectant. Both Roy and Freda proudly pointed out numerous pictures of children and grandchildren.

Hughes Family: Spring 1997

The family. Louise Hughes, a general informant, was the 50-year-old daughter of Lillian. Lillian was 81 years old and had right-side hemiplegia from three strokes in the past 1 1/2 years. She received Medicare and Medicaid insurance. Lillian could walk using an assistive device and could complete her own self-care; however, her stroke was difficult for the family on an emotional level. Louise was about 5 feet, 6 inches tall; her weight was appropriate for her height. She wore jogging pants and a sweatshirt but no shoes for the interview. She had five children; the younger two boys were in elementary school. Her three older children were from a previous marriage. Initially, Louise was the primary caregiver for her mother. Due to a family disagreement, at the time of the interview, her mother lived with Louise's brother several miles away. Louise continued to support the family's caring effort for her mother with occasional visits and frequent telephone calls.

Their home. Louise Hughes' home was located on a side street, four houses from a four-lane highway that led directly into the downtown business district. Businesses were located on each corner. The researcher recorded in her personal journal that on the day of the interview, broken glass covered the cement on Louise's street. Louise's two-story house had a brick front; five steps with railings on each side led to the front door. The main floor consisted of three rooms that were visibly clean. The living room had only a fake fireplace, a television set, and a couch. Louise apologized for the lack of furniture or places to sit. She said, "I once had money, but not anymore." The dining room had a wood table and chairs; a small kitchen completed the arrangement.

Plaster that had fallen from the living room ceiling had recently been repaired. There were many family photographs in both the living room and dining room.

Ivan Family: Summer 1997

The family. The Ivan family lived close to the business district. Dolly Ivan was 71 years old and had had two strokes. Dolly's first stroke occurred 8 years previously; her second stroke occurred a year later. Both strokes caused her to have left-side weakness. Mentally, she was able to make appropriate decisions. She was also a diabetic; her left leg had been amputated and she was on dialysis three times a week. She received Medicare and Medicaid benefits. A nurse's aid helped Dolly with personal care on the days she received dialysis. Dolly was a heavy-set woman with short, gray hair pulled back from her face. Dolly said, "The Lord will get me through this. It is through Him that I am able to go on; we are in His hands. God is powerful; it is this power that makes me heal." She pointed to a "Jesus Loves Me" band that she wore on her arm. Dolly had three living children. Dolly's son and husband died a few years previously. An older daughter also had had a stroke and, consequently, did not participate in this study.

Dolly's 29-year-old daughter Laura was primarily responsible for caring for Dolly and was the key informant. Laura was divorced and had a 4-year-old daughter. These two shared Dolly's home. Laura usually dressed in jogging suits or slacks and had short, straight hair. The resemblance between mother and daughter was striking. Laura worked with hospice clients as a home healthcare aid.

Maura, Laura's unmarried identical twin sister, and two of Dolly's sisters, Lena and Vera, participated as general informants in the study. Maura had moved out of the home 7 months prior to the study and lived a few miles away from the Ivans' family home. Maura, dressed in jeans and a stained green T-shirt for the visit, had short, curly hair. She worked two jobs and said that she was a workaholic. Both jobs were as a healthcare aid for two home health companies. Maura called daily and stopped in several times a week to help care for her mother; she managed Dolly's financial affairs and helped pay for her home care.

Lena was Dolly's 57-year-old sister. Lena was short and looked older than her stated age. She dressed in a cotton print house dress with her slip showing and wore no shoes during the interview. Her hair was covered by a blue hairnet. She wore wire-rimmed glasses to read. In addition to joining the family in caring for her sister, she had taken care of her 89-year-old mother in her home for the past 2 years. No adult male was present in her home. Lena had one child. She was caring for three grandsons (ages 7 to 12) from New York for the summer months. Both sisters, Dolly and Lena, lived in the same inner-city neighborhood within several walking blocks of each other.

Dolly's sister Vera lived five city blocks from Dolly's residence and one block from sister Lena's home. Vera was 65 years old, short, slightly overweight; her graying, curly hair was pulled back from her face. At the interview, she dressed in a white skirt, a cotton shirt, and loafer-type shoes without socks. Vera was retired from a job in the respiratory therapy department of a hospital. To supplement her income, Vera continued to work on an on-call basis for a home care company. Pictures of family hung on her dining room's walls.

Their home. Dolly and Laura's home was located near a major four-lane highway that led to the downtown district. Most of the houses on this side street needed repair. An old abandoned factory was boarded shut. The family's home was the third house past a cross street. The lot was no more than 40 feet wide, and the two-story, white single-family home was within a few feet of the neighboring houses. The paint was worn in most places and peeling in others. The second floor banister was hanging down. Large bushes in the fenced yard covered the front of the house. A wheelchair ramp led to the front porch. Laura stated, "The ramp is not up to code and we need to get it fixed." She said this was especially important, as it was the only way her mother could enter and leave the home. Even then, neighbors had to help with this process, as the ramp was too steep for her to maneuver on her own. The front porch was littered with paper and contained old metal chairs. The front door windows were covered with tin foil; heavy dark drapes covered the front windows. Two houses across the street from were in very poor repair; one was boarded shut and the other was open without window glass or doors. The Ivan's home had a living room, a dining room, a kitchen, and two bedrooms on the main level. The living room was extremely dark with the drapes closed. Many family pictures hung on the walls. The furniture consisted of two tables, a couch, and an arm chair. The dining room had more light with lace curtains at the windows. The dining room had a television set that was placed in front of a fireplace. The dining table was pushed to the side of the room by the windows. A telephone sat on a small table. One of the bedrooms on this floor belonged to Dolly Ivan. Dolly's bedroom was very small and contained a twin-size bed, a dresser, a television, a phone, a bedside commode, a walker, and several boxes full of papers. The room was large enough for a wheelchair to be placed in the center of the room. This was where Dolly spent much of her time. Other bedrooms for family members were on the second level of the home.

Emergent Themes

The domain of inquiry for this ethnographic research was family patterns of caring as they influenced the capacity of these African American UFCs to care for persons with stroke. The research content for discovery focused on the experience of caring and the meaning of caring. The research was conceptualized within Friedemann's (1995) Framework of Systemic Organization. Ethnographic methods and data analysis procedures were used. Data were gathered from interview and observation-participation sessions, as well as field notes and personal journal entries. The data were then explicated by using a domain, taxonomic, componential, and cultural theme analysis. Data from the key informants provided a portrait of the experience and meaning of caring for persons with stroke within an African American family setting. The general informants' data were added to make a more complete understanding of the contextual picture of the experience and the meaning of caring. The experience and meaning of caring involved three caring domains or patterns. Caring action and caring family function domains related to the experience of caring, and the caring expression domain related to the meaning of caring; all of these three domains worked in concert with the Framework of Systemic Organization (see Figure 3). The domains of caring represent multiple complex processes in constant motion between UFCs and their environment. Therefore, these data are interconnected and expected to cross boundaries.

The Experience of Caring

According to Friedemann (1995), families strive toward abstract targets of stability, growth, control, and spirituality by activating observable behavior patterns. These patterns tend to fall within four process dimensions. The experience of caring for the UFCs of persons with stroke concerned the domains of caring actions and caring family functions, relative to Friedemann's process dimensions of system maintenance, system change, coherence, and individuation. The domains of caring actions and family functions are observable patterns of behavior. The schematic representation of data related to the experience of caring in Table 2 is on the level of application. Table 2 can be used as a quick reference for the following in-depth presentation of caring actions and caring family functions relative to the process dimensions and as a basis for discussion throughout the chapter.

Descriptions of caring actions involved assistive or enabling activities, based on cognitive knowledge and without regard to successful or problematic outcomes, that occurred between UFCs and the person with stroke within the context of their family system. In terms of the family, the UFCs cited their perception of how caring actions

Table 2

The Experience of Caring and the Framework of Systemic Organization by Friedemann (1995)

FRAMEWORK OF SYSTEMIC ORGANIZATION:

MEANING OF CARING ←→ *CONGRUENCE SYSTEMIC TARGETS*

↕

EXPERIENCE OF CARING ←→ ***PROCESS DIMENSIONS:***

DOMAINS ←→

↕

DOMAINS		***Definitions:***	***System Maintenance***	***System Change***	***Coherence***	***Individuation***
Caring Actions -	Caring is: **Physical work**	Urban family caregivers (UFCs) of persons with stroke described caring actions that consisted of activities of daily living and instrumental activities of daily living. *[I] have to make sure that [the care recipient is] up and washed up and fed and [takes] medications. Since her last stroke, it's a battle with those....* *I wash [care recipient's] clothes, market for food and toiletries...make sure [she] has meds, meals, and doctor's appointments; these are my responsibility....*	X			
	Sacrifice	The UFCs put their lives on hold. All the UFCs told of giving up work hours, vacations, and most importantly to many, their independence in caring for the person with stroke. *It seems like ever since [the stroke] everybody's life been changed.... It's been very difficult on the family.... [Caring] been my life ever since she had the stroke. My whole life turned around.* *You know giving the sacrifice that we take, I don't think most people would have done it [taking care of mother.]... I don't have independence like I use to; now I have more responsibility."* *Sometimes I wanted to do somethin and I realize that I can't do it.*	X			
	Taught and shared	Most caring actions taught and shared centered on physical and emotional changes in the care recipient.	X			

(table continues)

	Definitions (con't):	System Maintenance	System Change	Coherence	Individuation
[I teach family members] to watch as she read...watch for blank or watery eyes, or if you call her and she don't hear you; watch her walk...to observe her. All that's important. Talk with her...look for changes in personality. Sometimes she don't seem as alert. Teach what she should and shouldn't eat; teach to watch her feet...check toenails....					
Structured	All the UFCs used a daily routine in caring.	X			
We alternate days [in caring for mother]...we all have scheduled times.					
Caring to organize/operate day-to-day business of caring.... You have to have a routine.					
Communication	Communication actions resolved arguments or disagreements, as well as arranged the processes related to caring. The UFCs used open and direct communication styles of communication to keep the entire caring process intact. Several UFCs mentioned the importance of communication so that all involved understood the caring situation. Most UFCs felt that decision making occurred through the action of communication by all involved in the caring situation. Some UFCs shared that while most of the time decisions were made together, when it was impossible to contact everyone, then the decision was made with whomever was present. They were not immobilized or ineffective in making decisions.	X	X		
Most of it [arranging for caring to occur] is done by my mother.... I don't think it's a problem.... Part of life we have to deal with.... If something happens [to cause conflict], someone is on the phone calling each other. We have five people talking: "What are we going to do?" And they talk it out and work out a plan...and things tend to work out in the end....					
There is a lot of communication, and so if anything at all, it's built a better communication between the brothers and sisters. Go right to the source [of the					

(table continues)

Definitions Con't		System Maintenance	System Change	Coherence	Individuation
problem]. Communication is the most important thing to anything. You have to communicate with anyone or anything you're having a problem with.					
Accommodation	The UFCs made accommodations in their lives and environment in caring for persons with stroke. They adapted their own personal plans and told of giving their time to the care recipient, such as staying home to be with the person with stroke.		X		
It's the privacy, because when my sister wants to be with [Mother], she's got to bring her kids. Little kids tear up everything.... Too many people comin' in here...[I'm still here because of] Mother.... *I have her brought here on Saturday till Sunday night...I keep her so they [family members] can do what they need to do....*					
Mutuality	The UFCs worked together and displayed a give and take process in caring relationships among all involved: both family and friends.			X	
Like to help people...do things that I can do...a lot of people help me out now as a result of that...people pay back. *My life was centered around my mom because see I was divorced, my mom would help me with my kids.... [Now I help her]...and she really gave it her all to take care of us.... She gave us the best.*					
Learned	Many UFCs, spouses, children, and siblings, had received care from the care recipients. Only a few UFCs talked of learning skills in caring for their family member with a stroke from healthcare professionals. Most UFCs described experiences related to caring as learned in childhood.				X
[I] care for [my] grandmother who had a stroke.... [It's] almost identical to what I'm doing now...[I] learned from this.... *[I] learned about [caring] from Mom and her brothers and sisters; mostly the girls. The sisters learned from the doctors at the*					

(table continues)

		Definitions Con't	**System Maintenance**	**System Change**	**Coherence**	**Individuation**
	rehab. They explained...I learned from watching them....					
	When we were coming up, I'm being honest with you, most of black families, I don't think they really knew too much about love or caring. I lot of it I got, it came from off of TV....					
Caring Family Functions -	Caring is: **Adaptation in families**	The families adapted to the circumstances of the stroke event with the caring actions. Losses of independence in personal and family actions focused on activities of daily living, bathing, dressing, grooming, and toileting, and instrumental activities of daily living, shopping, cooking, making appointments, and paying bills. Most UFCs implied or said that they just kept going on as before the stroke even though the type of activities had changed.	X			
	Mom's stroke...altered [my] lifestyle...Jolee helps me with weekends but [she] got pregnant so now all weekends on me. I had to alter [work] hours; brother had to alter his too; sister Ellen, too. Everyone altered their life....					
	No different to it.					
	Life is pretty much the same as before.					
	Adaptation in caregivers' enforcement of old values	All UFCs and their family members made adaptations in their lives based on old values and continued in caring for the person with stroke in their homes. Nursing home placement was not an option for most UFCs.	X			
	...Stuck by her as she stuck by me...if I don't do it, she'd be in a nursing home...she not like it, I not like it.... Not happy to put in nursing home...do everything to keep her here, not put in nursing home....					
	I don't believe in nursing homes. We just couldn't see Mom going inside a nursing home and we knew that she would not last long in a nursing home. We felt that. She was used to being around her children, I think that she...just give up and just die.					

(table continues)

Definitions Con't		***System Maintenance***	***System Change***	***Coherence***	***Individuation***
Adaptation in caregivers' watchfulness	The UFCs adapted a watchful vigilance in caring. *[In caring for the care recipient,] I watch her like a hawk.* Others described this watching as: *supervision.* In another family where the mother was often alone and did not require constant supervision, the daughter said: *I always checks on her by telephone.*		X		
Differences in filial function	How the family was able to function and grow depended on the level of interpersonal relations among the UFCs and others prior to the stroke event. These relationships drove the caring actions for the UFCs of persons with stroke. Caring actions were based on felt obligation toward the care recipient. For most UFCs, caring actions were centered on love and duty. Several UFCs said that it was like the whole family had the stroke. Other families experienced conflict with obligation if love was deficient. *...it was like the whole family had a stroke...close knit family...we're poor...we're used to it...we band together and get through it....* *I have a heart for him, but he's been such a cruel person that's why people don't come in. He's been very mean to people.... I got a feeling that he really don't want me here. But he don't got nobody else to help him. That's sad. I feel like I'm being used and controlled.*			X	

were incorporated into their family's functioning. Additionally, they mentioned how their individual change and adaptation that occurred with caring influenced their family's functioning. While each UFC used somewhat different words to denote the caring experience, overall, the group identified similar caring actions and caring family functions. Nevertheless, some individual UFCs' caring actions and caring family functions were disparate. In the following paragraphs grouped along the process dimensions, caring actions are described first, followed by caring family functions. Each caring action and caring family function section contains (a) a brief introduction to the action or family function; (b) rich and insightful, representative statements of the UFCs along with the researcher's pertinent observations with important identifying statements highlighted in bold type; and (c) a summary of the caring action or caring family function.

Caring Actions as System Maintenance

Caring is physical work. The physical work described by all the UFCs consisted of activities of daily living (ADLs) and instrumental activities of daily living (IADLs) used to maintain their family systems. The following examples from the Adams, Beck, Erwin, and Frank families depict this physical work. John Adams said, "**[The] worst job is BM [bowel movement] during day...get up and hold her [up off the toilet], clean her, put diaper on...do with one hand.**" In the observation-participation session, **John and his friend carried Mary in her wheelchair down the front steps of their home to the car to go to a doctor's appointment**. This process was repeated when they returned home. This was a difficult undertaking for these older men. Both were overweight and John was dealing with mobility problems due to arthritis.

In another family, Joan Beck also told about the physical work in caring:

> **I wash [Mother's] clothes, market for food and toiletries...make sure [Mom] has meds, meals, and doctor's appointments; these are**

> **my responsibility**.... [I] have to watch these meals, have to be careful with [her] special diet...restrict fat content, low salt, and no sugar....

Joan's sister Ellen noted that her role in helping with caring was "**to make sure that [the mother is] up and washed up and fed [takes] medications. Since her last stroke, it's a battle with those....**"

Two other stories which help understand the physical work of caring were provided by Gladys Erwin and Marcus Frank. Gladys Erwin shared,

> [Joe] has very limited endurance, not the stamina he used to have. He gets up and washes thoroughly; an hour or hour and half to wash. I get up at 6:30 am everyday...have things to do. I try to get him up. He'd just as soon stay in bed, but I don't want him to stay in bed and get lackadaisical. I want him to be up, like he used to be. About 9 am, I say now you have to get up...this is the way it has to be. **I have to get him up; he washes; can't bathe by himself. I have to help him in and out of the tub.** But he can wash himself thoroughly and brush his teeth, shave, and take care of himself that way. I can't leave him for long.

Marcus Frank, a long-time caregiver, said,

> **I take her up every morning [he lifts her out of bed] and prepare her breakfast. I always prepare the food. I take and feed her what she'll eat....** She has problems swallowing.... **Yes, I [help her bathe and dress]. I have to change her all through the night sometimes. Whenever she call, I get up and change her; keeps those Pampers on. Pads on the bed. I change her all the time. I do all the washing, take care of all her clothes. [Care for the house] mostly, yes.... She took care of the home.... Now I have to do it all.**

In summary, the caring action related to physical work described by all UFCs consisted of ADLs and IADLs. The informants uniformly said that daily caring actions involved bathing, dressing, grooming, toileting, and feeding activities. They also stated that caring actions were composed of IADLs, such as cooking, shopping, making doctor's appointments, washing clothes, giving medications, paying bills, running errands, and helping the care recipient with mobility and function. Jolee Beck made a succinct comment that was representative of the group: "It [physical caring] gets hard at times, because it takes away from your own personal life...."

Caring is sacrifice. The UFCs saw no other choice than caring for the person with stroke, and as a result, they put their lives on hold. All the informants told of giving up work hours, vacations, and most importantly to many, their independence. The Beck family described sacrifice in the following way. Ann Beck said, **"Everyone has rearranged their life in order to accommodate my grandmother. And people put a lot of things of their own off because they know they have to take care of her. I see that. They do a lot of sacrificing."** The sisters in the Beck family did not want to change their lives, but the stroke event dictated the results for them. Joellen noted, "I've altered my life; the whole family has.... Not much time left for me. We've all changed, but that's life.... We are committed to mother." Ellen Beck remarked, "It seems like ever since [the stroke] everybody's life been changed.... It's been very difficult on the family, because I would say my family is a very close-knit family.... [Caring has] been my life ever since she had the stroke. My whole life turned around." Jolee Beck stated, **"We have to work [caring] into our lifestyle...."** Joan's sister-in-law, Nancy, said, "I think just with her having the stroke, the whole family tends to put different things aside and do them another time." Brother Lee Beck noted, **"I don't have independence like I use to; now I have more responsibility."**

Other families also described what sacrifice was like for them. Rose Clark said, "I've been a caretaker all my life, been providing and making do with this and that...." Daughter Alice said, "...[I] help with [my parents] with their responsibilities; take a little bit more of my time for others...." Ruth Dawn concurred, **"Sometimes you have to sacrifice [you don't want to, but you do] just a little bit, not a lot."** Marcus's daughter Julia mentioned, "Long day [in caring for mother], cause I don't mind cause that's my mom. **Cause if I was in the same**

situation she was, she would do the sacrifice for me. I don't have any problem with that."

Freda Grant was openly resentful. She noted, "**He's always wantin' somethin', you know.... Don't want to, but I really do all of it [caring] here.**" Other families also made adjustments that they did not really want to do. Daughter Louise Hughes stated, "I sleep on floor on a mattress...took own bed down and put up hospital bed for mother." Laura Ivan said, "**If I wanted to do something and my sister was working and [Mother] needed somebody to be with her.... Then I wouldn't be able to go because I would have to stay here....**" Maura Ivan commented,

> [I had to alter my life] yes, when she first had [the stroke]. You know, we would just...never leave her alone. Someone was here with her constantly. We went to church, we would alternate Sundays. My sister would stay her, I would stay here or my sister's husband would stay with her...in the beginning when somebody had to stay with her all the time. It was kind of depressing cause **sometimes I wanted to do somethin' and I realize that I can't do it.** I would think about it, doin' this or doin' that thing...but now it doesn't bother me.

In summary, sacrifice in caring demonstrated by the majority of UFCs consisted of giving up their own needs and activities. True sacrifice occurs if, and only if, the UFC would rather not extend themselves to others. In many respects, there were no other choices seen in the caring situation by these UFCs. For some, these sacrifices signified their cultural values of family togetherness. Others simply made sacrifices to avoid conflict in the family. For the UFCs, caring was an all-consuming process resulting in no free time. Some said they did not mind; others were bitter. For example, Julia, Marcus's daughter, mentioned that she really did not mind giving up her own needs, as she believed her mother would "do the sacrifice for me." However, Rose Clark noted resentfully that she had no other choice but to continue caring for her husband. Nevertheless, the underlying belief for all UFCs was that there was no other recourse. The sacrifices made relevant to the caring situation were tied to love and duty and, even with anger, obligation toward the family members. The outcome was the same for all UFCs: They let go of what was important to them in order to help in caring for the person with stroke.

Caring is taught and shared. The caring actions taught to and shared with others were exemplified as principles to live by. For example, John Adams revealed, "**[I] instilled in [my] children [a responsibility for] caring for others [as well as family].**"

Caring actions taught to and shared with family members centered on physical and emotional changes in the care recipients. Joan Beck specifically noted,

> **[I teach my family to] watch for changes in personality. It could be a stroke or high blood pressure or high blood sugar. [I teach family members] to watch as she read...for blank or watery eyes or if you call her and she don't hear you; watch her walk...to observe her. All that's important. Talk with her...look for changes in personality. Sometimes she don't seem as alert. Teach what she should and shouldn't eat; teach to watch her feet...check toenails**...she had problems before; won't heal because she's a diabetic.

Rose Clark gave the following examples of teaching and sharing caring with her family. She said, "**[I teach caring] to daughter Alice, mother of five...she came over and [helped] dressed Father, she cook for him. [The] children [are] more close to me. I be on phone with girls and boys...we talk a lot. I got me a middle boy, Jake, who picks up on my wavelengths.**"

However, for the Erwin family, Gladys stated, "[Teaching about caring is difficult because] the children are [too] scattered...." In families in which the children lived nearby, it was different. Marcus Frank said, "I show them [children] how to handle [her]; how to keep her feet up and things like that.... I did all that I knew how to do, teaching them that way. It's been wonderful, the family. The boys help cook; my wife taught them...." Julia Frank commented, "[Children] see me doin' a lot of running; doing things for my parents.... Everybody has to help out and pull together, cause it shouldn't be just one person's responsibility."

Teaching also had a moral or ethical dimension. Alice Clark noted, **"That's the way [she] taught us. You can argue all night long, but we still have to have love for one another. So no matter what goes on between one of us, we still got to get along. Trying to teach our kids like that."** Jake Clark agreed, "[I] teach [my own children that] we're very 'for' the family-caring, love, sharing...."

In teaching others, Louise Hughes said,

> **I try to teach my sibling as well as my children how to care for her, how to encourage her, how to be an inspiration to her while they're caring for her. Always encouraging her and just carry on just being natural.... Be careful not to make her feel like that she just couldn't do things for herself.**

In summary, UFCs educated other family members in caring processes and values of caring. Only Gladys Erwin felt that she did not teach or share anything about caring with her children, as they did not live nearby. Most UFCs taught and shared caring actions to and with other family members. These actions centered on dealing with different bodily functions and/or emotive or affective changes in the care recipient as a result of the stroke. In addition, commitment and love were advocated.

<u>Caring is structured.</u> Caring consisted of a routine used by the UFCs to survive the situation on a day-to-day basis. John Adams described his routine: "Friends [are] like family...they come running [to help with caring]. I stick with her through [the] day. ...**[I use a] chart for the day...based on hospital's list of stuff to do**. Keeps me going."

Joan Beck in discussing how caring was structured commented:

> **We alternate days [in caring for mother]...we all have scheduled times**; two sisters stay in evenings, alternating days between Monday and Friday...come in at 6 pm and stay till bedtime...they give meds and snacks and put her to bed, then leave. Brother gets off work at 11 pm and comes in to be with mother at night. [In the morning, a] nurse aid from home health care comes between 8-10 am...gets Mom up dressed, bath, hair, cleans room, and gets breakfast. Then sister-in-law comes in about 9 am and stays the day; [she] makes lunch and dinner...use Meals on Wheels, too. This happens Monday-Friday.... I have her brought here [to my house] on

> Saturday till Sunday night.... I keep her so they can do what they need to do....

Joan's sister Ellen agreed, "**[Caring is] a regular routine...when I'm working I have someone take [my] son over there. I make all these arrangements before. Just a routine thing.... [Caring for mother] is my life. We have a system.**" Sister Jolee commented, "**Everybody knows my mom's routine and they know her and they know the care that needs to be provided for her....**" Sister-in-law Nancy noted, "**...We're all like on a schedule...a daily routine.... I know what time I'm usually relieved [by] her daughters. If her daughters are an hour or two late comin' to relieve me...one of her grandsons will [come instead]; somebody's here.**" Brother Lee commented,

> **We coordinate our time** so that one sister work third shift, one work first, and I work second. **We coordinate our time so that someone will be here [with mother]**. We just call on the telephone and usually my oldest sister Joan or Ellen will know who's comin' over. They try to keep it together.

Other families agreed that caring was organized in a similar manner. Gladys Erwin noted,

> **Caring to organize/operate day-to-day business of caring.... You have to have a routine.** My mother taught school and we all had a routine. I'm an only child so we had to do this and this. [Joe] always yells at me, you're watching the clock. I say I'm on a time schedule. I have to be.... I do my washing and drying in the morning. Joe says...he's never seen anything like it. [But] I feel that I know I have a certain amount of time to accomplish a feat...I know just how long it takes me to wash...I want to be ready.... I have to be organized. He has to have clean underwear. I have to wash it, sometimes three or four times a day...most of it is his.

Louise Hughes said, "**I liked to keep things on a normal, daily schedule.... One of my main concerns is just trying to keep things on a schedule whereby she would feel that things are...going to return to...normal.**" Caring was structured in a like manner, as Laura Ivan stated,

> **Since my sister moved out, I been doin' most of it. But she comes over and helps when she can.... She comes over two or three times a week and she's over here all the time on the weekend....** She was

> here today and yesterday; she gave my mom dinner yesterday, cause I worked a little later than I normally do.... [Mother] has an aid that comes in 3 days a week that helps her; warms up her meals. She has Meals on Wheels. We have our deacons come and sit and talk to her and do different things for her.

In summary, caring in a structured manner was a way to use a daily routine to organize and operate the day-to-day business of caring. Schedules allowed the family to divide caring among its members. In addition, having a daily routine for ADLs, such as bathing, dressing, grooming, and toileting, helped caregivers get through the day. Caring in a structured manner also helped care recipients maintain life or put simply by Louise Hughes: "She would feel that things are going to return to...normal."

Caring is communication. Communication actions revolved around arranging caring processes, as well as settling arguments and disagreements to maintain the family system. Joan Beck gave examples of the content of communication between family members that facilitated caring. She commented,

> ...[We] have arguments but usually they work them out or things don't fly...who do they call?...me. So in these situations, I get on the phone and try to calm down the person who is upset. I call the other person, I try to find out what happened, I call the other person back...[and say,] "We all need to work together; without your help, I can't do what I need to do, without my help, you can't do what you need to do, and Mom can't do what she's got to do." Either we work together or Mom goes to a home and when you mention the word home, that's it, they are not going to do that. So if we do not do that, then we need to do what we have to do. I'm the mediator. I do that a lot...need to remind them what their responsibilities are, remind them what we all are going through.

Joan's daughter Ann agreed,

> Most of it [arranging for caring to occur] is done by my mother.... I don't think it's a problem. I don't feel like it's a problem.... Part of life we have to deal with.... If something happens [to cause conflict], someone is on the phone calling each other. We have five people talking: "What are we going to do?" And they talk it out and work out a plan...and things tend to work out in the end.... There is a lot of communication, and so if anything at all, it's built a better communication between the brothers and sisters. Go right to the source [of the problem]. Communication is the most important thing to anything. You have to communicate with anyone or anything you're having a problem with.

Ruth Dawn shared, "**It's not hush-hush. It's open [communication]...but I do tell them when I get angry. I tell [mom] that she should ask the others. I tell [siblings], 'Why can't you take Ma here or there?' [Helps] to get the anger out....**" Gladys Erwin commented, "**I suppose we have an argument every now and then. [We work it out by] communication....**"

Louise Hughes told the following story about communication and arguments in her family:

> **I think the best thing to do is just answer their questions as briefly and as honest as possible and have it over with and let them go and reason with themselves**...and then finally they will come around.... But if you try to avoid answering their question, then they think you have something to hide and it prolongs the healing and it makes there a deeper misunderstanding and the hurt just goes on and on. **When they see that you're willing to answer any question...brought at you...and that you do answer them, it makes them come to reality....**

Laura Ivan concluded,

> **I was tellin' you about my grandmother being sick and we understand that [other family members, especially Dolly's sisters] can't come and do like they want to. But like I said they do call, call three or four times a day. But they are like my mom, like me and my sister, they talk to each other two and three times a day. And my sister said, "When we get older we not goin' to be like them. We not goin' to be talkin' to each other every single day two and three times a day." And what do we do? We talk on the phone more than they do....**

The Ivans' communicate with one another about how to arrange caring for Dolly and to give her emotional support. Vera Ivan noted, "**We were brought up to really love each other.... That there is a little conflict, but we get together and we talk....**"

In summary, these UFCs were no-nonsense, pragmatic people. They talked with one another often about the caring situation; sometimes many times each day. Communication actions centered on content that resolved arguments or disagreements. In addition, the UFCs used open and direct communication styles of communication to keep the entire caring process intact or, in Friedemann's (1995) terms, system maintenance.

Communication was important so that all involved understood the caring situation. Communication consisted of verbal actions used to maintain the family system.

Caring Actions as System Change

Caring is communication. Additionally, communication was used to decide if change was needed for the family system. Communication was a means to make decisions for change and accommodation, as described in the next section. For instance, Ellen Beck said,

> ...**We never made a decision on Mom, a permanent decision, unless everybody know about it.** So we call a meeting and we talk.... Talk it out, make a decision and then we let Mom know what we are going to do, cause we try to make sure that we don't put her completely out of the picture.... Don't want to put too much pressure on her...cause her to regress. But we do involve her in a lot of things. Cause we don't want her to feel like a little vegetable sitting in a wheelchair, can't do anything. We want her to be alive and be involved and just to live.

Silvia Clark noted that communication was used to facilitate decisions. She said, "**My mother [the primary caregiver] makes decisions. She talks to everybody [in the family]**. [My father is] well enough [to participate in the decisions]." Jake Clark summed it up: "**Everybody in this family talks to one another real good.**"

An example of open communication about major decisions was observed by the researcher in the observation/participation session: Joe Erwin said, "I want to drive again. They will test me in July at the doctor's office. Said I might be able to drive again." Gladys stated, "Probably not, Joe. Remember you have neglect." Joe explained, "That just means that I don't see well." Gladys replied, "No, Joe. It means that the stroke affected your thinking." Joe said, "I want to be independent. I want to drive again. Not driving means I depend on you." Gladys ended by saying, 'Let's wait and see what the doctor says.'"

In describing communication used to make decisions for change, Freda Grant said, "**I make all the decisions. I'm his [power of attorney]. We talk things over.**" Louise Hughes said, "**My oldest**

brother...lives in Georgia and so we would always consult with him and see what he has to say and let him make the final decision [in caring for mother]...."

In summary, communication was centered in decision making that pushed system change for the family. Most UFCs felt that decision making occurred through the action of communication by all those involved in the caring situation. Most of the time, decisions were made together. When it was impossible to contact everyone, then decisions were made with whomever was present. They were not immobilized or ineffective in making decisions.

Caring is accommodation. Accommodation consisted of UFCs making changes in their lives and environment in caring for persons with stroke. The caregivers' comments are representative of how they made these alterations. John Adams started with:

> She makes some improvements, I see this, but also see she is getting forgetful. [John has tears in his eyes, his voice falters, and he stops talking for a few seconds.]...[Mary] talks about people who died years ago.... **[I do] not sleep well, me upstairs and Mary down here since June...take naps in day now, get up earlier to take care of son and for nursing assistant to come [and help with caring].**

Others told of giving up their independence. Joan Beck said, "**I have her brought here on Saturday till Sunday night...I keep her so they can do what they need to do....** It's tolerable." Lee Beck added, "**It's the privacy, because when my sister wants to be with [Mother], she's got to bring her kids. Little kids tear up everything.... Too many people comin' in here...[I'm still here because of] Mother....**" The researcher observed and Rose Clark told about caring for her husband. Rose left her husband before his stroke, but she moved back into the home to provide caring for him.

During the observation/participation session, Gladys Erwin shared how accommodations with caring continued to be made. She said,

Last week I let him come into the bed. We made a night of it. I

> **put a pad on the bed and made sure that he had his [incontinence] pad on. He brought his pillow and we had popcorn and watched a movie. He slept all night there. This was the first time since his stroke that we slept in the same bed....**

Gladys also noted,

> **What I'm having a hard time with is adjusting to the way he is now, because he's not like the Joe that I knew....** He was so energetic and his endurance was phenomenal and now [he is weak]. Sometimes I find myself impatient. And, I say, "Now why am I impatient? It's not his fault." I would never let him know that I feel impatient. **But it's hard to adjust [to the stroke]. What you have to do is to put it to one side, and accept the Joe today...good insight.... Anybody that has to be a caregiver has got to realize that the person you're giving the care to is changed. You have to adjust to it; I have to adjust. That was hard, cause I was feeling so left out, so alone.... It's like I don't have anybody to be with me. He's not with me anymore. And, I have to adjust....** Anybody that is a caregiver should have somebody. I can't get away to go to a support group.... Together, we can go to a psychotherapist.... Doctor's need to advise this and have it taken care of through Medicare.

Two other caregivers spoke of accommodation with caring in the following manner. Marcus Frank noted, **"Well, the way I think, we think of others a lot of times...how would I feel if I was in that place...to be the same towards me [treat others like I want to be treated]."** Laura Ivan stated, **"I just remember when I was a baby and she took care of me. Just think about it like that [now it's my turn to be caring for her]."**

In summary, accommodation consisted of changes in UFCs' lives and environment in caring for the person with stroke. Several UFCs noted that you just have to adjust. Some spoke of actions that involved changing their physical sleeping arrangements and time of sleep. They adapted their own personal plans and told of giving their time to the care recipient, such as staying home to be with the person with stroke. Lee Beck told of losing his privacy as family members came into his home to help with caring for his mother. Laura Ivan poignantly shared that the care recipient took care of her as a child and now it was her turn to reciprocate. Rose Clark who had been separated from her husband before his stroke moved back into the home to provide caring for him.

The result of accommodation was the same for each family: an altered lifestyle and living environment.

Caring Action as Coherence

Caring is mutuality. Mutuality was an interdependence displayed as a give-and-take process in caring relationships among all UFCs and others, both family and friends. John Adams told the following story:

> Know people and enjoy to be with; women here to help as well as neighbors. Easy to ask for help and they come; they ask and we come. Share problems with friends and they are helpful...family, friends, neighbors help with Mary...helping others...the biggest secret is that it makes you feel good.... Now get up and take care of son and Mary...can't get out anymore unless someone stays with Mary. **Wife of best friend stays with Mary. I help her [the friend] with things...I balance her checkbook...like to help people...do things that I can do...a lot of people help me out now as a result of that...people pay back, for example [they] bring in food and woman does Mary's hair.** Feels good to know people [like that]...makes me feel good. Supportive family...children, neighbors, friends help with Mary.... Ladies [friends] clean house and bathe wife...If not for them I'd really be under...that would be a burden for me...makes my day with them helping...[I] never give up.... Mary takes precedence...call a friend to sit with Mary.... Affection for each other...tell each other of love...she helped a lot of people and a lot of people love her.

Gladys Erwin described mutuality as, "**We are both only children. Our children by other marriages live too far away to be of much help. My one son does call every week. This helps.**" This lack of family member support was not predominant in the caring actions. Marcus Frank shared the following story:

> **There's a lady friend that comes twice a week, she...mostly combs my wife's hair when it needs it.... She give her her bath and change the beds. She's very nice.** We pay her a little somethin', it's not very much. That's the hardest thing that I had to do was changing the bed and clean and everything. **So I asked if they would come and they said they would.... It's been wonderful, the family. The boys help cook; my wife taught them...rotatin' in and out and cookin' and helping by being able to call another in when one can't stay. That's what we do....**

Freda Grant told how friends unite and help with caring processes. She said, "I got a friend; she works. I don't bother her. If she ain't workin', she comes." In discussion, both women stated that they call each other everyday and help each other with whatever is needed. Louise

Hughes noted, "**My life was centered around my mom because see I was divorced, my mom would help me with my kids.... [Now I help her]...and she really gave it her all to take care of us.... She gave us the best.**" Laura Ivan echoed the same sentiments:

> **I guess you could say we...share problems with friends and family. The only thing I can say is, you got to take one day at a time and we have to work together, that's all....** Even in caring for my father, we worked together. ...I used to be in restaurant management and so often schedules would get switched around and we'd be here at night or somethin; change times around to be here.

On observation the identical twin sisters, Maura and Laura, shared words and thoughts that were almost identical too. They exchanged money for gasoline and cars. In addition, the one sister's child is watched over by both sisters, as is their mother.

In summary, mutuality involved not only the primary caregiver and care recipient but the whole family and community. It was made up of an interdependence demonstrated by the UFCs in caring for the person with stroke in this study. Representative of mutuality was John Adams comments that it was easy to ask others for help in caring for his wife. In return for their assistance with caring, he balanced their checkbook or fixed an appliance. These actions made him feel good. UFCs were taught to rely on one another in childhood. Today, many watch their grandchildren as their children participate in caring. In return for this service, they described receiving aid from their children with ADLs, such as bathing and dressing the care recipient and IADLs, such as shopping and cooking. The Ivan sisters spoke of a reliance on one another that involved sharing cars, money, and child care in addition to caring for their mother. Mutuality continued to be taught and displayed in the family systems.

Caring Action as Individuation

Caring is learned. The UFCs described experiences, caring actions, that were learned in childhood. The learning process was repeated, as these activities were now being taught to their children. The Adams family had a long history of caring. John told about a "...retarded son, who can't talk...." He described a day of managing medications and feedings for his wife, Mary. "Chart for the day [daughter and John put this together on paper]...based on hospital's list of stuff to do." **John stated that he learned to give medications and tube feedings and that he read and followed demonstrations of skills by healthcare professionals.**

Other UFCs commented how they learned caring in their families. Joan Beck commented,

> I don't like that position [as the oldest child caring for my mother], I didn't ask for it, it just happened.... **[I] care for grandmother who had a stroke when I was age 6 to 11.... [It's] almost identical to what I'm doing now....** It didn't seem like that much to me. We had to do because they [mother and family] had to work. Everybody did something, the boys' job was not to not to be bad, my job was to make sure Grandmother took meds and...make sure she had food.... **[I] learned from this....** Sister is a nurse. She helps with inside details of why Momma acts the way she does, different medications; brother Lee, he has read every book known to man, so with medications, I call him up and he knows what it is and side effects and everything else; sister Ellen works at a mental institution, used to mood swings. She can explain about that.... With this illness [mother's stroke], we learned about our bodies. Our family's background, our genetic code that we didn't pay attention to before.... We learned how to eat.

Joan's daughter, Ann, added,

> **[I] learned about [caring] from Mom and her brothers and sisters; mostly the girls. The sisters learned from the doctors at the rehab. They explained...plus I have an aunt that's a nurse who is also involved in doing that sort of things. I learned from watching them; watching my mom do it all the time....** I think my grandmother is a very wise person. She taught me a lot when I was little.

Rose Clark's children, Alice and Jake, made different comments. Alice agreed with the Beck family. She said, **"[I learned as a child] how to treat somebody warm, how to sit down and talk to them, help with them with their responsibilities, take a little bit more of my time for others. I used to help my friends' Momma, she was blind."** Jake disagreed with the Beck family:

> **When we were coming up, I'm being honest with you, most of black families, I don't think they really knew too much about love or caring.** I really don't. The reason why I say this is because a lot of times when I was comin' up as a young man, all I saw my parents

> do is fight. I mean, Mom leaves or he leaves, you know what I mean. To be honest with you, where did I get the caring from? I don't really know, cause it really didn't come from my family. You know what I mean, we showed love. Sometimes people show love in crazy ways.... **A lot of it I got, it came from off of TV...I watched a lot of good programs in my time.**

Ruth Dawn's, Louise Hughes', and Alice Clark's comments were more alike. Ruth noted, "**I guess [I learned about] caring when I [was]...growing up.... Mother took care of me; now I caring for her. [What I do for mother] is similar to what my mother did for my grandmother.**" Louise Hughes said, "**Learned about caring from Mother to care for siblings....** My aunt took me to a nursing home where she worked with retarded children...at 11 years I worked for a couple as domestic help with their family."

In summary, there was a history of caring in most families. The essence of learned caring were based on experiences that occurred in childhood. Many UFCs, as spouses, children, and siblings, had received care from the people who were now the care recipients. Ruth Dawn commented that her mother had always been there for her and now it was her turn to be there for the mother. Only a few UFCs talked of learning skills in caring for their family member with a stroke from healthcare professionals. Jake Clark said that he learned caring as a young child from watching television programs. Jake was a younger child in his family and different from the other caregivers. He was not included in a caring network. It is possible that in his family caring was a women's endeavor. If men were expected to participate in caring processes, they needed to find other sources for learning about caring. This was not the predominant view, however. The majority of UFCs learned caring early in life from mothers, siblings, and other family members, as they were caring for other members of the family. Even with Marcus Frank, he too learned caring from his family, especially the women. Marcus was included in the women's caring network, as he was an older child who was expected to participate in caring processes within his family setting.

Caring Family Functions as System Maintenance

Caring is adaptation in families. Adaptation in families to maintain the system consisted of adjustments made by the UFCs in dealing with the impact of stroke. The following two stories by the Beck and Clark family are representative. Joan Beck said,

> **Mom's stroke...altered [my] lifestyle...Jolee helps me with weekends but [she] got pregnant so now all weekends on me. I had to alter [work] hours; brother had to alter his too; sister Ellen, too. Everyone altered their life**...sister-in-law takes care of Mom.... We used to take vacations.... [We're] poor people but work hard.... We...had [only] one vacation in 6 years.

Rose Clark commented, "**Caring [has] good days, bad days.... I do it but...it wears me out because I never got used to it...selfish. I could bathe or dress at my leisure...but now I've got to get him dressed...I'm just being honest with you....**"

Families adapted to the caring situation and persevered. John Adams revealed, "**[I do] not sleep well, me upstairs and Marie down here since June...take naps in day now, get up earlier to take care of son and for nursing assistant to come.... Life is pretty much the same as before.**" Marcus Frank offered, "**The way I arrange things and way things work out are just about the same. No different to it.**" Laura Ivan stated, "**[At first] we rearranged our work schedules. Now during the day, life [is] pretty much the same; just keep goin'.**"

In summary, the core of adaptation in families was making adjustments to the circumstances of the stroke event with caring actions. All the UFCs gave examples of how they and their families' lives were different in caring for the person with a stroke. Losses of independence in personal and family actions occurred. And yet, Marcus Frank and John Adams said their lives now were "no different" and "pretty much the same as before" the stroke occurred. Most UFCs implied and Laura Ivan shared that they just keep going on as before the stroke happened. The family was maintained.

Caring is adaptation in caregivers' enforcement of old values. Caring in the home was a highly prized and deeply rooted family value. The UFCs and their family members made adjustments in their lives to continue caring for the person with stroke in their homes. Their comments were similar and reflected agreement. Home was the best place for caring, if it did not compromise the caregiver's health. John Adams shared his commitment to caring:

> ...**[I] stuck by [Mary] as she stuck by me...if I don't do it, she'd be in a nursing home...she not like it, I not like it.... Not happy to put in nursing home...would be lonesome without her...home is freer...never assumed this would happen...do everything to keep her here, not put in nursing home....**

Joan Beck's comments were very similar to John's statements in regard to nursing home placement:

> ...**Doctor said, "Put Mom in nursing home...." We all cry, we aren't doing this...we said we will take her home...we take care of [one another]....** My mother had a stroke, she doesn't want to be that way, she is the quietest, most gentle person I have ever known in my entire life...very determined.... If we can get her through another day of being with dignity, that's what gets you through.... We fighting this disease, we are helping her, that's it. **[She'd have] no quality of life [if] she [was] stuck in a nursing home. That's why we don't let Mom go to a place like that.**

Joan's daughter, Ann said, "**Either we keep her alive at home or we let her go to a nursing home where she may die.**"

Nursing home placement was deemed appropriate in some cases. Mae Clark commented,

> Hope that if [my father] keeps going and going the way he is, I hope he do turn himself into someplace that can take care of him. And there's a lot more people there that can handle him. Because like I said, he's either going to be that or we'll being burying my mother. Cause she already has high blood pressure; she's not supposed to be around cigarettes; then he wants the heat up high all day long and she's not supposed to be in that. **So in the long run, to save my mother, yes, I think he should go to a nursing home, you know.**

This belief in nursing home placement was not dominant in other families. Maura Ivan's comment was representative of all other caregivers and captured the essence of continuing to provide caring in the home. She said, "...**If we didn't care [for Mother] somebody else would be caring.... She probably...would have went to a nursin' facility, but she would not be here with us today.**"

In summary, the adaptation in caregivers' enforcement of old values consisted of adjustments made by UFCs in their lives so that they could continue in caring for the person with stroke in their homes. This facilitated maintenance of the family system. For most of these families, placing the care recipient in a nursing home was not an option. Representative of this thinking was Ann Beck's remark, "Either we keep her alive at home or we let her go to a nursing home where she may die." All UFCs equated nursing homes with death of the care recipient. The only time nursing home placement for the care recipient was considered, regardless of available financial support, the situation involved the health of the caregiver. This only occurred in the Clark family. Mae Clark's concern for her mother's high blood pressure and exposure to cigarette smoke reflected of the children's feelings. The children thought the father should be placed in a facility in order to save the life of their mother and to maintain the family system.

Caring Family Function as System Change

Caring is adaptation in caregivers' watchfulness. The sum and substance of the UFCs' watchfulness, a new dynamic, was derived from the realization that the care recipient could no longer fulfill their past role obligations. On observation, Mary Adams sat and watched television while John talked about caring for her. Mary had physical and mental limitations due to her brain damage. In simple terms, she was not safe in her cognitive and psychomotor abilities. John always sat where he could watch her.

Joan Beck also commented about watchfulness:

> ...I have to...be careful with special diet [for Mom]...restrict fat content, low salt, and no sugar; sometimes [Meals on Wheels] don't send the right [food].... She would sit in a chair all day, so you had to check the chair to make sure the padding wasn't wet. Stand her up; if wet, put another one under her.... **I watch her**

> **like a hawk....**

The other family members agreed. Daughter Ann said, "**Still in the end, she's never been in the house alone. There's always somebody with there.**" Joellen Beck noted, "**We never leave her alone.**"

In the Clark home, Rose sat in the living room; Roland in the dining room. Roland was always in her sight. Margaret Dawn was observed to be often by herself; but daughter, Ruth, checked on her when she was present and would frequently telephone her mother when she was away from the home.

Gladys Erwin told the following story about being vigilant:

> [Joe] can go up and down steps now.... I go with him. I don't want him to fall. I don't let him go up alone. I make his bed and change it, get him up, and he goes in the bathroom maybe an hour, hour and a half. **I check all the time. [Ask] are you all right?.... But I have to keep telling him, watch your left side, as he veers to the left. It is hard. I can't leave him for long.** It's not that [he] will do anything but...I can't leave [him] for 2 or 3 hours. What if [he] did have a stroke and didn't know it? What if [he] fell? And I wasn't here. **This isn't being overly protective. It's being smart.... He doesn't remember what he sees.... Caring is watching [to make sure he doesn't choke]; it's supervision.... I'm with him.... I always keep my eye on him....**

In the observation/participation session, Gladys said, "**I always take him with me. I can't leave him alone. It wouldn't be safe. He has left neglect; can't remember things.** [A disorder of attention, neglect of a portion of space or body is common after a stroke.] **I need to watch him; be vigilant, watchful vigilance....**" Gladys was observed to continually coach Joe to think about what he is doing. Another observation concerned Joe's decision making ability. As we, Gladys, Joe, and the researcher, sat at the table, Joe reached to the stove and turned it on. Gladys stated, "You shouldn't turn it on till I look."

A caregiver for many years, Maura Ivan said, "**When she [mother] first had [the stroke], we would just...never leave her alone. Someone was here with her constantly." Now, the mother wears a call button around her neck that, when activated, can summon help for her.**

In summary, the UFCs were observant of the care recipients. They adapted a watchful vigilance in caring. As Joan Beck said in caring for her mother, she "watched her like a hawk." The majority of UFCs kept this person in their vision. Most care recipients were never alone. For some families, there was a history of the care recipient falling and being unsafe. Several UFCs even observed what the person with a stroke ate, making sure they did not choke. Gladys Erwin described this watching as "supervision." She noted that she always takes her husband, the care recipient, with her. In another family where the mother was often alone and did not require constant supervision, Ruth Dawn said that she always checked on her mother by telephone. They all tried to make sure that the care recipient was safe. Watchfulness was a new function for the UFCs and family that was a change required by the care recipients' thinking and behavior resulting from the stroke event.

Caring Family Function as Coherence

Caring is differences in filial function. The essential quality that defined differences in family relationships that enabled them to grow and function was dependent upon the level of interpersonal interactions among the UFCs and others prior to the stroke event. These relationships drove the caring actions for the UFCs. Many spoke of love- and duty-based relationships in their families; others described obligatory relationships. The following statements are representative. Joan Beck noted,

> ...**It was like the whole family had a stroke...close-knit family...we're poor...we're used to it...we band together and get through it...we don't like to ask [others]...we give and take...we pitch in [always like that]**.... My daughter knows what to do...all children [including siblings] know the routine so that if something happens and I couldn't get back here others would take care of her.... Her brother came when we were caught in a pinch and stayed with her; he's retired and on Social Security...he's there when we need him...this is his only sister.... We think of Mom's welfare....If [there is] a difference of opinion; we listen, then work it out.... We were taught to work as a unit [togetherness]. Love...teaching from Mom at an early age. As a family we are responsible for ourselves...work, pay bills, food, shelter [are important] so we not feel guilty.... **Being raised to work as a unit, we pull together**. We can do and so...easier for a

> large family to work together than only two or three.... You can get angry, there's sadness, but generally a happy family. Nobody is happy all the time...some get depressed...then we talk...that's family...be some support.

Rose Clark told a different story. The caring relationship involved a mixture of felt anger and obligation for Rose:

> [Roland is] a controller. People explained to me that, my sister-in-law tells me, I think what it is...that you are like two kids fighting...all your life, he has controlled you. And all of a sudden now I'm...this happened way before he got sick...I'm like a rebellious child. I no longer listen to him, what he says. That's one reason why I had left him. I used to just go along with him, but once the children got grown and I got out there and made my own money and stuff, I figured that I don't have to do whatever he say. That's stupid.... Now I don't know...**I have a heart for him, but he's been such a cruel person that's why people don't come in. He's been very mean to people...even his friends [don't come to see him].... Not very satisfied [with this situation of caring] not that much. Well for one thing, I guess, I got a feeling that he really don't want me here. But he don't got nobody else to help him. That's sad. I feel like I'm being used and controlled.**

The Clark children helped clarify perceived anger and obligation as well as love and a sense of duty in their family relationships. Silvia said, **"There's a lot of anger in the family; a lot of anger.... My father beat my mother years ago.... We [siblings] still live with all that. It's hard to take care of him, because of how he was.... We obligated to him; he's father. So we do what our momma need. We love her; we do whatever needs to be done for Momma."** Jake agreed and said, "I love my mother. **We are family, mother, father, sisters, and brothers.... Feel obligated to them...[so in caring for Father] it's been between me, [Mother], sisters, and another brother; [we] work together."**

Other families' thoughts were more like the Beck story. Gladys Erwin said, **"We're happy....** When you live in a small house, you have to get out of each other's face once in awhile. Cause he likes his privacy. I don't need privacy...I like to be with people.... **He likes to be alone once in awhile. So I have to give him his space. Sure I respect and love him."** Marcus Frank noted, "Family is close...loving family.... Every now and then they say things mostly of me going, mostly it's concernin' that; somethin' like that or you stayed too long and we had somethin we wanted to do, like that.... Other than that, not too bad." During the discussion with the researcher, Marcus said he had been a deacon for his church for a long time. He valued "communing with church members and doing things for the church."

Laura Ivan concluded, **"I just remember when I was a baby and [Mother] took care of me. Love her. Just think about it like that [now it's my turn. I am] not really [dissatisfied with caring]."**

In summary, the essence of differences in filial function centered around previous family relationships. For the Clark family, caring actions were based on anger and obligation toward the care recipient. Conflict occurred between values related to obligation for caring and their sense of justice and fairness. In the Clark family with a history of anger and abuse, the husband was viewed as a controller by Rose. She had left the marital relationship shortly before his stroke occurred. Rose returned after the husband's stroke, because he had no one to help him. She said she felt used and controlled by her husband and the situation. Rose felt obliged, but it was not fair that she should sacrifice herself. Rose said she was not very satisfied with the caring situation. The Clark children worked together with Rose in caring for their father, because they felt love and duty toward her. In most families, caring actions by UFCs were centered on love and duty. Several UFCs said that it was like the whole family had the stroke. As Joan Beck said, nobody is happy or satisfied all the time, but the family works as a unit in caring for their mother. Thus, while there were filial differences based on prior kinship interactions, all UFCs perceived that their family worked closely together in their caring actions for the person with stroke.

The Meaning of Caring

The meaning of caring, the caring expressions, is concerned with how the UFCs of persons with stroke interpreted or explained their situation; specifically how they adjusted to individual changes and respected each other's opinions and how they maintained effective emotional relationships among family members. The UFCs' meaning of caring pertained to their understanding of how personal growth and enrichment versus pain and disappointment occurred; how mutual support and management of conflicts happened; and how emotional, spiritual, and cultural aspects of caring affected their own well-being and their family's functioning. Some distinctions became apparent for UFCs as individuals. Nonetheless, the aggregate of the caring expressions shared by the UFCs presented an integrative cultural view of the meaning of caring drawn to Friedemann's (1995) Framework of Systemic Organization. The caring expressions are more abstract at a theoretical level than are the caring actions and family functions. Therefore, through the process dimensions, the caring expressions were linked to Friedemann's systemic targets of stability, growth, control, and spirituality displayed in Figure 3. The schematic presentation of data related to the meaning of caring in Table 3 shows these relationships. Many caring expressions drawn through the process dimensions, as diagrammed, address more than one systemic target. The following discussion of caring expressions is organized under the one systemic target seen by this researcher as primary.

Positive meaning associated with caring processes by the UFCs of persons with stroke promoted congruence (pictured in Table 3) and were felt as satisfaction or well-being and health. Through the domains of caring action and caring family function, in combination with the domain of caring expression, the meaning of caring was known. The UFCs shared feelings of happiness, peace within themselves, or love of family. Incongruence was mentioned by UFCs as emotional burden, unhappiness, and dissatisfaction with the caring situation in their family setting. The findings of this study confirm reported stress levels in the literature

Table 3

The Meaning of Caring and the Framework of Systemic Organization by Friedemann (1995)

MEANING OF CARING ↔ ***FRAMEWORK OF SYSTEMIC ORGANIZATION: CONGRUENCE***

↕

SYSTEMIC TARGETS:

DOMAIN ↔ ***Definitions:***

↕

Domain		***Definitions:***	**Stability**	**Growth**	**Control**	**Spirituality**
Caring Expressions -	Caring is: **Emotional burden**	Adjustment by all urban family caregivers (UFCs) to mental confusion and memory loss of the care recipient was a clear description of the pain involved in lack of system change: Change from the family as it was with mother or father as a leader to acceptance of their new role of being dependent. There was a struggle by the UFCs between wanting stability (correcting the care recipients, seeing them in lucid moments, and thinking it is only temporary) to making the change and growing into new roles. *Dissatisfied with memory loss and confusion...don't dwell on it...or like it...realize it's mental a thing with stroke.* *[I have] pain that they don't have medical technology to make her better. That's very painful. The fact that I know my mother is a good mother...gave 1000% to her family.* *It's going to hurt, if you love your mother...you have to accept it.* *I think the hardest thing was when I had to tell her to do something. And I became the parent, and she was the child under me. That was hard for me to accept, cause all my life she had been the parent...everything reversed and I felt so.... Some days she has a clear mind, some days it's cloudy....* *...Her depending on us so much is what's hard...mental fatigue.*	[a]X			

(table continues)

		Stability	Growth	Control	Spirituality
	Definitions Con't:				
Evasion of conflicts	The UFCs avoided conflicts to maintain filial relationships and resources. The major point made by all the UFCs was not to argue with one another. It was important to just try to accept, and in one case perhaps avoid, the other person.	X		[a]xx	
When we argue in front of her [care recipient]...she'll say really quickly that she is in the way. If she wasn't here then maybe we wouldn't be doing all this and that...but we just stop and let her know that "Mom, we love you and we are glad that you are here." *Try to say nothing rather than argue....* *I'm learning how to get along with him more...agree with him, not argue so much. If it's not correct, I just say..."Well I'm not going to correct him." At first, I was trying to say "You wrong"...but now I say "Maybe you right, I don't know".... Good day is to ignore him.*					
Motivation: Love and a sense of duty between caregivers, care recipient, and their families	Caring was centered for most UFCs within love; for one family, caring was cold obligation, as the husband had no one else to help in caring for him. Nevertheless, all the other UFCs told of love, dedication, determination, and commitment in caring.	X			xx
Without love, caring is like a man taking care of a child that he feels is not his: no bond is established [only obligation]. *I'll do anything for her, dedicated to that...care...love each other.* *Well, to me caring is somethin that an individual should want to do, cause that's a loved one. [I] guess it's just a part, my duty to care like that for family members.*					
Self-development	Over and over again, the UFCs used the same words: learned *patience and tolerance* from the caring situation; this diffused their stress and anxiety. They told of survival or coping skills to deal with the caring situation. Many of the caregivers and care recipients developed increased tolerance and became		X		

(table continues)

	Definitions Con't:	**Stability**	**Growth**	**Control**	**Spirituality**
	closer as a result of the interdependence on each other.				
At first, I thought, "Oh my God, how can we do this and work?" I learned that illness can be a positive. [The situation] taught all of us, including grandchildren. Younger people, taught them to look at their lives, that they are going to get old too.... Taught them about illness, that you do grow up, get old. Taught them about patience. Taught them to be more understanding toward senior citizens, that you don't have to put them away.... [To take care of self]...not to worry. *[I learned] tolerane.... [I learned to]...try to have patience....* *I try not to let myself get stressed out. [I learned to] read a book, look at a movie, go to the mall, walking and shopping...doing something in the house, whatever. If you find it's to much for you, do something that you like to get over that bad feeling that's coming up on you. Get on the phone and talk to somebody. But don't sit there and sulk in it. I learned to do this for self. To relieve the stress, sometimes I exercise. You get involved in it, that you just forget about the stress.*					
Fairness	There were two viewpoints in caring for others expressed by the UFCs in this study. In one view, the UFCs felt a sense of fairness in caring. Simply put, families with good boundaries accepted limitations of support from other family members in support roles. The majority of UFCs were happy or satisfied in the caring situation. In other families, there was a sense of disappointment that all family members did not share equally in the caring process. Many stated that the women were expected to do and did more than the men. But even in these situations, they were not necessarily dissatisfied. Other UFCs felt that caring for others was not fair. In the family with the history of long-standing anger and abuse, the caregivers agreed that caring was not a			X	

(table continues)

Definitions Con't:		*Stability*	*Growth*	*Control*	*Spirituality*
	fair situation, but there was no one else to do it.				
Happy with caring.					
Disappointed that sisters, that family members involved with [mother's] care don't always take on the responsibility that I feel they should.					
[I'm] not necessarily dissatisfied, but I think the boys could do more than they do; that the men, my uncles, they could do more. But I understand, they have a family and my uncles are all in their 40s. They were raised in the South. That meant that the men took care of the financial situation, the women took care of everything else.					
Not very satisfied [with this situation of caring]. Well for one thing, I guess, I got a feeling that he really don't want me here. But he don't got nobody else to help him.					
Filial ethereal value	While there was a degree of burden in caring and some dissatisfaction; caring for the care recipient was a family spiritual value for these UFCs. Many caregivers commented that they worked together in the caring situation. The warmth of family pictures displayed in their homes outweighed the coldness of their environmental surroundings; the pictures also indicated that they depended on family for caring and not on material things. The UFCs focused on positive attitudes; they focused on what they had and not what was not or gone.	xx			X
In a way [caring is worth it], it is and in a way it isn't. If you feel like you are wanted and needed, then it's worth it.					
Little boy right over there [picture of daughter's child]...children help.... I feel good most of the time. And be thankful of being able to do what I am doin'.					
Caring is a good experience; no burden. He can do little things for himself...that's good.					
Self-contemplation	The UFCs were able to look within themselves. Their		xx		X

(table continues)

	Definitions Con't:	*Stability*	*Growth*	*Control*	*Spirituality*
	refletion, a philosophical introspection, was based on their Christian values. These values provided more validation that their actions made a difference for self and the care recipient. Most UFCs said that they accepted life and kept going. Many UFCs felt rewarded from the caring situation; in that, happiness was seeing the care recipient do something they were not supposed to be able to do. They received an inner reward from caring: peace of mind and love from God. The UFCs were able to find the intrinsic goodness of caring. *I feel rewarded when I see other people happy. If I can give somethin' to somebody and I see somethin' back in return, that they picked up, you know, then I'm happy....* *I talk to God when I need someone to talk to.* *So you just have to go on and do what you can do. And put it in for God, in His hands. I say, "Lord it's in your hands." I feel better.... Put your yoke on him and carry His, which will be lighter. He tell you to talk to him and give it to Him, a weary, heavy burden.... Happiness is seeing the person do what they weren't supposed to be able to do. That's the reward, to me....* *I think it makes us a better person.... I love to help people. Rewards in caring come from others: a smile, a touch, a look.... It makes me feel good, where I can lay down at night and I can go to sleep knowin' that I have done somethin' for somebody today; I can go to sleep in peace.*				
Motivation: Philosophical introspection	The motivation for reflection by the UFCs were feelings of vulnerability. They were able to reframe their values and reframe the situation in order to make the caring situation acceptable. There was no guarantee for vulnerability, so the UFCs looked to God. Faith made the vulnerability tolerable in that the ultimate reward for		xx		X

(table continues)

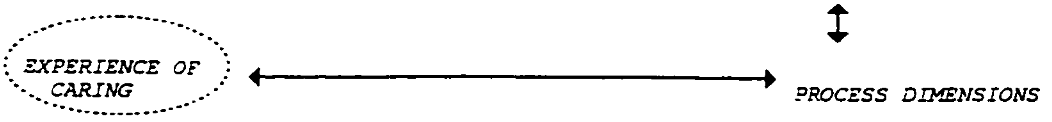
	Definitions Con't:	Stability	Growth	Control	Spirituality
	the UFCs was heaven.				
	From above...God gives energy and attitude to get through.... God is only thing in life that moves me...He will take care of me...satisfied with life...under control.				
	[I don't] worry about things or [care recipient] ...God take care of things in time.				
Filial piety	First, there was the initial crisis of the stroke. During this time, the family members pulled together and made the commitment to caring. Now, the UFCs work as a unit in caring for the care recipient. All the caregivers shared examples of taking turns in caring for the person with the stroke.			xx	X
	[Family] work together...a team effort when giving care....				
	Grandmother [is] like backbone to keep everyone really close, tight knit. Since she had the stroke, we haven't strayed from each other...everyone a little closer... you have to deal with these people....				
Living in the moment and hoping for the future	The UFCs were able to live in the present and had hope for the inevitable future. The majority of UFCs were grateful to have the care recipients alive, in that they were able to laugh and talk with them. Caring had become a mission and purpose for the family. A few UFCs were hoping for realistic, and sometimes unrealistic, changes in the care recipient's physical and emotional states. All UFCs hoped the future would be better. Several UFCs commented that they needed to be strong and alluded to the need to be able to continue caring in the future. The UFCs usually did not share these concerns with the care recipients. Most UFCs hoped that God would get them through their caring situation.				X

(table continues)

	Definitions Con't:	Stability	Growth	Control	Spirituality
	Future will accept as it comes. *[I'm] happy that she's still here and I am able to laugh and talk to her.* *Hopefully, it will be better [in the future]...maybe. We're hoping that we can get her memory back a little better. Maybe we can get her back a little ways before she had this last stroke. But all we can do is hope and pray and keep going and keep her happy and healthy.* *The only thing that bothers me is sometimes she calls me all through the night...but I don't let her [wife] know it. Try to keep it from her, because to me it shows weakness and I don't want her to think that I can't. I just feel like I should be strong for her, for myself and her.* *The Lord will get me through this. It is through Him that I am able to go on; we are in His hands.*				
Purpose	The caregivers voiced a sense of determination or purpose in caring. Many UFCs spoke to giving the person with stroke the best quality of life possible. These caregivers were able to reframe their perceived purpose for caring to one of satisfaction and fulfillment. A few UFCs shared that caring was not related to satisfaction but rather patience and endurance.				X
	The purpose for me [in caring] is to give her the best quality of life she has left. *I find meaning and purpose [with caring]. Sometimes I think of it as [a] thing to learn you to have patience and endurance.* Many UFCs said, *Caring is loving, sharing, being there to help, giving of yourself, being at peace with yourself, and seeing the other person grow.*				
Motivation: Approval by care recipient	The approval of care recipients helped the UFCs get through the day and helped in maintaining their lives. Most of the care recipients valued the caring provided by the UFCs.				X
	I know that my mother is thankful, OK [for the caring provided.]...the reward I get is from helping her.				

(table continues)

Definitions Con't:		Stability	Growth	Control	Spirituality
[Mother] does say, "I appreciate what you're doing." This makes me feel like I've done a good job.					
Christian piety	The UFCs became overwhelmed with the caring situation and turned to God. Caring was rewarded in religion.				X
God take care of things in time.					
To get through the day, I use] prayers...go in bathroom...first I was having a pity party...why, why, and then I talk to God, just like I'm talking to you. I say, "God, you got to help me. I'm just a mere human. I'm not a super, God, but you know that, Lord. I'm your child. You know me from the tip of head to bottom of toes, you know me before I was born. You know what I can handle and it brings peace...."					



Note. As designated by the researcher, [a]X denotes primary target; [b]xx denotes second target.

about caregiving. Nonetheless, the findings also facilitate a beginning understanding of congruence, well-being and health, of UFCs of persons with stroke in their African American family systems.

Table 3 is provided as a source for rapid review of the meaning of caring and as a base for further discussions presented in this chapter. In the following paragraphs, each caring expression section contains (a) an introduction statement to the caring expression, (b) rich and insightful representative quotations by the UFCs along with pertinent observations by the researcher with important identifying statements highlighted in bold type, and (c) a summary paragraph for the caring expression.

Caring Expressions as Stability

Caring is emotional burden. Pain and disappointment was involved in maintaining stability of the family system, as its members adapted to new roles brought on by the stroke event. Specifically, emotional burden consisted of an adjustment by all UFCs to mental confusion and memory loss on the part of the care recipient. Several quotations illustrate these views. For example, John Adams said,

> **Dissatisfied with memory loss and confusion...don't dwell on it...don't like it...realize it's a mental thing with Mary's stroke**.... Like her to be more talkative.... She makes some improvements, I see this, but also see she is getting forgetful. [Tears in eyes, his voice falters, and he stops talking for a few seconds.]...[Mary] talks about people who died years ago...this bothers me...rather see her as normal...that's life...accept life as it comes, hurts me that she talks about these [people] a lot [voice chokes up].... Happy with self...happy that I get up...no sadness...**if I were to be sad [it's only] that she can't get around as alert as before...don't ponder...just accept**...and that we are still here.

Joan Beck said how painful caring was for her: **[I have] pain that they don't have medical technology to make her better. That's very painful. The fact that I know my mother is a good mother and she gave 1000% to her family. I'm disappointed that her senior years turned out like this.** Joan's sister, Ellen, described her personal struggle:

> We take care of our mother because she had the stroke...about 7

years ago.... Ever since then, she's been progressing. **When she first had the stroke it was very difficult for the family to accept.... But we all had to just accept it.... More so in her long-term memory...now she's getting better...had to deal with her going back to the past, talking about her dead husband and thinking about her mother not being deceased and her father, you know. We had to deal with all that...it's very hard, cause when you look at her, you see her like she used to be, but we can't....** The doctor said when she start doin' that, just correct her, don't let her continue on thinkin' that.... She was determined that we was wrong and she was right.... It's hard because I love my mother a lot and it was hard to see her thinkin' and actin' like that. I knew that it was not my mother.... So we had to cope with it. It's even hard now because after the years go by you relax with it, ...and it just seems like you know what to expect and everything. You're still working with it, you're still fighting this...just like a cancer or something. Constantly fighting until you can't fight no more. Like a battle, I'm in a battle with her and I don't want her to think that we, cause we are her children, you know how parents are, they are still in control. We are still the children. We have to obey her. **I think the hardest thing was when I had to tell her to do something. And I became the parent, and she was the child under me. That was hard for me to accept, cause all my life she had been the parent...everything reversed and I felt so...sorry for her.... Some days she has a clear mind, some days it's cloudy. When it's cloudy, we just remind her that they're long gone. Sometimes she don't believe it.... With me I take a deep breath and...even now when I look at it, it hurts. It's going to hurt, if you love your mother and you want her to be better, want things like they used to be, you have to accept it. The hardest part is accepting it....** But it's still hard for [other family members] to even look at her. It still is, cause [caring for] Mom is a complete job.... [My 15-year-old son] said, "Momma, Grandma just don't want to listen." I had to talk to him cause sometimes she frustrates him. She frustrates you, if you just be relaxed with her, sometimes it's hard if you are going through something, too. [Caring] takes a lot of energy and you will find yourself just really tired at the end of the day, you be tired.... She is constantly on my mind. I get depressed and angry about caring, I can't lie about that. It all comes, emotions, everything because you feel like, how long is she goin' to stay like this? How long do I have to do this? And, then I don't think anyone can say that they enjoy it.... **It weighs you down, even though you are goin to do it, because [Mother] needs your help. But it still weighs you down.... You have to get totally involved with caring. You have to get mentally and physically involved. It's a mental and physical thing, but most of it you just have to go in with a positive attitude....**

Rose Clark also talked about pain and disappointment:

He watches TV, smokes, cries, relives the past over, sobs, sobs, angry like that all day long. Think he's getting worse.... He's confused. I get irritable cause he wants to live back when we was first married.... The [grand]kids don't understand...want him to be like he used to be...they don't understand.... It takes a lot of energy, physically and...more mental. Seems like my brain...he has me thinking I'm almost gone.... He talks about...anger [about things in the past].... **Memory is hard [to deal with], it takes a**

> **lot. At first we battled every day until I went stark raving crazy that this man is sick.... Lot of pain and disappointment been going on for a lot of years.**

Rose went on to say that in order to maintain the situation, herself, and family she just "ignored" him.

Ruth Dawn struggled with acceptance of the situation and fought her own impulses:

> **I think caring for her is mostly mental then physical, because she likes to know that we're there for her.** It's not about us doing for her, cause she can do for herself. ...Even on the phone she depends on me for opinions and decisions what she should do. I try to push it back on to her and say, "What do you think you should do?". Sometimes she calls a lot. Sometimes I think maybe too much, she wants to talk awhile. I really don't want to talk that long.... Even if I really don't have to do anything, I just didn't want to be on the phone that long. Sometimes she'll just call and I think she does it to just get attention from me, because there is no reason...she'll call me back for no reason. ...**Her depending on us so much is what's hard...mental fatigue.** As I look back, her mother did the same thing...I would tell her, "Why can't Grandma call and make the appointment?" and then we just take her. But she would want my mother to do this and that or make this decision for me.... She can very well do it. Mom does the same thing. Exactly.

Gladys Erwin searched her inner self to find the strength to carry-on:

> **Caring is caring for the person. You love the person. It is draining [emotionally]. It's the physical and emotional caring that is exhausting. I get physically exhausted because I'm tired but inner stuff.... It's emotional, that constant caring. You care so hard that I just can't describe it. It's such an emotional insight thing. The physical labor you can do; you're tired, it's strength, it's draining. But not like the emotional is, that's really draining....** I love to read and I haven't had time for me to read...this is a big problem.... It is hard, that's draining.... It's physically exhausting; but it's such a pleasure to see him become stronger.... When he was real ill, that caused a lot of pain. I guess that would be dissatisfaction, because I felt...the progress was so slow at the start. I felt like I wasn't doing enough.

Daughter Julia Frank added,

> **Caring is a lot of mental...[work].... She remembers things, like the long-term memory is there; her short-term memory sometimes isn't [there]. So you never know what she remembers.... The only thing that gets me, not really depressed, is that my mom is not able to get around. That's the only thing(not really depresses me, that just hurts.** You know what I'm saying? You see her as a vibrant individual and then every couple of years she had another stroke. You saw her get weaker and weaker. Not really depressing but like it was aah...you hate to see it. **It hurts.... You always**

> **remember your mom...going and doing this and helping others, people. To see her, the tables turned around, her in that position, that kind of hurts. Cause you don't want that for your parents no matter what age they are.... You always want your parents to be healthy and getting' around and doin' things on their own.** But that's not being realistic either, cause of their age. That's the only thing I hate, cause I can't get her and come by and pick her up and go to the mall like we used to or come get her and spend the day at my house and the kids running in and out talking to her or out in my yard helping me plant flowers...you can't do those things anymore. That's the only thing, the bad part of it [stroke] that I don't like.

Louise Hughes agreed, "...**There is much more to caring than the physical**. There is the emotional side of her being.... My mom was a real go-getter. You could say that she was a workaholic and...**the emotional part of that is, her not being able just to get up on her own and go anymore.**"

Laura Ivan offered that to go forward and to deal with the emotional burden she turned to prayer. She said, "...It's hard when it gets down to the end but you need prayer." Vera Ivan explained,

> **I do talk to [my sister Dolly] each morning on the phone and many times a day too; she gives me support and I her. I do think caring is more than just personal care.... She calls a lot of people and just talks. I mean she's very uplifting...to talk to. You can talk to her and you can get strength from just talkin' to her, I do. I mean, she has been an inspiration to our family. We have gone through a lot of things, because of her, lookin' at what she has gone through. And all the things, the strokes and things that she has gone through and just watching her day by day and the "oomph" that she have is given us the strength to do that much more.... For instance, if she call me at 3 or 2 o'clock in the morning, I'm tired or whatever, Dolly says, "Can we pray?" I just drop everything, and [say] "Yes, we can pray...."**

In summary, the emotional burden was an adjustment made by all UFCs to the care recipient's mental confusion and memory loss. The UFCs gave clear descriptions of the pain involved to keep the family's stability. There was a lack of accepting the system change: The change from the family as it was with the mother or father as a leader to acceptance of their new role of being dependent, a return to their childhood. There was a struggle by the UFCs between wanting stability by control (e.g., correcting the care recipients, seeing them in lucid moments, and thinking it is only temporary) to making the necessary change of accepting the permanency of the situation and new roles. Overall, the UFCs just adjusted; there was little structural change in their family systems. Rather, they did everything possible to maintain the stability of the family process. Ellen Beck stated that caring was emotionally draining. Julia Frank said that caring was mental work, referring to dealing with changes in her mother's memory abilities. She went on to comment that to see her mother like this "really hurts." In caring, whether out of love and duty or anger and obligation, the UFCs had no choice. Caring was painful for all UFCs. Several UFCs mentioned the importance of prayer to help them through the caring situation. This provided stability for the family.

<u>Caring is evasion of conflicts.</u> There were conflicts in the families. The UFCs used avoidance in dealing with conflicts to maintain stable family relationships and resources and, ultimately, control the situation. For instance, John Adams stated, "Happy with things way they are...Mary is my sweetheart since school...**no arguments...few disagreements...don't worry about anything.... OK not to talk about feelings** like daughter's divorce." Ellen Beck added, "**When we argue in front of [Mother]...she'll say really quickly that she is in the way. If she wasn't here then maybe we wouldn't be doing all this and that...but we just stop and let her know that 'Mom, we love you and we are glad that you are here.'**" Jolee Beck told the following story about coming into the mother's home to participate in caring:

> **When [disagreements] come up for instance, if my sister wants me to stay over with my mom, sometimes she'll just say... "I'm not coming." She never comes. So I know somebody has to stay there and I'll stay. Just do what you have to do. And, I understand that, cause it's hard, you know, she gets tired and she doesn't have the best of health all the time, she's sick here and there.... Then I say to myself, really you haven't spent as much time in the household as they have and this is your mother as well, so I just do it.** Then I go home 11 or 12 o'clock at night sometimes with my kids and then I have to get them back up in the morning...it's hard but we make the best of it. We won't ever leave [Mom] alone.

> We try not to argue in front of her. We do have our disagreements. Sometimes we talk them out and sometimes we just blow up and don't say anything for a day or so. It's extremely hard because [Mom's stroke] has changed all of our lives.

The Clark family gave clear examples of how family stability was maintained by evading conflicts. Rose Clark commented, "**I'm learning how to get along with him more...agree with him, not argue so much. If it's not correct, I just say... 'Well, I'm not going to correct him.' At first, I was trying to say 'you wrong'...but now I say 'maybe you right, I don't know.'**" Silvia Clark agreed and offered,

> **Try to say nothing rather than argue about it**...come over and help out.... I used to come in with Mother to keep up with him. But he just got too grouchy and mean for me and I say hey, when he's like that I'd rather take care of what I can do over the phone...rather than go over there and be angry with him.... Before he had the stroke, he was awful. He was a bastard. [Now] some days you can get on the phone, you talk to him real nice; some days you just want to get away as quick as you can.

Mae also agreed, "**There's a lot of anger in the family**.... You had to go through it when you were 14 or 15, a little kid. **But you don't have to put up with it now. No we'd rather walk away, which is the best thing to do.**"

Gladys Erwin evaded conflicts by distracting her husband:

> **I suppose we have an argument every now and then. [Work it out by] communication. [Really] the only disagreements would be between [Joe] and me. He wants to do something [and I don't].... He gets up in the morning and looks at me with those bright little eyes and says, "Where are we going today?" Cause I try to get him out everyday, even for a ride. Just to get him out and get him dressed.** That's why he's come as far as he has. I know this.

Marcus Frank and Freda Grant simply did not believe in arguing. Marcus said,

> **But with caring, encourage people to have faith and believe that things can be worked out by reasoning with one another. Not to have arguments with one another, cause you got differences of opinions. Don't bring them out and argue over them. Try to accept the other person, cause you have a right, I have a right. I don't believe in arguing....**

Freda Grant's comment concurred with Marcus Frank's, "[Conflict with caring, for example] the TV here, if it's somethin' he want to look at, I let him look at it. [If there's] somethin' I want to look at, I go back in the bedroom and turn the TV on back there. That's the way we got that."

In summary, the UFCs viewed conflicts as not being beneficial; they avoided conflicts to maintain stability in family relationships and resources or they worked hard to solve them. They let a lot of things go, so that they did not waste their time and energy with nonbeneficial conflicts. This was one way to control relationships and resources. John Adams stated that there were no arguments and few disagreements in the family. Rather than be involved with conflicts, Jolee Beck said that you do just what you have to do. In yet another family, Silvia Clark commented that her father was a bastard before he had the stroke and now he was no better. Rose Clark stated that rather than argue with her husband, she just agreed with him and moved on with her life. The major point made by all the UFCs was not to argue with one another. They needed each other to provide caring. It was important to just try to accept, and in one case, perhaps avoid the other person. Nevertheless, anger persisted in several families and was an indication that conflicts were merely suppressed, never resolved.

<u>Caring is motivation from love and a sense of duty between caregivers, care recipient, and their families.</u> Love, dedication, determination, obligation, and commitment to caring composed the basis for this motivation in caring to maintain stability in the family. There was an underlying spiritual essence in the UFCs' motivation for caring. John Adams and Rose Clark shared the following stories. John said,

> Always responsible person...kids see and father that way too...decision maker...discuss things...have biggest influence...left up to me to make decisions.... One day at a time.... God is love; most important thing/word...love fellow man and do what can do to get by...live that way. Some people are selfish...problems stem from that...most people are good...**I'll do anything for [Mary], dedicated to that...through years [together]...care for each other...love each other.**

Rose Clark shared,

> **I would tell anybody that [caring] is not bad when the person is sick, but I think you got to have love between you all. It's not so hard. It's not a burden, cause you love that person and they love you. Everything you do for them, they are going to be grateful and you don't mind. If there's no love there, it just like a man taking care of a child that he really don't feel is his, that he's just going along with the program. Can't be no bonding like that...[there is] no bond in [my] situation...only obligation....**

While Rose understood love; there was no love between her and her husband. There was love only between Rose and her children. So the children helped Rose in caring for their father out of the love for each other.

Ruth Dawn also noted that love was a strong bond in caring:

> **[Mother] calls me all the time.... Actually when I really think about [caring for Mother] it's...I want to keep her,** I'm going to cry, oh gosh [crying]. I just want to keep her as long as I can. So sometimes I don't always do like I should do but **I feel good about what I do, because I know that the less worries she has, the longer she'll stay [and not die]. I love her.**

Love also motivated Gladys Erwin and Julia Frank in her caring for their family members. Gladys said,

> **I love him to death....** We're both very dependent on prayer. We pray together every night. We hold hands and we pray. I just ask for strength and sweetness, because I'm not sweet. I'm tough...I want to be nice; I don't want him to hate me for the decisions that I sometimes have to make. I pray for forgiveness when I have lost my temper, but yeah, we pray. Do a lot of praying.... Gets you through the day.... I feel I've done more than I ever thought I could do. **When you love somebody and you care, really care, when you say love and you mean it until death do you part; what else you gonna do? This has been a real bad time, I think. I love him to death; the dearest thing in the whole world...I have to watch over him. We love each other, been married over 20 years. He would do the same for me...the love. If Joe died tomorrow, I've done the very best that I can and I've improved and he's improved. You grieve forever...you're numb...this is because you care.**

Julia Frank said that "...caring comes from my heart. I don't even think twice about it."

And finally, Freda Grant said, "...But I like that old knucklehead. We are good friends...." Laura Ivan noted, "Showing love [in caring].... My sister, she doesn't stay here right now, but she comes over and sometimes she sees that I'm kind of tired. And she'll come over and give me a hug and tell me she loves me." Lena Ivan said, **"Well, to me caring is somethin' that an individual should want to do, cause that's a loved one."** Vera Ivan added, "[I] **guess it's just a part, my duty to care like that for family members.** I care for people like that.... I don't know who's going to have to care for me, and I would want to have good care, if I needed it.... I just feel good about my knowin' that I can help somebody."

In summary, motivation for caring was centered for most UFCs within love. However, for the Clark family, which had a history of anger and abuse, caring was obligation toward the care recipient. Rose related that without love, caring is like a man taking care of a child that he feels is not his; no bond is established. She went on to say that no bond existed between her and her husband. Caring for Rose and her children was seen as an obligation to the care recipient, as he had no one else to help in caring for him. All the other UFCs told of love, dedication, determination, and commitment in caring. Sometimes, there was a spiritual connotation woven through their stories. Even in the Clark family, the children supported caring efforts based on love for their mother. The stronger the values related to family, the stronger the sense of responsibility for caring by UFCs for the person with stroke. Julia Frank commented that caring came from her heart. Lena Ivan shared that caring is something people do because it involves a loved one. This motivation for caring provided stability in the family.

Caring Expression as Growth

Caring is self-development. By caring for the person with stroke, the UFCs learned patience and tolerance as they worked together in caring; this diffused their stress and anxiety. Personal insight led to self-development, and shared understanding led to family growth. Several quotations illustrate the caregivers' growth. Joan Beck commented,

> **At first, I thought, "Oh my God, how can we do this and work? None of us on welfare, how can we do this?" I found out that if you put your mind to it, you can get through it. I can work, still do this**

> **and have a life. [I] just go on. I didn't know that before. I learned that illness can be a positive. [The situation] taught all of us, including grandchildren. Younger people, taught them to look at their lives, that they are going to get old too.... The young can't imagine being old. Taught them about illness, that you do grow up, get old. Taught them about patience. Taught them to be more understanding toward senior citizens, older people, that you don't have to put them away, that you don't have time for them...taught them and me that my family is very diverse, but it's a pretty good family. [I learned to take care of self]...not to worry. Stress will kill you. It killed my father. I try not to let myself get stressed out. [I] read a book, look at a movie, go to the mall, walking and shopping...doing something in the house, whatever. It relieves the stress. If you find it's too much for you, do something that you like to get over that bad feeling that's coming up on you. Get on the phone and talk to somebody. But don't sit there and sulk in it. I learned to do this for self. I learned to be very good at it too. To relieve the stress, sometimes I exercise. You get involved in it, you get so tired that you just forget about the stress.**

Joellen succinctly noted, "**[Caring] has learned me patience. Learned me that everything is not going to go the way you want it to in life.**" Lee Beck said,

> **[that he learned]...Tolerance, to tolerate most of the time....** I don't do that side of it [the physical, bathing and dressing caring] usually. I just can't do that.... **[But I learned to] keep a level head and try to have patience, peace, and love,** you know. It holds your blood pressure down and your heart from racing from goin' to explode. We all have trials and tribulation, we all get tested....

Rose Clark also stated that the caring situation had taught her to have patience:

> **...And I have to have some kind of patience. God put you in a situation for a reason.... I have patience, but can only take so much and I'm learning now...if he says things mostly to me I'll just look at him and continue to read my book or something...not quick to respond.... You to have patience, endurance...you have to have patience for a lot of situations and it teaches you not to flip up.**

Gladys Erwin told the following story about what she had learned from the caring process:

> [You need] kindness rather than impatience and that's why being a stroke caregiver is not a burden. **[I've] learned that I didn't know that I had this much patience. I thought that I was the most impatient, selfish person in the whole world. And I found out that I'm not. I found out a lot about myself.** I've always had patience with animals. I can train a dog to do anything...but I got patience with animals, but I never had patience with people,

> because I thought they could know. They got a brain, they can think, they can reason. Dogs can't. I've always had more patience with animals than I did people. **Well, I found out that I've got an immense amount of patience [from caring for Joe with the stroke].** Repetition, repetition, repetition.... It doesn't drive me crazy, it's just like teaching a dog the things you want to train them. It's the repetition that's going to put the wrinkles in his brain. It's the repetition and consistency; do the same thing over and over and pretty soon that wrinkle will be permanent. I know these things. I've read everything I can read [about stroke]. I'm not a doctor, but I'm bright enough to understand. Yeah, I really found out that I had patience. I'm nicer to other people now, cause I found out. I would be quite rude. I always thought, they can take care of themselves, they don't need anybody. But I found out that he does, he desperately needs, he needs me to take care of him. More than he ever has in his life; always loved me, but now he needs me, truly needs me. It's the repetition and consistency.... If you don't expect very much, you don't get very much. I have learned so much....about me [that I have patience].

Marcus Frank said too, "**I don't say I'm learning anything but patience, patience, more patience.**" His daughter, Julia, said, "**You know you got to have a lot of patience**.... I think my momma had three or four strokes, so her memory is slow and she can't remember things. And the things you think she knows, she forgot."

Maura Ivan concluded and said, "Basically you got to be very, very patient. Very patient, I've learned [that]...." Vera Ivan noted, "...Caring is teaching me patience [and] long-suffering love."

In summary, the UFCs used the same words over and over again: They "learned patience and tolerance" from the caring situation. They told of learning survival or coping skills to deal with the caring situation. Joan Beck's story of reading books and going walking, shopping, and to movies to relieve stress related to caring was representative of the group. Many of the caregivers and care recipients developed increased tolerance and became closer as a result of the interdependence on each other. Joan Beck also shared that she had learned that even a stroke can be positive. She viewed the stroke as a lesson to the young children in the family what it is like to get old. Vera Ivan said she learned how blessed she was to be able to do for others. She realized that a stroke could happen to her at any time; she learned patience and long-suffering love from caring for her sister. These realizations furthered growth in the area of self-development for UFCs that had an impact on the growth of the family system.

Caring Expression as Control

Caring is fairness. Fairness was a dichotomy of viewpoints for the UFCs and reflected how family systems were controlled. For some, caring was perceived as fair and they were satisfied with the situation. For others, the caring circumstances were not fair and they felt disappointment. John Adams saw the rewards of caring:

> I do a lot for others.... Friends bring food in, so I gave a meal away to friends, poor people that came by...help fellow man...always comes back to me. My life to help others out...people pay me back now...wife's friend came house to do hair, not take any money. I had helped her in the past...these things work out. I help older people, poor people...is an enjoyment of living. I help [the friend] with things...I balance her checkbook...like to help people...do things that I can do...a lot of people help me out now as a result of that...people pay back, for example, bring in food and woman does Mary's hair. Feels good to know people like that...makes me feel good. [I receive back].

John was observed to help a male friend with an electronics project; in return, the friend helped take Mary to the doctor's office for a check-up. This friend helped lift the wheelchair down and up the steps of the home, because John was unable to accomplish this task by himself. John continued, "[Mary] took care of me and I'll take care of her.... Living from day to day...stuck by her as she stuck by me...best thing in life. **Happy with caring for Mary**...if I don't do it, she'd be in a nursing home. I wouldn't like it; she wouldn't like it."

Joan Beck described disappointment in caring for her mother:

> **Disappointed that sisters, that family members involved with her [mother's] care don't always take on the responsibility that I feel they should.** We have unfairness, then we sit down and talk it out. Sometimes I wish it wouldn't have to go to that point...but they are just people. I'm a little disappointed at that. I just wish people would be more responsible. Caring is not spread out fairly amongst the siblings. Three do most of the work. At first, we looked at this a lot, but then we realize...it be better if we just did it because things get mixed up and not done. So they do what they can and the rest of us just go ahead and take care of her. You get further that way than if you put something on somebody that doesn't know how to do it or don't have the understanding to do it.

Daughter Ann clarified her disappointment in caring, as she stated:

> **[I'm] not necessarily dissatisfied, but I think the boys could do more than they do; that the boys, the men, my uncles, they could do more. But I understand, they have a family and my uncles are all in their 40s. They were raised in the South. That meant that the men took care of the financial situation, the women took care of everything else.** And I can understand that's how my uncles think. But this is their mom, you got to put aside that stuff and come over here and take care of her just like the rest of us. OK, you're going to wallpaper her kitchen, that's fine.... But come over here and spend some quality time, just sit and talk with her.... It's [caring] not fair. But like I said, they all put in what they know how to do.

Brother Lee concluded, "Almost impossible to get things equal, nothin' is equal; that's OK. Life certainly is ain't fair."

Rose Clark and her daughter Silvia told about a sense of disappointment, unfairness, in caring. Rose stated,

> **Not very satisfied [with this situation of caring], not that much. Well for one thing, I guess, I got a feeling that he really don't want me here.** But he don't got nobody else to help him. That's sad. I feel like I'm being used and controlled.... To other people he's sick, but to me he's not. He still hasn't changed none. He's still evil.... It's [caring] a very unfair situation.

Daughter Silvia commented,

> **[Fairness] better to care to do the best you can do for him then be six feet under, cause some people don't have that. I call every day, but I'm not there half of the time.... [I] am mad about him blaming her for everything. I think he shouldn't do that. I think it's wrong.** If he be making it hard on her, she could have a stroke, than who to take care of him if she gets sick. **I'm not going...to take care of him. I'd take care of her but not him. I will not do that.... You need to talk to people like you want them to talk to you; it's not fair.**

Freda Grant said that caring was a mixture of fairness and unfairness:

> **Well, I got one member of my family that's really careless and inconsiderate and sometimes they think of themselves more than other members of the family.... I really do all of it here [caring].** Very seldom do I sees them [children]. I don't mess with their life. Whatever they goin' do, they do; I don't interfere with them.... **[But] sure it's [caring is] fair, cause don't have nobody else to help.... It's a give and take.**

Laura Ivan concluded, "...I feel good [about caring], but some days, well, here's another day and I got...more hurdles to go over.... Just think about it like that [now my turn to be caring for her]."

In summary, there were two viewpoints in caring for others expressed by the UFCs. In one respect, the UFCs felt a sense of fairness in caring. Here, they accepted limitations of other people in order to receive help. Simply put, families with good boundaries accepted limitations of support from other family members in support roles. The majority of UFCs were happy or satisfied in the caring situation. Most spoke about others helping them; and then in return, they helped them. For instance, John Adams said that he gave food away to friends but they helped him with the physical care of his wife. He believed that if you helped others, you received back help. In another family, Lee Beck commented that caring mirrored life. Neither were fair, but that was just how it is.

In other families, there was a sense of disappointment that all family members did not share equally in the caring process. Many stated that the women were to do and did more than the men. But even in these situations, they were "not necessarily dissatisfied." Other UFCs felt that caring for others was not fair. In the Clark family, Rose's and Silvia's comments were typical. They agreed that caring was not a fair situation. They participated in caring because they saw no other options. Silvia said clearly that she had no intention of caring for the father. So in the end, the children helped the mother; the mother continued in her caring for the husband with the stroke. Perceived fairness was an integral part in how UFCs viewed and controlled the family system.

Caring Expressions as Spirituality

Caring is a filial ethereal value. The UFCs worked together with a positive attitude and focused on what they still had to maintain family connectedness in the family system. While some dissatisfaction was voiced, caring for the care recipient was a family spiritual value for these UFCs. John Adams said, "Caring, not a burden...married 53 years...sweetheart [Mary]...care very much for her...keep her with me...." Many old and new pictures of all family members were displayed in the home. In addition, a framed placard in the living room said, "**As for me and my house, we will serve the Lord.**"

Ann Beck found ways to relive connectedness they had once experienced in their family:

> **[A situation that is satisfying to me is] when we talk about old times**. Like she can remember things that happened in the past. That's pretty good.... Stuff like that. But if you talk about, in my case, when I was little: **How we use to cook in the kitchen, take care of me; that's the most satisfying times we have now; when we are talking about the past**.

Rose Clark also described connectedness. She stated, "**In a way [caring is worth it]; it is, and in a way, it isn't. If you feel like you are wanted and needed, then it's worth it.** Happiness is seeing the person do what they weren't supposed to be able to do. That's the reward, to me.... That's the good part."

On observation, Rose Clark showed photographs of her children and grandchildren. The pictures demonstrated connectedness, in that families depended on each other for caring. Marcus Frank also agreed. He pointed to pictures of children on the table and said,

> **Little boy right over there is hers [his daughter's child]...children help, yes they do.... I feel good most of the time. And be thankful of being able to do what I am doin'. That's just the way I feel. I can be thankful.** I thank God for being able to allow me the opportunity to keep pressin' forward.

In the Grant home, old photographs of the Roy's parents were on the wall of the living room. Freda proudly pointed out numerous pictures of her children and grandchildren. While the family pictures did demonstrate connections to others in the family, these family members did not participate in the caring situation. Freda said,

> The children all work and have their own lives and don't really help her in caring for Roy. **[For me,] caring is a good experience; no burden. Good experience is just caring for Roy. He can do little things for himself but not that much. [Seeing him be able to do a few things], that's good.**

In summary, many informants commented how their family valued working as a unit in the caring situation. The warmth of family pictures displayed in their homes outweighed the coldness of their environmental surroundings; the pictures also indicated that they depended on family for caring and not on material things. The UFCs focused on positive attitudes; they focused on what they had and not what was not or gone. Ann Beck captured this feeling in discussing her grandmother's memory loss. There was a strong spirituality interwoven through family togetherness that maintained the family's identity.

Caring is self-contemplation. The UFCs were able to look within themselves and, through this contemplation, growth occurred for the family. They were able to find the intrinsic goodness of caring based on their Christian values. John Adams explained his acceptance of the caring situation that led to his growth:

> **Accept life as it comes...control some things, not control others...do what can.** Not discussed care of Mary with [own] kids...my decision...stay here as long as I can...married 53 years...sweetheart [my Mary]...care very much for her...keep her with me.... [These are individual values that impact the family as a whole]. **Happy with what I'm doing.**

They accepted life and kept going forward. They focused on rewards from the situation, as Jolee Beck commented,

> **What keeps me going, well, I keep saying one day I won't have all this to do. There is a light at the end of the tunnel.... So, we had to learn some things about ourselves. The fact that we could do this [caring for Mom].... Within a month or two, she was walking. And she got control of her bladder back.... I think to me to keep my mother here with us as long as we possibly can and to make her happy and comfortable as we possibly can. To me it's worth it.**

Sister-in-law Nancy agreed with Jolee Beck, "**I feel rewarded when I see other people happy. If I can give somethin' to somebody and I see somethin back in return, that they picked up, you know, then I'm happy.... Caring is worth it. Just like I said, everything together; seeing them how they achieve.**" Lee concluded, "The fact that the reward that I get from helpin' someone, OK. Plus it makes me feel good on the inside, OK. Also the fact that being this is my mother, you know, I'm glad to have her here for just this long."

Rose Clark gave the following account of self-contemplation:

> **I talk to God when I need someone to talk to....** I'm learning maybe God want me to learn to get out of this thing of on myself, cause I've had days in here when he's said things and I just sit around.... Sometimes your blessing comes from just feeling good. I just sat out on the steps this morning, look at all the birds...I thought about flowers and said, "God, you so are good, you are good. I praised Him and I looked at the bird and said you know, you are doing just what you are supposed to do. You are very obedient.... That's the reason that God takes care of you all, is because you do what He tells you to, to make music and sing they do." ...Some days I just go in the bathroom and have a good cry. I call the bathroom my praying closet. I say, "God, this is a ridiculous place to be.... I am your child...and you are my Father...." I remind Him of what He said, I talk and I come back out and say, "You want something for lunch?" Just like that...helps you get through it. No matter how, I'll never be as good as Christ. But it do make me think.... So I think He helped me reason to show you that sometime, no matter what you have to do, the best that you can do and you'll still be, you still ain't done enough. **So you just have to go on and do what you can do. And put it in for God, put it in His hands. I say, "Lord it's in your hands." I feel better.... Put your yoke on him and carry His, which will be lighter. He tell you to talk to him and give it to Him, a weary, heavy burden. Just give it to Him.... Happiness is seeing the person do what they weren't supposed to be able to do. That's the reward, to me....**

Ruth Dawn noted, "If I couldn't do it [caring] then I would probably be really miserable. I wouldn't have a meaning to anything. [Life] wouldn't have meaning." Gladys Erwin said, "I must [get something back from caring] or I'd be unhappy. I must...I don't feel that I'm put upon or anything...I feel great.... Never wanted to give up, never. [What keeps me going comes from within], it's me. Yeah, you do it [caring] because you want to." Marcus Frank added,

> I walk with a smile. It really helps me...to have a peace of mind, cause I get joy out of a lot of things that I do..... **[I have a] peace of mind, an inner reward. See, the blessings that you receive you can be more appreciative of the blessing. You can have that peace of mind.... [Caring is] worth it because of love. Makes it worth it to me because, let me see how I can say this, it's natural. It's family. And for family you do these things...cause that's all I've ever known. Family, you just do it, it's natural.**

And finally, Laura Ivan said, "...Learning to actually show how you really feel about the person when you care for them, how you really feel about them. At times it can be a real big burden, you know...." Lena Ivan said, "I like to see the smiles on their faces after I've been with you. That's it for me...that they appreciate what I do. They are happy with what I am doin'." Vera noted,

> **I think it's [caring] a good experience. Some people may think it's a burden. I think it makes us a better person. It makes us better to know how to treat people.... I love to help people. Rewards in caring come from others: a smile, a touch, a look.... It makes my life better each day. It makes me feel good, where I can lay down at night and I can go to sleep knowin' that I have done somethin' for somebody today; I can go to sleep in peace.**

In summary, their self-reflection grounded in their Christian values was a base for growth in the family. These values provided more validation that their actions made a difference for themselves, the person with the stroke, and the family. Most UFCs said that they accepted life and kept going. Many UFCs felt rewarded from the caring situation in that happiness was seeing the care recipient do something they were not supposed to be able to do. Vera Ivan felt that the reward for caring came from others: family and friends. Some UFCs shared that they received an inner reward from caring: peace of mind and love from God. With self-contemplation, a philosophical introspection, the UFCs were able to find the intrinsic goodness of caring.

Caring is motivation for a philosophical introspection. In addition to strong family ties, the UFCs also turned to God. The UFCs' motivation for reflecting or making a philosophical introspection about caring involved feelings of vulnerability. Faith in God made vulnerability tolerable and resulted in spiritual growth for the family system. John Adams started with:

> **From above...God...God gives energy and attitude to get through**...I don't allow to get upset; have past history of stomach ulcers.... **God is only thing in life that moves me...He will take care of me...satisfied with life...under control. [I don't] worry about things or wife...God take care of things in time.** Satisfied with caring...still here...[Mary] smiles a lot...makes my whole day. Dissatisfied with memory loss and confusion...don't dwell on it...don't like it...realize it's a mental thing with Mary's stroke.... God is love; most important thing/word...love fellow man and do what can do to get by [for them]...live that way. Some

> people are selfish...problems stem from that...most people are good.

Joan Beck and Mae Clark commented about vulnerability. Joan said, **I worry more than I used to.... Think positive.** What would be the sense of doing all this for nothing? [Got] to keep her in mind.... **May get better tomorrow. You never know....** Mae noted,

> Like I said, the stroke he had, he ain't going to die soon, because first he's got to pay for what he did. He's going to be punished for that, you know. I **think God's taking care of him. He can't move one arm, he can't drive no more, can't be out there messin' with those $2 prostitutes and come home talking crap. So...I think it was God's way of showing him, "I ain't going to kill you. I'm just going to make you a vegetable. When I get ready for you to go, you're going to suffer before you leave this world. Just like you made a lot of other people suffer."** That's why we don't fuss with him, we don't argue with him.

There were no guarantees for life and the caregivers looked to God. Ruth Dawn gave the following example:

> **God gives us most of it [energy].** I don't really think about it that much.... I feel good about what I do, because I know that the less worries she has the longer she'll stay [and not die]. She gives back to us so much.... She just gives so much...and the little things that we do don't amount up to what she does for us. I don't feel terrible or bad [about self], I guess OK.

Marcus Frank offered, "**I feel good most of the time. And be thankful of being able to do what I am doin'. That's just the way I feel. I can be thankful. I thank God for being able to allow me the opportunity to keep pressin' forward.**" Laura Ivan said, "Well sometimes I feel good, but some days, well, here's another day and I got...more hurdles to go over. Most of the time it's good. Today is not one of my good days [cries]." Maura noted, "**I feel that we've grown closer and a little bit more religious...a little bit more closer to the Lord through all my mother's ailments....**" Lena stated, "Caring gives you that good feeling that you are doin' somethin' for somebody." Vera Ivan concluded,

> I feel good [about myself] because I can get up myself and nobody has to help me up. I'm putting my own clothes on and get my shower. **I thank God that I can do all that.... We just take so many things for granted today and all of us, the little things, [such as] feeding ourselves, seeing, hearing we take for granted. These things are blessings and we should just count our blessings**

> **each day**. Takin' care of other people is taken care of me, I feel like it. I don't even want to do for somebody else; I'm takin' care of me. The more I do for people, I feel like I'm bein' cared for."

In summary, feelings of vulnerability provided the motivation for UFCs' philosophical introspection. This vulnerability increased when they perceived a decrease in the care recipient's mental or physical function. In order to make the caring situation acceptable, the UFCs reframed their values and the situation. There was no guarantee for vulnerability, so the UFCs looked to God. In simple terms, to cope with vulnerability in an unpredictable world, they used faith in God. Faith made the vulnerability tolerable in that the ultimate reward for the UFCs was heaven. They were very thoughtful and deliberate as they spoke. John Adams stated that he did not worry about his wife, as God takes care of all things in due time. In another family, Joan Beck shared that she worried more than she did before her mother had the stroke. She could not allow herself to think that her mother would not get better, although clearly her mother was not. Joan commented that her mother might get better tomorrow; you just never can be sure. The role of the care recipient was to try harder to improve. When this did not happen, the UFCs did not feel valued, and motivation for caring decreased. A story worth remembering is the vivid image told by Mae Clark: We are all vulnerable and only God knows the inevitable outcome. Spirituality was the impetus for caring. Most UFCs believed that they and their families were good; they had a good sense of self. The majority of UFCs stated that caring for the person with stroke gave them a good feeling. Others said that the more they did for the care recipient, the more they felt like they were being cared for in return. Their motivation for philosophical introspection was perceived vulnerability; the result was a spiritual, growth-producing process that affected the family system.

Caring is filial piety. The UFCs were proud to be part of their families. There was a strong spiritual connectedness as they worked together in caring. This connectedness, a filial piety, was also a means for control in the family system with regard to the caring situation. The Beck, Clark, Dawn, Frank, and Grant families described the essence of this connectedness.

Joan Beck commented, "**[Family] work together as a team...a team effort when giving care.... We were taught to work as a unit [togetherness].... Everybody [has ups and downs]...strong family. [We] survive and work together and keep going.**" Joanne Beck's granddaughter Ann described connectedness in terms of reverence for older family members:

> **Grandmother [is] like [the] backbone to keep everyone really close, tight knit.** Since she had the stroke, we haven't strayed away from each other.... It's brought everyone a little closer, cause you have to deal with these people every day now. **We've always just been a caring family and take care of each other when we are sick.**

Joellen and Ellen Beck agreed respectively, "We cover for one another...**the stroke has brought us closer [as a family]**. We work together in caring," and "**Cause we are all together.... Cause we are supportive of each other...I'm proud to be part of my family. We are supportive of each other. When one is having problems, we all pitch in and find out how to solve that problem. That's how we was raised, close.**"

Rose Clark noted how others in the family could be more helpful in caring for her husband:

> **Some could be more helpful...the kids.** At first, [the children] helped a lot. But after awhile, he wasn't supposed to be doing this good. He was supposed to be bedridden...he walks...he can get up when he wants to. But what it is, is he has got just so far and give up. He used to go down these steps [refers to the four steps leading into the home]. My boy put that rail up for him. [Kids and others have said] what you need to do is kick his ass...[they] say good luck...good luck. He's a handful.... They here not as much as they were when first came home...they have their own lives....

The Clark children told the following stories. Silvia said, "We [siblings] do it. Everyone do the best they can do...some live around here.... Mother is responsible for caring, she is there 24 hours with him, you know. **Everybody comes in....** Everybody in my family do the best they can do." Even with the anger and abuse that permeated the relationships in the family, they remained connected. Mae added, **"We had our downs when we were being raised by this man. [Now] our ups and downs is going over there and try to do for him, you know. Then you get cussed out.... We do what our momma need us to do."**

Ruth Dawn also said, **"[We work together, but] my brothers are more abrupt [in caring for Mom] and they just say it...I would say my sister helps a lot too...."** Marcus Frank noted too, **"Children help, yes they do.... [We work together as a group] to help Myrtle."** Daughter Julia stated, **"Everybody does their part; doin' it for...years.... We got to pull together like that."**

Even friends demonstrated connectedness. Freda Grant explained her friend's role in caring:

> I got a friend, Helen; she works. I don't bother her. If she ain't workin', she comes.... I have somewhere to go. I call this friend of mine. Sometimes she send her son over.

Friend Helen added,

> [Gladys and Roy] are my good friends. Both of them and my family, my sons, all of us are; we're just an extended family into their family.... See, we're that support for her [Gladys].... **We call her mother-dear, cause they know that I'm goin' be there for them...they know that.** Like I said, we all do it together, cause they can't do it alone. I wouldn't expect them to. Everybody just pitches in.... We have to do it together.

In summary, first, there was the initial crisis of the stroke. During this time, the family members pulled together and made the commitment to caring. Now, the UFCs work as a unit in caring for the care recipient. There was a reverence displayed among family members, as they participated in caring. In addition, this family piety based on spiritual values was a means for exerting control over family members. Nonetheless, there was a powerful spiritual commitment or connection as they told how pleased they were to be a member of their family. They shared examples of taking turns in caring for the person with the stroke. UFCs in support roles told of staying with the care recipient so primary UFCs could be relieved. In some families, the UFCs believed that children or siblings could be more helpful in caring for the person with stroke. Additionally, a few women, as UFCs, commented that the men in the family did less or participated in different ways in the caring situation. For instance, it was noted by more than one UFC that men did not share equally in physical or emotional caring. Men did not provide assistance with bathing, dressing, grooming, or toileting unless there were no alternatives. Some men did assist with cooking and cleaning, but this was not the norm; nor did the men sit and talk with the care recipients to provide emotional assurance or reassurance. What they did provide was home maintenance or a limited amount of money, and they were proud of this accomplishment. This, too, was a component of filial piety.

Caring is living in the moment and hoping for the future. The UFCs lived in the present and hoped for the future. Spirituality was reflected in their lives and hopes and reflected in the following comments. John Adams said,

> **Future will accept as it comes**...sit here and take care of her...not worry too much, just accept as it comes. Goal is to see new century in with Mary...I'll be able to...I want to see it with her.... What keeps me going...attitude on life ongoing living and understanding what life is....I didn't expect stroke...accept it...that's what life is.

Joan Beck commented too, "**[I'm] happy that she's still here and I am able to laugh and talk to her. She's not dead yet, can't walk that good and with her memory losses...but she's still here. A lot of people don't have their parents to talk to....**" Ann Beck said,

> **Hopefully, it will be better [in the future]...maybe. We're hoping that we can get her memory back a little better. Cause she's in the stage now to where she reflects a lot into the past. The extreme past. Maybe we can get her back a little ways before she had this last stroke. But all we can do is hope and pray and keep**

going and keep her happy and healthy.

Rose Clark said, "[In the future, I need] to be strong.... Hope the [future] will be better. Hope for myself it be better than this." Ruth Dawn said, "I just don't want her to be that way forever, because he has good years ahead." Gladys Erwin also noted, "[I need to be strong].... We've only got each other. That's it." Along these same lines, Marcus Frank stated that he did what he needed to do to continue to live:

> **The only thing that bothers me is sometimes she calls me all through the night. Now that do bother me sometimes but I still don't, you know, try not to say anything about it and just get on up. I be tired and sleepy and I have problems, too. It do bother me sometimes but I don't let her [Myrtle] know it. Try to keep it from her, because to me it shows weakness and I don't want her to think that I can't. I just feel like I should be strong for her, for myself and her.**

Louise Hughes commented, "It's very important not to give up. Not to ever give up on them. It's not over until it's over. And it's not over until they've taken that last breath." Dolly Ivan said, "**The Lord will get me through this. It is through Him that I am able to go on; we are in His hands. God is powerful; it is this power that makes me heal.**" She pointed to her "Jesus Loves Me" band on her arm.

Laura Ivan said, "I have no idea [what the future will be like; but it is important to have Mother here and to be caring for her in the home]. Right. True." Laura continued, "[Our religious beliefs are] what been keepin' us together so long...[God helps get through] umhum, right." Maura Ivan agreed, "**[Future]...well, I don't know. The Lord only knows that. I can't really tell.**"

In summary, the UFCs were able to live in the present and had hope for the future. John Adams said that he would accept the future whatever it turned out to be for him and his family. He related that in caring he does "not worry too much, just accept it as it comes." A few were hoping for realistic, and sometimes unrealistic, changes in the care recipient's physical and emotional states. All hoped the future would be better. Several UFCs commented that they needed to be strong and alluded to the need to be able to continue caring in the future. The UFCs usually did not share these concerns with the care recipients. Maura Ivan believed that only the Lord knew what the future would be like. Most UFCs hoped that God would get them through their caring situation. The majority of UFCs were grateful to have the care recipients alive, in that they were able to laugh and talk with them. Caring became a mission and purpose of the family.

Caring is purpose. The UFCs voiced a sense of determination or purpose in caring. Purpose was the personal interpretation of the UFCs for caring. Purpose gave the caregiver the opportunity to love, taught self-restraint, and led one to be a good person. The following stories are representative of the purpose the caregivers ascribed to their situation. For example, John Adams said, "**[Caring means my wife] smiles a lot...makes my whole day. [I'm] satisfied with caring...still here....**" Joan Beck said too, "**The purpose for me [in caring] is to give her the best quality of life she has left. [Satisfaction with caring]...it's tolerable. I would like it to be a lot better. It's manageable now. [Caring] it's worth it...she [Joanne] has a purpose in life. She don't have to be on anybody.**" Joan's daughter Ann commented, "I'm satisfied [with caring] because everyone works as hard as they can to do the best that they can.... **[Caring means] loving, sharing;** have to make sure that Grandmother lives out the rest of her life in a stable, family-oriented environment." Sister Ellen told the following story: "**[For me] caring means that you love the person enough to help them no matter what the situation might be. You put aside your own desires or whatever for awhile and you take on this extra responsibility and it goes beyond your feelings at that moment.**" Caring was a way to show love. Sister Jolee captured the essential intent of love:

> [I'm happy about the caring situation] the fact that she is still alive.... So just having her approval, her satisfaction is more than what I could ask for. My mother means a lot to me...and having her approval means more than anything [crying]. She is just the center of all of our worlds. And I love her more than I can say.... **Caring means love and giving of yourself and not to be selfish with it.** To me it means to give of yourself.

Dimensions of the purpose of caring were expressed by other families. Rose Clark said,

> **I find meaning and purpose [with caring]. Sometimes I think of it as [a] thing to learn you to have patience, endurance....** Not very satisfied [with this situation of caring] not that much. Well for one thing, I guess, I got a feeling that he really don't want me here. But he don't got nobody else to help him. That's sad.

Ruth Dawn commented further,

> **What would my purpose be if I couldn't give to someone, my mother**...if you can't, it's really...I wouldn't be a daughter, I guess if I couldn't. No meaning or anything. I'd really be drab and unhappy maybe if I couldn't give...feel like I was useless.... I would be just a blob. I guess I'd be doing things for myself all the time, if I didn't.... **[Caring is] maybe a happy feeling you get or satisfaction, just the happiness when you just feel real good. To be able to do things for her.**

Caring also meant giving of yourself to another. Gladys Erwin said,

> **[Caring means] you give of yourself, you care...give of yourself. My mother always said, "To have a friend you have to be a friend. That's caring. You...be a friend first." This is caring....** My husband is my friend, too. He would do the same for me if the situation was reversed. Caring is giving of yourself, that's what it is to me....

During the observation/participation session, Gladys said, "**[Caring] it's a 24-hour-a-day job with Joe. But caring is a celebration of joy....**" Caring was also viewed as peace. Marcus Frank offered, **[Caring means] a peace of mind and being able to understand others as well as understandin' yourself. Caring means I don't want to hurt you; means peace of mind and understandin'....**

In summary, many UFCs alluded to giving the person with stroke the best quality of life possible. Caring was hard work, but they were able to reframe their perceived purpose of caring to one of satisfaction and fulfillment. A few UFCs shared that caring was not related to satisfaction but rather patience and endurance. Nevertheless, all UFCs shared that caring meant loving, sharing, being there to help, giving of yourself, being at peace with yourself, and seeing the other person grow. There was a spiritual undertone in their lives and family that gave them purpose for caring. Gladys Erwin's comment that caring is a joyous celebration was representative of the group.

Caring is motivation from approval by the care recipient. The care recipients' approval of the caring provided by the UFCs gave motivation to the caring process for the family. The following comments are representative of this motivation for caring. Joan Beck said,

> **Determination gets me through the day, and prayer, the Lord...faith in God...helps you get through it all. It gets hard but it's not just the fact that it's my mother, my mother had a stroke, she doesn't want to be that way, she is the quietest, most gentle person I have ever known in my entire life...very determined...when I see her like this, if we can get her through another day of being with dignity that's what gets you through**...we fighting this disease, we are helping her, that's it. Determination, the fact we're not going to quit, to give up.

Joan's daughter added, "**My grandmother is a very humorous person.... You get that [reward of caring] wisdom; you get that quality time with someone who raised you. And it gives you a chance to give back; to help take care of them, now that they're in a time of need.**" Lee Beck commented, "**I know that my mother is thankful, OK.... The rewards I get is from myself from knowin' that I'm helpin'. It outweighs the sacrifice....**"

Ruth Dawn offered too, "**[Mother] does say 'I appreciate what you're doing.' But it's not really needed for her to do that or anything.**" Gladys Erwin noted, "[Bob, a family friend] makes me feel like I've done a good job [in caring for Joe]. You know, sometimes your ego needs it. I know you [Joe] tell me all the time but coming from Bob [means a lot, too]...."

Marcus Frank commented, "We joke a lot.... So she [Myrtle] laughs and we joke a lot. We have fun together...if it makes her happy, then I'm happy...." Freda Grant said, "[I receive back in return for caring for Roy] just his blessin'. [Important], yes, it is. He always said that he wouldn't know what to do if I wasn't around, cause he don't have no family here. Nothin'. Just go day by day."

The care recipient in only the Clark family did not value the caring provided. The caregivers were motivated, not by the care recipient but by the feelings of obligation to the family, to continue their caring. Rose's statement is indicative of this felt obligation:

> **[The children] they come and take him, just as long as they don't have to be cooped up together.... It's easy for them cause when he go through his rantin' and ravin', they can hust say, "See you and be back tomorrow." It's easy for [them] to tell me, "Rose, you ought to do this or that." But they all go home. I'm here.**

In summary, the approval of care recipients is what helped the UFCs get through the day and helped in maintaining their lives. This approval motivated the UFC and their family in the caring process. In only one case, Roland Clark was viewed as a mean person. Clearly, caring was not valued by him. Here, the UFCs felt that it was hard to go on with caring. Rose Clark commented that her husband "ranted and raved" so that other family members left the caring situation. She said that the children all go to their homes, but I am the one still here caring for him. And yet, the children returned to help this mother. There was resentment about the lack of gratitude or positive reinforcement for caring from the care recipient, but the children's love and duty toward the mother and family persisted even though the father was not accepted. Most of the care recipients valued the caring provided by the UFCs. Freda Grant captured motivation related to the care recipient's approval in that she received Roy's blessing for the caring that she gave. And because of his blessing, she was able to go on caring, taking one day at a time.

Caring is Christian piety. Nonetheless, when all else failed in the caring situation, the UFCs turned to God. Spirituality was an ever present force that guided their lives. In the Adams' home, a sign that hung in the living room stated, "As for me and my house, we will serve the Lord." John said, "**[I get energy] from above...God...God gives energy and attitude to get through.... God is only thing in life that moves me.... He will take care of me...satisfied with life...under control. I don't worry about things or wife...God take care of things in time.**" Joellen Beck said, "**My belief in God is stronger since mom had the stroke. God helps; we all prayed that Mom would get better.... God taught me to take one day at a time; this helps me feel better.**" Ellen Beck stated,

> **It seems like God has placed certain people in our pathway to help us with our mother. To me, religious belief is important...my situation, I feel that He doesn't give you anymore than what you can bear.... God gives me hope. If you don't have hope, what do you have? He gives you hope.... I think caring is worth it. Because as far as Mom is concerned, I think by her knowing that we care for her, it has helped her tremendously. Like I said before, it gives her strength to go on.**

Sister Jolee said,

> **God won't put upon you more than what you can bear. And sometimes you think, "Oh Lord, I'm drowning. But I know you said that you shouldn't give me more than what I could bear." And you have to hold on to that and maintain. We haven't drowned.** We pray that she doesn't perish or anything. We don't want the burden to be lifted by her death. Not at all. Rather maintain the burden then have that happen. I love my mother dearly without a doubt.... **I get a lot of it from [God]. I pray a lot.** I have a little Bible...I keep it with me...we have one girl that calls and leaves little messages on the phone, scriptures. I've been keeping track of all of them and I've been writing them down.... I write these down so that I can go back and read them [for example: do not worry about anything]. I keep these real close to me. So that helps a lot...I also have a list of things that I will never say again. I hang on to. I go to church faithfully and pray every night. I don't miss my prayers ever. I do take time out to give reference to the Lord at all times. Every night I set aside a time regardless of how tired I am.... Like I said before I feel like we are being punished. [To get over these feelings] I pray and I keep, I have this hope and I have this prayer that God is going to deliver us...not in the sense that He is going to have her perish but she's going to get eventually to the point where she can care for herself or close to that point where she doesn't need 24-hour-a-day surveillance. I keep holding on to that faith. You got to have

faith.

Rose Clark shared how prayer helped her to continue with caring:

> **[To get through the day, I use] prayers...go in bathroom...first I was having a pity party...why, why, and then I talk to God, just like I'm talking to you. I say, "God, you got to help me. I'm just a mere human. I'm not a super, God, but you know that, Lord. I'm your child. You know me from the tip of head to bottom of toes, you know me before I was born. You know what I can handle and it brings peace...."** Sometimes feel like I can't stand this man. He ruined my life. I have to take it to the altar. Do a lot of praying. I'm not over it. I have to revoke the devil in the name of Jesus...he has no power, no authority...I pray for both of us. I find we don't fight as much [now]. I believe in God, I talk to him a lot, I pray to him. [For] myself it stops a whole lot of darkness...I ask for that peace and He gives it to me. We had a prayer right in church, no talking, lay in aisles or sit up...I noticed, I saw, I prayed...prayers is important...I needed to cry...I felt better...thank you, Jesus. I believe this helps. If not have God in life, you just can't make it.

God helped Jake Clark go on with caring too:

> **I tell you, without the Lord in my life, me myself, I'm a young man, I just turned 30 years old, I feel very fortunate.... Like the old me was you accept pretty much whatever you get from society; whereas God blesses you to set goals in your life and you can believe that someday that you will accomplish this, accomplish that and if you really keep the faith and hang in there and really believe in yourself.... The only reason why I'm where I'm at is because I believe God is blessed me to get here.... It's difficult. It really is difficult. Without God in my life, I know I had many times when I felt like committing suicide, everything. It's like I've been blessed, fortunate with a wife and family. It keeps you strong.... Because I thank God that I'm able to do it. I feel blessed.... Cause I know that when you do good deeds and good things on other people, you reap what you sow. If you produce good I really believe that you're going to receive back good.**

Marcus Frank explained how the Lord helped him:

> **I think more spiritual feeling, cause I believe the Lord blesses me to be able to carry on as much as I do here in the home and for her.... I don't think I would be able to do it, if it wasn't for the goodness of the Lord. I depend on Him and He is merciful to me. I feel that way and that's the way I feel...[the Lord doesn't put on you] more than you can carry; more than you can bear. That's the way I feel.**

Freda Grant agreed and commented, "**I think God makes everything possible. Man only do what God has allowed us to. So that's it. He don't give you any more than you can bear. And you say, 'Oh my goodness, can I keep goin' on?'...God, God really help me make it through. A lot of**

spiritual, a lot of prayers." Louise Hughes said,

> **It's better to give than to receive.... More blessed to give. Church, prayer, religion-[Mother] taught us holiness with which you will see the Lord**...read scriptures, the Bible to her...to inspire her...use prayer to rebuke death and to change things...keep her here...my faith important. Oh yeah.

Maura Ivan concluded, "**Trust in the Lord and put everything in His hands.... He knows how strong you are. He knows how much you can bear. I do say that, cause God must know our family is very strong....**" Vera Ivan stated, "**My faith in the Lord is what really keeps me goin'. If I didn't have the faith to believe that. That's what keeps me goin' today...spiritual guidance. I go to church a lot, I pray a lot. That's how I get it, spiritual. I couldn't do it on my own.**"

In summary, the UFCs became overwhelmed with the caring circumstances and turned to God. Jolee Beck stated that she was "drowning" in the caring situation, but that she "prayed a lot." Caring was rewarded in religion. Jake Clark shared that "you get back what you give." John Adams captured the expression of Christian piety in that God will take care of "my life, wife, and entire family." There was a matriarchal hierarchy in caring, at times, in that the caregivers displayed martyred giving: The Christian belief that it is better to give than receive. The UFCs said again and again that it was better to give than receive. Religion values giving. Ellen Beck commented that God placed people to help them in caring for her mother. John Adams and Marcus Grant shared that God gave them the energy to carry on in caring for their wives. All in all, nothing in this world matched the promise of heaven and eternity; this was God's blessing for the UFCs. They had a strong, filial caring ethic related to religion. The majority of UFCs commented that God does not give you more than you can handle. Maura Ivan succinctly put it that "God must think her family is very strong," as they were dealing with many issues in caring for her mother. Many UFCs said that what kept them going was spiritual guidance; they prayed.

SUMMARY OF CHAPTER

A total of 24 UFCs of persons with stroke in African American families participated in this study; 8 were key informants and 16 were general informants from a community in the northwestern region of Ohio.

Eight caring actions and four caring family functions described the experience of caring. The UFCs said caring actions were **physical work**, consisting of ADLs and IADLs. True **sacrifice** occurred. The UFCs saw no other choices than caring for the person with stroke and, as a result, they put their lives on hold. Nonetheless, UFCs educated other family members in caring processes. Caring actions **taught** to **and shared** with other family members centered on physical and emotional changes in the care recipient. Caring in a **structured** manner was used by the UFCs to survive the situation on a day-to-day basis. **Communication** actions resolved arguments or disagreements to maintain the family system or to decide if change was needed, and arranged the processes related to caring. **Accommodation** consisted of UFCs making changes in their lives and environment in caring for persons with stroke. **Mutuality** was an interdependence displayed as a give-and-take process in caring relationships among all involved. The UFCs described experiences related to caring as **learned** in childhood. The learning process was repeated, as these actions were now being taught to others in the family.

Additionally, the UFCs cited their perception of how caring actions were incorporated into their family's functioning. **Adaptation in families** to maintain the system consisted of the UFCs using caring actions and making adjustments in dealing with the impact of stroke. Caring in the home was a highly prized and deeply rooted family value. The **adaptation in caregivers' enforcement of old values** consisted of adjustments made by the UFCs in their lives so that they could continue caring for the person with stroke in their homes. An **adaptation in**

caregivers' watchfulness, a new dynamic, was derived from the realization that the care recipient could no longer fulfill his/her past role obligations. The UFCs adapted a watchful vigilance in caring to try to keep the care recipient safe. The essence of **differences in filial function** centered around previous family relationships. How the family was able to function and grow depended on the level of interpersonal relations among the UFCs and others prior to the stroke event. Many spoke of love- and duty-based relationships in their families; others described obligatory relationships.

The meaning of caring was revealed via 13 caring expressions. **Emotional burden** consisted of an adjustment by all UFCs to mental confusion and memory loss on the part of the care recipient. There were conflicts in the families. The UFCs used **evasion of conflicts** to maintain stability in family relationships and resources. **Motivation from love and a sense of duty between caregivers, care recipient, and their families** involved love, dedication, determination, obligation, and commitment to caring that helped maintain the family. The UFCs learned patience and tolerance as they worked together in caring; this diffused their stress and anxiety. This personal insight led to **self-development**. **Fairness** in caring was a dichotomy of viewpoints. For some UFCs, caring was perceived as fair and they were satisfied with the situation. For others, the caring circumstances were not fair and they felt disappointment. While some disappointment was voiced, caring was a **filial ethereal value** in that the UFCs worked together with a positive attitude and focused on what they still had to maintain the family system. The UFCs were able to look within themselves and, through this **self-contemplation**, growth occurred for the family. With self-contemplation, a philosophical introspection, the UFCs were able to find the intrinsic goodness of caring. Feelings of vulnerability provided the **motivation for philosophical introspection**. Faith in God made vulnerability tolerable. **Filial piety**, a strong spiritual connectedness, was displayed as the UFCs worked together in caring. The UFCs were **living in the present and hoping for the future**. Most hoped the future would be better, as they continued to deal with current issues related to caring processes. Caring became a mission and **purpose** of the family. Caring was hard work, but they were able to reframe their perceived purpose of caring to one of satisfaction and fulfillment. **Motivation** for the UFCs came from **approval of care recipient** for the caring provided. This approval helped them get through the day and helped in maintaining their lives. When all else failed in the caring situation, they turned to God. **Christian piety** was expressed as God giving them the energy to continue with caring processes. With these results, the research questions are answered and linked to supporting literature in the next chapter.

CHAPTER 5

DISCUSSION OF FINDINGS

The results of data analysis were delineated in the previous chapter. In this chapter, a summary of the findings linked to the literature related to the demographic and ethnographis profiles and each research question is presented. The research questions are stated in bold text. The general discussion with references to pertinent literature is presented.

Summary of Demographic and Ethnographic Profiles

The families living in similar inner-city environments were satisfied with their surroundings. They were caring for individuals with stroke who were at different points in their recovery. Some care recipients continued to make physical, cognitive, and emotional progress, whereas others' conditions had stabilized. For several families, the length of caring was more than 5 years. These findings were similar to the work of Bronstein et al. (1991). The outside environment was barren, but their inside environment—homes and families—was filled with people united around the UFCs that was similar to the family caregivers described by Boaz and Hu (1997) and Stack (1974). In agreement with Lindgren (1990, 1993), Musolf (1991), and "What Do We Owe the Elderly?" (1994), the findings revealed that caring was predominately done by women as UFCs. The primary caregivers who were wives ranged in age from their late 50s and 60s, whereas the primary caregivers who were daughters were in their middle 20s to late 40s. The two husbands who were primary caregivers were in their middle 70s. As found by Bunting (1989) and Lindgren (1993), the older UFCs were dealing with or, in some cases, ignoring disease and chronic illness. In this study, the UFCs had vision problems, cancer, asthma, and mobility issues due to arthritis. The majority of men and women designated as secondary caregivers were younger; their ages ranged from the 20s to 60s. The commitment for caring for the persons with stroke in their family setting was based on a strong value held by these UFCs who had made adjustments in their lives and continued caring for the person with stroke no matter how difficult it was. This described commitment was parallel to the findings of Chatters et al. (1985), Hines-Martin (1992), Markson (1979), Martin and Martin (1978), Mitchell and Register (1984), Price (1994), Taylor (1985), Taylor and Chatters (1986), and Wykle and Segal (1991). To ease the burden, many used other family members, friends, and home care aids as personal care assistants. Some families had access to home care services through community agencies at a reduced cost. Adams (1980), Kinshef and Yeolin (1981), and Ward and Carney (1994) found that caring within families included financial assistance for needed services. In agreement with these findings, the UFCs indicated that family members had contributed to pay for assistance with caring.

The strategies for caring in all the families were similar, although their motives for their caring varied. Most UFCs' motives for caring centered around love and duty to the care recipient. Even in the Clark family, which had a long history of anger and abuse from the care recipient, their motive—love—was the same as the other families. The UFCs in the Clark family participated in caring because of love for their mother rather than the father who was mean-spirited and unappreciative. All the families displayed a strong sense of duty and/or obligation based on family commitment and a lack of choices that resembled the work of Stone et al. (1987). To leave caring to someone else was simply not an option. As one primary caregiver stated, "There is no one else to do it." In summary, these findings adhered closely to the literature in regard to the caring situation for low-income family caregivers.

Research Question One

The Experience of Caring

The first major research question for this study was: **What is the experience of caring for UFCs of persons with stroke within their family system?** Caring as experience was demonstrated by two domains, caring actions and caring family functions (see Table 2). These assistive or enabling actions based on cognitive knowledge and without regard to successful or problematic outcomes occurred between UFCs and the person with stroke in the context of their family system. On a concrete level, families worked toward Friedemann's (1995) abstract systemic targets of stability, growth, control, and spirituality by activating observable actions and functions. The caring actions and caring family functions occurred within Friedemann's four process dimensions of system maintenance, system change, coherence, and individuation for the UFCs within their African American family setting.

System Maintenance

All in all, the UFCs used physical work at a personal level and together with others at an interpersonal level to maintain the care recipient's ADLs and IADLs. The UFCs sacrificed. For example, entire families put aside things that they needed to do, as they saw no other choice, and structured their daily lives with the caring actions the care recipient needed. Additionally, they taught and shared caring actions to and with others to preserve the caring situation for their family. Communication was important in maintaining the family system in caring. Through communication with others involved in caring, the UFCs were able to structure or organize caring process, solve problems, make decisions, and deal with time management issues. The families adapted, but they also persevered. The UFCs incorporated changes in care recipients' function to keep going with caring processes in their home. This caring in the home was an adaptation in the caregivers' enforcement of long-held values. Thus, they maintained their family system (Friedemann, 1995).

System Change

Communication was used by UFCs to determine if change was needed. System change (i.e., a significant reorganization of family values, attitudes, and behavior patterns) was present but evidenced to a lesser degree than was system maintenance for these UFCs (Friedemann, 1995). In actuality, system change occurred in the past for many of the UFCs, as some had been involved in the caring situation for 5 or more years. Nevertheless, there was accommodation. All UFCs reported how they accommodated or changed due to feelings of love, duty, or obligation. For instance, UFCs had given up personal freedom to meet the needs of the caring situation. The caregivers' watchfulness also indicated adaptation. The entire family was changed with the use of a sense vigilance in making sure the care recipient was safe at all times. The UFCs controlled their caring situation with change and thus promoted system maintenance.

Coherence

Mutuality, a sense of togetherness defined as coherence or emotional bonding and caring relationships among family members, was seen among the UFCs. Coherence for the UFCs was a cultural expectation and a value present within these African American families (Friedemann, 1995). All UFCs worked with others in give-and-take relationships in caring for the person with stroke and they demonstrated a strong sense of family unity. Even in the family that had a history of anger and abuse, mutuality occurred between the mother and her children in caring for their father. Perceived differences in filial function were driven by prior relationships based on love and duty or obligation for the families. Yet the outcome was the same in all families: caring for the person with stroke.

Individuation

The UFCs were expected to unite and take care of one another, a value they learned growing up in their families. They individuated in that behaviors were used to gain new knowledge and insights (Friedemann, 1995). The UFCs learned about the care recipient's medical health status from their physician. Most UFCs learned caring from other family members, whereas a few learned caring from professional nurses and the media. Other sources of learning about caring were not utilized by these families. They individuated and changed, then stabilized again. The families evidenced coherence as well as spirituality and stability as a result of the individuation process.

Caring Actions and Process Dimensions

What are the perceived and observed caring actions of UFCs of persons with stroke within their family setting in regard to Friedemann's (1995) four process dimensions of system maintenance, system change, coherence, and individuation? Specifically, the caring actions consisted of eight subsets. In the final analysis, each subset was drawn to Friedemann's Framework of Systemic Organization (see Figure 3 and Table 2). This section discusses the caring actions found in each process dimension.

System Maintenance

Caring actions (caring is physical work, sacrifice, taught and shared, structured, and communication) were centered in system maintenance. The UFCs of persons with stroke maintained their family system with these actions aimed at stability and control of the family situation (Friedemann, 1995).

The actions associated with ADLs and IADLs, referenced as instrumental caregiving by Bowers (1987), represented significant obstacles for the UFCs. The UFCs said that caring was physical work, focusing on ADLs such as bathing, dressing, grooming, and toileting. The

ADLs involving personal caring were the hardest physical work mentioned. Additionally, caring included other physical actions—IADLs such as shopping, paying bills, making appointments, and arranging for services for care recipients and their families. These actions were somewhat lighter than the ADLs involved in caring, but they were strenuous, too.

Commitment and support actions to assist care recipients with tasks of daily living were considerable for family members (Payne, 1988). The UFCs and their family members received their medical care in clinic settings affiliated with hospitals (Spector, 1991). The UFCs assumed difficult new roles and responsibilities previously carried out by the person with stroke (Grant & Davis, 1997). One family commented how hard it was to just get to the clinic. The UFC did not drive and her husband was unable to drive due to the results of the stroke. Because regular bus service was impossible for the care recipient to negotiate, they took a cab. Once there, the cab left them with no way to return home. The wife said that she did not know what the doctor found because she was too busy arranging for a cab ride back home. The cab never arrived; the wife had to call her son to provide transportation for them. The researcher accompanied two different families during the observation-participation sessions to doctor's appointments. With the first family, the physician never even removed the care recipient's coat during the checkup of listening to her heart and taking a blood pressure reading. This physician and a resident talked among themselves and literally over the heads of both the UFC and the care recipient. The UFC commented to the researcher later that he was not dumb. For the second family in this example, the researcher provided transportation to the appointment. Here the physician sat with both UFC and care recipient in discussing answers to their complaints; however, the physician's suggestions were rather prescriptive in nature and did not get at the heart of the matter. This researcher was left with thinking that this physician did not truly know what this family was dealing with or what they really needed in the caring process. Caring was overwhelmingly difficult at times for the UFCs.

The UFCs of persons with stroke spoke of sacrifice. The sacrifices made were due to limited choices from living in poverty and cultural values that formed the UFCs' expectations for daily survival in caring (Boaz & Hu, 1997; Stack, 1996; Ward & Carney, 1994). True sacrifice occurs if, and only if, the UFCs would rather not extend themselves to others. The underlying truth was that there was no other recourse for the UFCs; this in itself was a source of resentment that flared up at least occasionally (Ward & Carney). This contradicted doing caring for love, which is in accordance with their cultural values, and led to ambivalence and conflict. Ambivalence and sacrifice were greater where there was resentment toward the care recipient and conflict in the relationship (Stack). Overall, the sense of duty identified as a reason for caring was a strong factor in sacrifices made by UFCs (Nkongho & Archbold, 1995). Some UFCs said the whole family "did a lot of sacrificing" in the caring situation to evade conflicts. With caring, the entire family tended to put things aside for another time. Some UFCs mentioned that their whole life was affected by the stroke event. Sacrifice involved not being true to one's own feelings. This became severe where love was replaced by obligation. Basically, however, for most UFCs, caring was congruent with their cultural values of family and togetherness and, therefore, was not a genuine sacrifice.

Caring was taught and fostered as a part of culture (Noddings, 1984; Watson, 1988). The UFCs felt that caring was important and needed to be passed on to others in the family. These actions maintained the family system (Friedemann, 1995). They instilled in their children the value of caring for others. The UFCs were teaching to and role modeling for family members about physical caring and supporting one another.

Caring, for the most part, was linked to tried and true accomplishments and social connections previously established by the

UFCs (Noddings, 1984; Watson, 1988). Caring was structured in that a routine was developed by the UFCs that helped maintain their family system (Friedemann, 1995). Caring routines were integrated into their daily lives. This structured routine for caring became part of the coherence that fostered system maintenance. All the UFCs used good organizational skills to survive day-to-day in the caring situation. They shared schedules and plans developed in their families that enabled the caring process; they worked together. Some told of "coordinating" everyone in the family; all family members participated in a caring schedule. The motives behind the caring actions varied for some UFCs of persons with stroke. Two UFCs told of routines in which they ignored the wants and demands of the care recipient. They just did what they had to do in caring and got it over with in the quickest manner.

Communication was a caring action utilized by the UFCs that helped to maintain their family system or to decide if change was needed (Friedemann, 1995). In structuring the caring processes, the following comment was representative: "Communication is important when so many are involved in caring" so that everyone can arrange their schedules. Communication was also an important organizational skill that was used to settle arguments and disagreements in caring. The UFCs talked it out; they worked out a plan so that caring continued. There was a lot of communication in the families.

System Change

Caring involved a human interpersonal connection; it was an interactional process for the UFCs (Leininger, 1988). In this way, communication by the UFCs facilitated control of their family system not only through system maintenance but also to decide if system change was needed (Friedemann, 1995). Communication needed to solve problems in caring was affected by the UFCs' coherence, and in reverse, communication had a significant effect on family coherence. For example, one daughter clarified communication processes in deciding to make changes in the following manner:

> We usually pull things back in life...Sometimes they get off track, get back on track. That's what I meant by being determined...I've been sick, my own personal problems, all this going on at the same time...easy to say I won't do it...easy to give up and start crying. Well, if you stop nothing gets done. So I just hammer it out [talk it out], take care of this, that, take care of this right now, just work through it.

Their communication style was direct and open; they were pragmatic, no-nonsense people. The communication skills used led to good problem solving, time-management, and decision-making processes. Communication was a way to make decisions for change and accommodation.

Genuine system change, according to Friedemann (1995), refered to significant alterations of system operation with repercussions for the family value system that require cooperation and agreement among all family members. The only real change exhibited by these caregivers was in their caring actions in order to accommodate to the caring situation. Sometimes, very painful realizations of the irreversibility of the effects of stroke and subsequent change of family cooperation led to a kind of new stability. Many changes happened early on in dealing with the effects of stroke; the UFCs and their families, had already reestablished their family system.

Nonetheless, the UFCs told about making accommodation in their lives relative to the caring process. Accommodation differed from sacrifice in that the UFCs willingly gave of themselves in caring for the care recipient. In other words, they agreeably adapted to the circumstances of caring to help control the entire caring situation. The UFCs placed more emphasis on evasion of conflicts and gave more weight to the importance of spirituality (Smerglia et al., 1988; Wykle & Segal, 1991), as they accommodated to one another. They told of losses they needed to accept (Grant & Davis, 1997). One daughter cited loss of freedom as a result of having her mother at her home every weekend; a brother told of the loss of his personal privacy. The UFCs made the commitment to family and gave up some independence; this was a conscious decision and signaled a change in their priorities. A positive consequence from this accommodation in commitment to family was that they realized they enjoyed each other's company (Farran et al., 1991). Sometimes, their roles became reversed as children acted as the parents in caring for the care recipients (Bowers, 1987). Several spouses mentioned alterations in sleeping arrangements as a problem. Because of the stroke, they slept apart from the care recipient. Even when the care recipient was doing better, the needs of the care recipient represented first priority. Some UFCs actively accommodated and supported the care recipients by covering up their functional inabilities and the importance of the caring support they provided. In many respects, the UFC became the parent and the care recipient became the child. Protective caring occurred for UFCs when the parent or spouse were unaware of the reversal of roles. Protective caring included carefully orchestrated activities to appear to keep the parent-child relationship intact (Bowers). System change for the family occurred, while the result for UFCs of persons with stroke was system maintenance, as roles shifted permanently. The care recipient's dignity was preserved by maintaining the status and respect the parent or spouse deserved.

Coherence

Caring by UFCs was an interpersonal process of mutually working together for the family (Watson, 1988); a coparticipation of those involved in caring processes occurred (Leininger, 1991b). Through mutuality, the families were maintained. Friends also took on roles for caring in the family. These friends were like family; this contributed to family coherence (Friedemann, 1995). Family members watched over one another and provided moral and emotional support in a give-and-take relationship. In these ways, they demonstrated family coherence and contributed to the stability of the family. Family and friends worked together in caring.

Friedemann (1995) denoted mutual caring under the process dimension of coherence for the family system. The families gained coherence through providing emotional support for one another. Relationships were characterized by mutuality in the power relationship. In successful caring, the caregiver and the care recipient benefited from the caring actions, and both experienced rewards (Watson, 1988). Such dynamics were evidenced even in the family with a history of anger and abuse. Mutuality was observed in and verbalized by the UFCs and the mother. These children helped the mother both physically and emotionally in caring for their father; they displayed love and a sense of duty to her.

Individuation

UFCs gained coherence through caring for the person with stroke; they individuated by gaining new insights, changing their priorities, and re-examining their values (Friedemann, 1995). The meaning of caring was learned by the UFCs in their family situations. Caring was a primary value that grew out of the natural caring experienced by UFCs in childhood. The UFCs continued caring due to a natural imperative to care based on learned values (Noddings, 1984). In addition, the UFCs and their families fostered caring processes (Watson, 1988). The UFCs told of learning caring from mothers, siblings, and other family members as they grew up. One daughter captured this action by saying, "[We were] raised to be caring...learned from mother and siblings." Other UFCs said they also learned caring from health professionals and even television. Individuation on the family level occurred through sharing of learned values, teaching each other skills, and helping each other to see these actions as something meaningful. Thus, individuation enriched the families and facilitated needed changes. Many UFCs said they learned to work together in childhood; this value of togetherness carried over into their adult lives. They were still teaching each other in that actions for caring, such as successful strategies for ADLs were shared. The UFCs' actions for caring resulted in giving purpose to their lives.

Caring and Family Functioning

What are UFCs' perception of how caring actions are incorporated in family functioning? The UFCs verbalized their thoughts about how their families were able to function as a result of the caring situation. Thus, they shared numerous ways the caring actions displayed in Table 2 were incorporated into their family's system.

The ways in which the UFCs of persons with stroke and their families developed, functioned, and continued to grow were perceived by the caregivers to be driven by prior relationships. Caring originated from the ability of the UFCs to be open to the needs of the care recipient (Buber, 1965). Most UFCs addressed these needs and engaged in an active interchange with the care recipient that sustained the caring process. Through this interchange, family systems were maintained and eventually growth and changed occurred (Friedemann, 1995).

Nonetheless, there were differences in filial function. Basic to any approach to caring is the relationship of the caregiver to the care recipient (Vezeau & Schroeder, 1991). The majority of the UFCs told of working together, coherence, and spoke of love and duty in implementing caring actions (Friedemann, 1995). The UFCs who experienced a positive relationship with the care recipient had less tension or anxiety because they found caring inherently meaningful (Archbold et al., 1990). Likewise, lifelong family caring relationships were experienced as sustaining and purposeful (Chesla, Martinson, & Muwaswes, 1994). On the other hand, for a few UFCs the caring relationship depended on the strength of the felt obligation, commitment, and affection that varied in intensity and duration (Noddings, 1984). This relationship involved power. In one family that had a history of anger and abuse, the wife, in instituting caring actions for her husband with a stroke, functioned on the basis of cold obligation and little affection. She thought that she was controlled and used by the care recipient. And yet, she stayed in the relationship because she believed there was no one else to care for her husband. The children loved the mother and displayed Friedemann's coherence in that they helped her with caring for their father. Family togetherness facilitated growth, as the UFCs examined and used the caring actions.

Caring and Changes in Self and Family

What are UFCs' perceptions of how changes in themselves and in their families occur with these caring actions? The UFCs shared their view of how their individual adaptation and change that occurred with caring influenced their family's functioning. The UFCs were introspective as they spoke using a variety of words to describe the caring experience. The UFCs' remarks in the subsequent paragraphs drawn to Friedemann's (1995) process dimensions depicted in Table 2 are reflective of these data.

The stroke event for care recipients modified the families' situation, and there was adaptation in families as a result. The UFCs used control strategies to minimize the impact of change. Change seemed to be a part of their family script. As Friedemann (1995) noted, the flexibility to change belongs to system maintenance. If a family values flexibility and expects disruptions of family process as normal occurrences, changes come about easily and there is no need for true system change. The system, adaptive as it is, is maintained by making necessary adjustments. The following citations support this phenomenon. The UFCs perceived their lives and their families' lives to be altered and, yet, no genuine changes were identified. One husband said, "...The way things work out are just about the same. No different to it." In another family, a daughter agreed that while they had rearranged their work schedules in caring for their mother, "life was pretty much the same...just keep goin'." New scripts were written for old values (Stack, 1996); the UFCs did not think their system had really changed

(Friedemann). Instead, their system was perceived to be maintained by continuous adaptation to the caring situation. Caring was an intentional human enterprise and an action mode that maintained and eventually changed family systems (Gaut, 1986). System maintenance happened in a continuing cycle over time through system change. Compromises were made by UFCs in all the families.

The caregivers perceived great worth in providing caring processes in their home settings. This resulted in an adaptation in the caregivers' enforcement of old values with regard to caring in the home. These values demanded an adjustment in personal patterns for the good of the family. The UFCs placed great significance on caring that was energized by love and obligation (Stack, 1996). Coherence relevant to system maintenance was evidenced by the UFCs and their family members as they worked together in caring for the persons with stroke in their home settings (Friedemann, 1995). Kin work was paramount in these African American families (Adams, 1980; Boaz & Hu, 1997; Kinshef & Yeolin, 1981; Stack; Ward & Carney, 1994). For these UFCs, placing the care recipient in a nursing home, even if it was affordable, was not an option (Picot, 1995; Stack). Sending the person with stroke to a nursing home was equated to death for the care recipient. A daughter captured the essence of all the UFCs' thoughts when she said,

> We [siblings] developed this plan when Mother first had her stroke. She is our mother; she would not like being in a nursing home. She is a fighter; she would give up if in a nursing home. If we had put her in a nursing home, I think she would be gone...given up. Family is important to all of us.

Nursing home placement was an option only to save the life of the UFC. For the one family in this study who dealt with a care recipient who was mean and angry, nursing home placement was suggested, as his behavior was adversely affecting the primary UFC's health. If nursing home placement was to occur for this family, this would be an extensive initial system change for the family system. However, placement was just one way to control the situation and reestablish a quality family life

(Friedemann). UFCs adapted new ways to old family values (Stack).

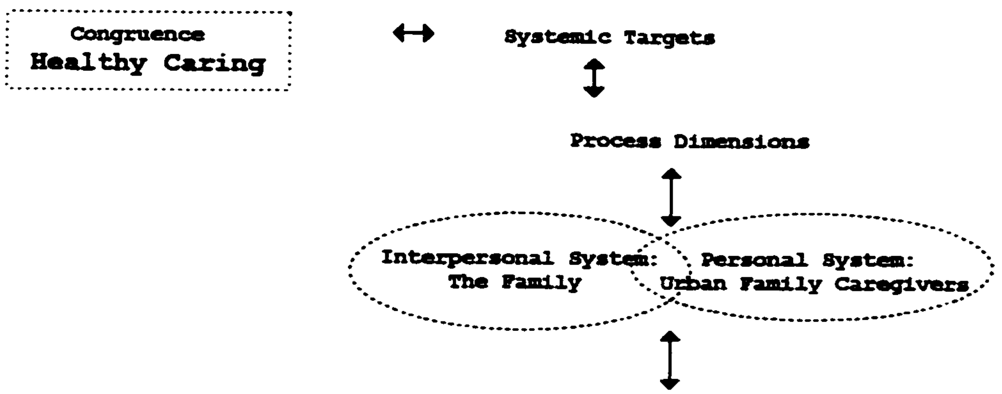
Overall, the UFCs evidenced system maintenance targeted at stability and control, as they worked together to keep the care recipient safe and in their homes (Friedemann, 1995). The UFCs not only believed that the home, rather than a nursing home, was the best place for their afflicted family member but also that they needed and expected more help in caring for their family member (Kelly, 1994a; Picot, 1995; Wykle & Segal, 1991). There was an interdependence among family members. Their support of one another facilitated individual and family maintenance (Friedemann). Table 4 presents recommendations for healthy caring by UFCs. These strategies further explained Friedemann's Framework of Systemic Organization by the UFCs of persons with stroke. The composite of self-maintenance strategies for healthy caring, used by the UFCs and presented in Table 4, are holistic in nature and suggest thoughtful and commonsense ways to promote healthy caring. The intellectual, social, physical, and spiritual strategies implemented by UFCs affect the family and help maintain the system.

System change is a realization that the family is no longer the same. The watchfulness displayed by the UFCs seemed to signify the first sign that this was occurring. The change involved the acceptance of the disability as permanent and a role shift that was irreversible. The process was painful. Change vacillated with denial (e.g., Will the care recipient get better?) a clinging to hope, and the realization that this was going to last. Watchfulness showed that reality had sunk in. The UFCs' behaviors followed this realization. A shift occurred from interdependency in the relationship to dependency of the care recipient, resulting in vigilance of the UFC. Through watchfulness, UFCs made sure that the care recipient was safe at all times. This was an apparent change for the entire family as all members participated in protecting the care recipient. UFCs displayed in one caregiver's words "a watchful vigilance" over the care recipients. Vigilance was described in the

Table 4

Recommendations for Healthy Caring by Urban Family Caregivers of Persons with Stroke and the Framework of Systemic Organization by Friedemann (1995)

Framework of Systemic Organization



Self-maintenance Caring Strategies:

Intellectual

- Plan a daily routine
- Reason and look for answers
- Read
- Watch television or movies
- Listen to music

Social

- Take time to relax
- Call someone on the telephone
- Make plans to go out
- Use respite of other family members
- Do something fun
- Visit close friends

Physical

- Find some place to go, like shopping or the mall
- Go walking
- Maintain good nutrition

Spiritual

- Reflect on your feelings
- Say prayers
- Read the Bible
- Ask God for strength

literature by Bowers (1987) as protectiveness on the part of the caregivers. The UFCs were ever observant of the care recipient. The care recipients were never left alone, as the family realized that they made unsafe decisions regarding their physical and cognitive skills. Only if the UFCs thought care recipients were safe in their surroundings did they leave the house for a period of time. Even then, they frequently called the care recipient on the telephone to make sure everything was all right. The family worked together in providing this watchfulness.

Synthesis

In brief, to work toward determining if health exists, the behavior patterns, caring actions and caring family functions, that fall within the process dimensions were observed. The UFCs and the family practiced at least a few behaviors relative to each process dimension of system maintenance, system change, coherence, and individuation and, in this respect, they were considered healthy. While the emphasis within each dimension varied among families, their processes did not produce overwhelming anxiety with systems in their environment, and most members expressed general satisfaction with the family situation (Friedemann, 1995). To truly examine if health existed for these UFCs and families, congruence must be examined.

Research Question Two

The Meaning of Caring

The second major research question for this study was: **What is the meaning of caring for UFCs of persons with stroke within the family system?** The results of the ethnographic data analysis, displayed in Figure 3, revealed that the meaning of caring centered in one domain: caring expressions. The UFCs' caring expressions concerned how they interpreted or explained their caring situation, specifically, how the UFCs adjusted to individual differences, respected each other's opinions, and maintained their relationships with family members. The caring expressions shared by the UFCs included 13 subsets exhibited in Table 3. Each subset was drawn in the final analysis to the systemic targets of stability, growth, control, and spirituality in Friedemann's (1995) Framework of Systemic Organization.

Stability

There was an emotional burden connected with caring that caused incongruence. This was displayed as pain and disappointment with the care recipient's mental confusion and memory loss, which caused the family members to change roles. Daughters and sons took over the role of parent for their mothers and fathers. The caregivers grew into new roles. Family growth was always secondary to change in individual family members. Congruence among family members and with the environment was a difficult task of finding a balance between growth and stability (Friedemann, 1995). In this respect, UFCs showed incongruence, as little true growth occurred. Mostly the UFCs demonstrated stability.

In addition, congruence for these UFCs focused on stability of their lives by evading conflicts that were not beneficial among all parties concerned in caring for the person with stroke. In most families involved in caring processes, conflicts dealt with the structure of caring (i.e., who was going to do what and when). Here, the majority of UFCs picked only those issues deemed important enough to defend their position. If the issue was not important, they accepted the others and/or the events and simply turned their attention to other more pressing matters. At first glance, evasion of conflicts may not be considered healthy; however, when used in this way, it actually promoted satisfaction for the UFCs. For the one family with problems related to anger and abuse as well as the consequences of stroke, they differed in use of evasion of conflicts. These UFCs suppressed issues of long-standing, unresolved problems that had an impact on the caring situation (e.g., the wife wanting to leave the marriage). They did not frankly discuss any conflicts in an open problem-solving manner with the care recipient, as he was unable to fully understand since his stroke. Suppression did produce stability of the family system, but only for short periods of time. This was not healthy, and conflicts continually erupted between the care recipient and his family. Although they used suppression with the care recipient, nevertheless, the UFC and her children were able to problem-solve together using open communication skills that were healthy for all involved. The motivation of love and a sense of duty between caregivers, care recipients, and families occurred for most UFCs. For the family that had a history of anger and abuse, caring was centered within obligation toward the care recipient. They felt there were no other choices. Nonetheless, even in this family, there was love and a sense of duty among the UFC and her children. All UFCs told of love, dedication, and commitment to caring processes. Strong evidence of stability related to the caring circumstances helped maintain the UFCs' families' coherence and system (Friedemann, 1995).

Growth

Congruence was also established with self-development by the UFCs that facilitated growth (Friedemann, 1995). The UFCs repeatedly told of how they had developed patience and tolerance from the caring situation. This diffused the stress and anxiety they felt. Patience and tolerance became their survival skills.

Control

Many UFCs perceived a fairness in caring. The UFCs controlled the family with expressions of fairness (Friedemann, 1995). When fairness was apparent, they voiced a sense of growth and satisfaction with caring. UFCs in families with good boundaries accepted the limitations of support from others. Nonetheless, incongruence came about when some UFCs thought others could do more to help with caring. For the family with anger and abuse in their lives, the wife and most of the children stated that caring was not fair. They stayed in the situation because they perceived no one else was available to do the caring.

Spirituality

Through spirituality, the UFCs felt congruence, connected and comforted in difficult times related to caring (Friedemann, 1995). Caring for the person with stroke was a filial ethereal value. They focused on what they had, not what was gone. Through self-contemplation, the UFCs looked within themselves. Based on their Christian values, most accepted life since the stroke event occurred. Many felt rewarded from the caring situation; happiness was seeing the care recipient do something they were not supposed to be able to do anymore. They were able to find an intrinsic goodness, an inner reward from caring: peace of mind and love from God. The UFCs felt vulnerable, which was the impetus for philosophical introspection. They were able to reframe their values and situation to make caring acceptable. Their faith in God made their vulnerability tolerable in that the ultimate reward for the UFCs was heaven. Threats from the environment were collectively reduced and energy carefully channeled to gain congruence. Control, to be effective, must be based in spirituality (Friedemann). This occurred for these UFCs.

There was a filial piety in all these families in that they worked together to accomplish what needed to be done in caring. They were living in the moment and hoping for the future. While most UFCs were grateful to have the care recipient with them, all hoped for realistic and unrealistic changes in the care recipients' physical and emotional status. Even in the family with a history of anger and abuse, there were hopes for a better future. All believed that God would support them in caring for the person with stroke. The purpose in caring for all UFCs was loving, sharing, giving of yourself, being at peace with yourself, and seeing the other person grow. For many, motivation involved the approval of the care recipient, as this person valued their caring for them. For all, there was a Christian piety. As they all became overwhelmed, they turned to God. Caring was rewarded in their religious beliefs. What gave the most feelings of congruence for the UFCs was satisfaction with spirituality.

Synthesis

These caring expressions, abstract in nature, happened within Friedemann's (1995) systemic targets of stability, control, growth, and spirituality. Through caring actions and caring family functions pertaining to the process dimensions, the caring expressions became evident for the UFCs and took on meaning and provided understandings of their caring situations. The caring expressions were associated with the systemic targets of the family process. Thus, congruence, a balanced interaction of the systemic targets felt as satisfaction or health, gave definition to the entire caring situation for the UFCs of persons with stroke (Friedemann). These UFCs within their family systems were generally healthy. Their strong spirituality served as counterpoint for health. However, there were areas for improvement. Rather than just continuing to make adjustments in dealing with the emotional burden associated with caring and to continued with evasion of conflicts, the UFCs and the families needed to make changes and grow from it.

Congruence and Incongruence with Caring

What are the perceived and observed personal and family congruence in regard to caring: (a) pain and disappointment versus personal growth and enrichment, (b) conflicts versus mutual support, and (c) meaning concerned with the spiritual and cultural aspects of life for UFCs and the family? Congruence (i.e., health and well-being) was estimated by determining if a balance of systemic processes occur for UFCs and the family. Anxiety was basic to all other emotions; it was the antithesis to well-being. A deficiency in health was anxiety, an emotional burden, that resulted in system incongruence for the UFCs and the family. Health was the product of anxiety and well-being interacting and vacillating as caring situations changed, became stable, and changed again. Well-being for UFCs and the family was a sign of high-level health, in which the target of spirituality was exceedingly important. Strong spirituality helped to diffuse the UFCs' and the families' anxiety (Friedemann, 1995). The UFCs were healthy or congruent, as they described a process of finding a balance, finding meaning, and dealing with emotions and relationships within the family.

Incongruence (i.e., pain and disappointment) was also present in the caring situation for the UFCs. Significant emotional burden occurred as a result of caring provided in the home setting (Baldwin, 1988; Dellasega, 1991; Lindgren, 1993; Pierce et al., 1989; Segal & Schall, 1996). Most UFCs of persons with stroke used little formal support, but they overwhelmingly utilized their strong support network of family members and friends in caring for the care recipient. Additionally, all UFCs either implicitly or explicitly told of feelings of family support and unity in caring for the care recipient. Even so, stress was expressed as emotional burden or pain and disappointment by these UFCs, as the families continued in a caring relationship for the care recipient (Carlson & Keller, 1992). The care recipient's state of psychological well-being also affected the UFCs, which, in turn, affected the care recipient (Burgener & Chiverton, 1992). The UFCs used problem- and emotion-focused coping in almost every stressful encounter (Folkman & Lazarus, 1980). The UFCs described strategies of system maintenance and change, problem-focused coping, as well as coherence and individuation, emotion-focused coping (Friedemann, 1995; Folkman & Lazarus).

Pain and Disappointment Versus Personal Growth and Enrichment

All in all, all UFCs resisted system change. Pain and disappointment or emotional burden resulted from a sense of losing control for these UFCs, as pictured in Table 3. They expressed an inability to change, as they held onto the past. This represented adherence to stability instead of shifting to spirituality and acceptance (Friedemann, 1995). The UFCs expressed emotional distress related to decreased mental and affective capacities of the care recipients that is captured in the following UFCs' comments (Draper et al., 1992; Stone et al., 1987; Williams, 1993). One daughter thought that when the care recipient "regresses back to when she was younger.... It gets a little frustrating." A daughter-in-law said, "You are used to the person being a certain way and then seeing them a different way, it's really hard to adjust.... She understands most of what's goin' on and it hurts her as it hurts me...." In another family, the man with a stroke had always been hard to get along with, and now with the stroke, he was even more difficult. He did not understand that his thinking was not always correct and that his behavior was, quite frankly, obnoxious. Two of his daughters shared, respectively, "Yes, caring is hard; painful to watch Mother go through this.... But it's not easy, easy to live with someone like that.... She do the best she can do, it's rough," and "It's not easy to work with him.... I don't go every day." In another family, a daughter commented, "Caring is a lot of mental...[work].... She remembers things, like the long-term memory is there; her short-term memory sometimes isn't [there]. So you never know what she remembers...."

UFCs' burden can be explained, in part, by their interconnectedness with others in the family (Archbold et al., 1990; Bowdoin, 1994; Homer & Gilleard, 1990; Smith, 1994). The UFCs who had a poor relationship with the care recipient and without satisfying social contacts experienced elevated levels of perceived burden (Archbold et al.; Wolf, 1988). This was the case with the one family where there was anger and a history of abuse. The wife felt that "a lot of pain and disappointment" had been present in their family for a long time. Even with the stroke, the husband still verbally abused the entire family. The wife told of dissatisfaction and talked of many stressful issues with the caring situation. In general, few social contacts occurred for this wife.

This increased level of burden for the caregiver led to neglect and/or abuse of the care recipient in this family (Pillemer & Finkelhor, 1989). While no physical abuse was uncovered, verbal abuse by the husband directed at his family was reported by the UFCs. Neglect and abuse occurred in small ways, such as impatient words between the care recipient and his wife and children (Hinrichsen & Niederehe, 1994). Additionally, the wife said that a good day for her was being able to ignore her husband; that left the care recipient isolated from human company or social happenings. Codependency, a common theme in neglectful families, was displayed by the UFC and care recipient (Williams-Burgess & Kimball, 1992). This UFC stayed in the relationship, as she thought no one else was available to help with caring. Her rewards, perhaps, were God's blessing, as well as keeping the family home. Sometimes, caregiver abuse results not from the increased needs of the victims, but from the deviance and dependence of the abusers (Anetzberger, 1987; Hwalek & Sengstock, 1986; Pillemer, 1985; Wolf et al., 1982). This may be true in the findings presented above, although it can only be confirmed longitudinally, which this study was unable to do. Nonetheless, power and control were key issues for this family in neglectful and/or abusive caregiving situations (Phillips & Rempusheski, 1986). Overall, rigidity of behaviors used for stability by all UFCs increased their burden, and thus, created more incongruence (Vitaliano et al., 1993). Of course, this was especially true for the UFC who spoke of "being controlled and used" by her husband in the caring situation described above.

Nevertheless, all UFCs told of personal growth and enrichment related to caring of persons with stroke. The UFCs expressed feelings of living in the moment and hoping for the future that reflected spirituality, which is defined as turning to others to find congruence, such as acceptance, forgiveness, and love. Meaning was found in spirituality; therefore, it concerned coherence and individuation

(Friedemann, 1995). Hope was a way to maintain the UFCs' coherence and perhaps even their family's coherence, as they struggled in caring for the person with stroke. Self-development was expressed by the UFCs as they individuated that targeted growth (Friedemann). Personal growth and enrichment for the UFCs within their African American families occurred. This growth, which centered on learned patience and attuning to others, was spirituality. They hoped, either realistically or unrealistically, that the future would be better with regard to the care recipient's physical and emotional condition. The majority felt they would just accept whatever the future brought and would not fret about it. The point here was staying together; coherence was not taken for granted. Every day had value and meaning. They were living in the moment and hoping for the future in order to maintain coherence in their families. Coherence provided a sense of belonging and safety for the UFC and their family (Friedemann). Satisfaction with caring was evident in the majority of UFCs. A basic factor leading to satisfaction was the UFCs' ability to protect their own psyche from negative self-perception and threatening emotions, such as guilt. They had a good sense of self; the majority felt good about caring for the care recipient (Nolan & Grant, 1989). This sense of goodness is further discussed in regard to motivations for caring. At a higher level, this positive self-image provided a chance for self-development and an opportunity to better understand the human condition. This reflected growth and spirituality for the UFCs (Friedemann). All UFCs spoke of "patience and tolerance" gained from the caring situation. Most felt that the caring situation brought them closer together. One UFC captured the essence of self-development as she said, "We were all close, but...we all got even closer. I can say that in the caring with him havin' the stroke, we all got closer to him.... [I learned with caring] tolerance, patience, maturing.... Need patience and tolerance, I have all that...." Such individuation led to insight and understanding; shared individuation led to family growth (Friedemann).

Conflicts Versus Mutual Support

The sense of success with the UFCs' caring for the person with stroke to maintain their system and coherence, to individuate and learn, and to adapt and ultimately change their system, concerned how conflicts versus mutual support were established (see Table 3).

Family resourcefulness as well as resolution was tested (Stack, 1996). The UFCs let a lot of things go, so that they did not waste their time and energy with nonbeneficial conflicts. In simple terms, evasion of conflicts occurred in order to maintain stability in family relationships and resources. One husband summed it up by saying, "But with caring, encourage people to have faith and believe that things can be worked out by reasoning with one another. Not to have arguments with one another, cause you got differences of opinions, don't bring them out and argue over them." Others agreed and shared the following two comments:

> Try to say nothing rather than argue about it...come over and help out.... Before he had the stroke, he was awful. He was a bastard. [Now] some days you can get on the phone, you talk to him real nice; some days you just want to get away as quick as you can. There's a lot of anger in the family.... You had to go through it when you were 14 or 15, a little kid. But you don't have to put up with it now. No, we'd rather walk away, which is the best thing to do.

While there were conflicts, the family members did work together in caring for the person with stroke.

Motivation for mutual support came from love and a sense of duty between UFCs, care recipients, and their families. Duty involved love and is defined here as commitment and perseverance between these individuals. This love and sense of duty helped to maintained the UFCs' family coherence (Friedemann, 1995). The UFCs valued positive aspects of relationships and especially love from the care recipient. The majority of UFCs expressed feelings of love related to duty in caring (Farran et al., 1991). The following comments are representative of these expressions. As one man said, "Care for each other...love each other." A woman UFC shared, "I just love him to death.... We love each other, been married over 20 years. He would do the same for me...." In another family, a sister of a care recipient commented, "Well, to me, caring is something that an individual should want to do, cause that's a loved one." Her sister added, "...It's just a part, my duty to care like that for family members." This sense of give-and-take in the relationships seemed to play a role in the UFCs' motivation and satisfaction (Nolan & Grant, 1989).

For the family with a history of anger and abuse, caring was based on obligation with little or no expressed love between the care recipient and the family. This wife's comments said it well:

> I get the feeling, he tells me that he appreciates everything that I do, but it seems like at times that I'm the enemy that "I got you where I want you." But [sometimes]...he just snaps me up. He don't have to kiss my butt, but...[he said], "Do you have to be ornery 24 hours a day...you can smile sometimes?" So I said, "You are not going to ruin my day." Cause I know how to get up out of here. I would tell anybody that [caring] is not bad when the person is sick, but I think you got to have love between you all, it's not so hard.

Most caregivers reported that caring was embedded in a relationship where they felt needed (Nolan & Grant, 1989). The UFCs used kin relationships, defined to include friendship networks, to create mutual aid, domestic networks of obligation. Simply, there was a sharing of responsibilities based on obligation of kinship for the UFCs (Stack, 1974). One wife, as UFC, stayed in the caring relationship out of obligation, as she told there was no one else to care for him. This couple's children participated in caring out of love, duty, and obligation for the mother and felt obligation for the father. The approval of the caregiver did not provide motivation for the caring process. However, this was not the dominant effect.

Motivation was strengthened, for most of the UFCs, as a result of approval by the care recipient that reflected spirituality and coherence (Friedemann, 1995). Most of the UFCs were thankful and appreciative of the caring provided by the UFCs. The UFCs found meaning in aspects of caring from seeing the care recipient appreciative of that caring (Farran et al., 1991). Most UFCs felt that the care recipients were thankful for the caring provided. This helped the UFC get through the day. There were feelings of vulnerability on the part of the UFCs. A wife commented, "You know bad things happen to good people."

Additionally, motivation occurred through a philosophical introspection by the caregivers which allowed them to individuate and grow. A philosophical introspection occurred in which they were able to reframe the situation in order to make the caring circumstances acceptable. The UFCs turned to God for energy and mental fortitude to get through the caring situation. They thanked God for allowing them the opportunity to keep going forward in the caring process. Most of the UFCs expressed that they felt good; caring gave them a good feeling for doing something for somebody. The philosophical introspection facilitated the UFCs' individuation of new attitudes in regard to the caring situation within their family setting. The UFCs individuation was the first step to family change (Friedemann, 1995).

All UFCs and their families worked together as a unit in caring, since the initial crisis of the stroke event. Family relations seemed to be a source of strength (Evans, Bishop, & Ousley, 1992). There was a family commitment or filial piety based on different motives expressed by these UFCs to maintain the stability of their family system. Most felt they were strong families who were brought even closer in caring for the person with stroke. For just one family where anger and a history of abuse were present, the children helped the parents at first when the stroke occurred. But as caring continued over time, the children helped less with the caring. UFCs in other families felt that family members could be more helpful, too. Many expressed that the men in the family did not help with the physical work or emotional reassurance in caring unless there were no other choices. The men were usually responsible for providing home maintenance and giving whatever financial assistance they could manage. Nevertheless, for whatever reason even in the family with anger, as one daughter put it, "Everybody in the family do the best they can do." Her sister shared, "We had our downs when we were being raised by this man. [Now] our ups and downs is going over there and try to do for him, you know. Then you get cussed out.... We do what our momma need us to do." The meaning here was associated with belonging or coherence; it was gaining strength through others (Friedemann, 1995). In the end and over time, healing may occur for both the care recipient and the UFC.

Meaning Concerned with Spiritual and Cultural Aspects of Life

Meaning concerned with spiritual and cultural aspects of caring that affected their well-being and their family's functioning were shared by the UFCs and are displayed in Table 3. The UFCs expressed feelings focused on control and spirituality within their African American family system.

Urban culture, an environment created by living conditions, such as poverty, played a significant role in defining the caring situation for the UFCs. While each family developed its own unique culture that depended on how the family system interacted with the urban environment and applied the information to its daily pattern of caring, differences and similarities occurred among the families (Friedemann, 1995). The UFCs shared different feelings about the fairness of caring. For the family with a history of anger and abuse, there were feelings of unfairness with the caring situation. All in all, the children helped the mother; the mother continued in caring for her husband. In other families, there were feelings of disappointment with caring for the person with stroke related to inequality in gender caring. The women were expected to and did more caring than the men in their families (Stack, 1996). Some men did participate in caring similar to women, if they were an older child in the family and if they were socialized to that role early in childhood. One granddaughter's comments were representative of the UFCs of persons with stroke:

> [I'm] not necessarily dissatisfied, but I think the boys could do more than they do; that the boys, the men, my uncles, they could do more. But I understand, they have a family and my uncles are all in their 40s. They were raised in the south. That meant that the men took care of the financial situation, the women took care of everything else. And I can understand that's how my uncles think. But this is their Mom, you got to put aside that stuff and come over here and take care of her just like the rest of us. OK, you're going to wallpaper her kitchen, that's fine.... But come over here and spend some quality time, just sit and talk with her.... [Caring is] not fair. But like I said, they all put in what they know how to do.

However, the majority of UFCs were satisfied with the caring situation and felt that it was fair. Families with good family boundaries accepted the limitations of others in caring for the person with stroke. Many UFCs stated that if the roles were reversed, the care recipient would do the same caring for them. Thus, fairness was a component in how family systems were stabilized and maintained (Friedemann). Once UFCs learned, through individuation and spirituality, they moved and, ultimately, changed their system and experienced healing. They found some degree of satisfaction when there was a give-and-take relationship (Nolan & Grant, 1989).

The UFCs and their families placed more emphasis on spirituality, a Christian piety, as a way of dealing with the caring situation (Gonzalez, 1997; Smerglia et al., 1988; Wykle & Segal, 1991). All UFCs felt that faith in God kept them going in their caring situation. Religion was a binding force. Each UFC found comfort in religion through individuation and, by sharing their beliefs, religion became a uniting force or coherence (Friedemann, 1995). One woman's comments summed up these feelings for all the UFCs as she related that prayers and God helped her continue with caring.

Caring was purpose for the UFCs. There was a sense of direction in caring for the person with stroke voiced by the UFCs within African American family settings. Published literature did not directly focus on the purpose UFCs of persons with stroke ascribed to caring and the influence of that purpose on the family's capacity to care. Purpose helped to explicate Friedemann's (1995) Framework of Systemic Organization in that individuation by UFCs targeted spirituality. Through individuation new attitudes that encompassed the purpose or meaningfulness of the caring situation entered the family system. This purpose of caring was then built into system maintenance and passed on to the next generation. Culture is a dynamic process within which UFCs, interacting with other family members, were always engaged. One daughter captured this feeling when she said, "The purpose for me [in caring]...it's to give her the best quality of life she has left." Many UFCs were able to reframe the caring situation to one of satisfaction and fulfillment. For example, one daughter commented, "I wish [Mother] was better. Satisfied, it's OK.... But it still hurts to see her like that." Other UFCs felt that caring was endurance and patience rather than satisfaction. One wife expressed, "I find meaning and purpose [with caring]. Sometimes I think of it as thing to learn you to have patience, endurance.... Not very satisfied [with this situation of caring], not that much." And yet, all UFCs shared feelings that caring involved loving, sharing, being there to help, giving of yourself, being at peace with yourself, and seeing the other person grow. One wife summed it up by saying, "[Caring is] a 24-hour-a-day job with [him]. But caring is a celebration of joy."

The UFCs of persons with stroke also expressed caring as a filial ethereal value. UFCs valued positive aspects of relationships and of the caring situation in a family context (Farran et al., 1991). As discussed previously, caring was an emotional burden for the UFCs of persons with stroke; nevertheless, caring for the care recipient was a spiritual value. One woman said, "The physical work is a burden, the caring is a mental burden, but a burden you love. You do it for somebody you love. You know, it isn't like it's a burden that way." Emotional burden was re-routed by positive filial relationships. Many expressed happiness in seeing the care recipient do things that they relearned.

The UFCs valued family relationships and the pictures of family members were symbols of these relationships. All UFCs revered family and displayed photographs of living and nonliving relatives, including in one home, pictures of animals as family members. These pictures reflected humanness and warmth in their homes, which were set in cold, stark environmental settings. They focused on what they had, not what was lost due to the stroke event, and they relied on family members for support.

Self-contemplation, about the caring situation based on Christian spiritual values, was expressed by the UFCs as they looked within themselves. The majority of UFCs felt they accepted life and kept on going. The intrinsic goodness of caring was voiced by many UFCs as an interpersonal reward in a smile, a touch, a look from the care recipient. The UFCs described feelings of positive family and social relationships (Farran et al., 1991); family relations seemed to be a source of strength for the UFCs (Evans, Bishop, & Ousley, 1992). One husband's comment is reflective of these personal feelings. He shared, "Accept life as it comes...control some things, not control others...do what [you] can." Another wife further clarified these expressions. She said,

> Sometimes your blessing comes from just feeling good. I just sat out on the steps this morning, look at all the birds...I thought about flowers and said, "God, you so are good, you are good." I praised Him and I looked at the bird and said, "You know, you are doing just what you are supposed to do."

Research Question Three

Caring and Cultural Patterns

The third major research question for this study was: **What expressed caring actions (i.e., the experience of caring) and what expressions of congruence (i.e., the meaning of caring) are universal or**

cultural bound for UFCs? The growing amount of literature regarding African American families supports the experience of caring as a universal cultural concept found within the UFCs and the family system in this study. The decision to provide caring by UFCs in their African American family settings, for the most part, was culturally prescribed. According to traditional values, African American families, especially the women as UFCs, provided most of the caring (Adams, 1980; Baines & Oglesby, 1992; Kinshef & Yeolin, 1981; Stack, 1974, 1996; Ward & Carney, 1994; Wykle & Segal, 1991). The caring actions as system maintenance, system change, coherence, and individuation were described consistently by all UFCs of persons with stroke within their African American families. Few individual and family differences among family members existed. The all-encompassing resultant caring actions and caring family functions displayed by the UFCs were more similar than divergent and culturally dictated in these African American families.

The literature also helps understand the meaning of caring as a universal cultural process. Providing care for family members is normal for many African American families (Chatters et al., 1985; Hines-Martin, 1992; Markson, 1979; Martin & Martin, 1978; Mitchell & Register, 1984; Price, 1994; Taylor, 1985; Taylor & Chatters, 1986; Wykle & Segal, 1991). Cultural patterns rested upon shared assumptions and values and were evidenced as expressions of caring linked to caring actions and caring family functions that UFCs and their families developed to survive the caring situation (Friedemann, 1995). Caring for family members in these African American families was a value thought useful enough to be passed on to succeeding generations. The UFCs role-modeled their beliefs for other family members. Each UFC's family developed their own unique culture that depended on how the family system interacted with the environment and applied information to its daily patterns (Friedemann; Schein, 1985). There were differences between the

UFCs' families and among the family members' descriptions of incongruence and congruence as revealed in the previous paragraphs. The major differences of reported satisfaction with caring were related to the emotional attachment of family members before the stroke event occurred. Additionally, spirituality was more pronounced, as spiritual aspects were interwoven into the UFCs' daily life. Nonetheless, the caring expressions drawn to the cultural themes of Friedemann's systemic targets of stability, growth, control, and spirituality were universally the same for the UFCs in African American families.

The findings of this study support the work of Friedemann (1995) in consonance with the Framework of Systemic Organization. According to Friedemann, the interpersonal or family system implements the cultural expectations of society. Culture is lived in the family and is the sum of human life patterns. "Ethnicity represents those stable cultural patterns that are shared by a group of families who have the same historical roots" (Friedemann, 1991, p. 173). The UFCs of persons with stroke were deeply analytical in terms of finding meaning in cognitive ways within their African American family settings. This is also reflected in the following discussion.

Caring and Culture Maintenance and Transformation

What are the components of cultural maintenance for UFCs and the family and what are the components of cultural transformation for UFCs and the family? Cultural patterns were evidenced in the experience and meaning of caring and focused on cultural maintenance that the UFCs and their families developed to survive the caring situation. Culture transformation could only occur if the UFCs' circumstances changed, such as being open to more options. For the most part, these UFCs were doing everything in their power to maintain their family system. There was little change for the UFCs and the family. They were stuck, and their culture helped them to survive.

Culture Maintenance

The pattern of system maintenance and coherence constituted culture as the UFCs lived it and maintained stability. The maintenance of ethnic patterns happened at the family system level. These cultural patterns were based on values of stability and mutually held beliefs that guarded against conflicting environmental trends and ideals (Friedemann, 1995).

The caring actions (i.e., caring is physical work, sacrifice, taught and shared, structured, and communication) were centered in system maintenance targeted at stability and control. Caring described by the UFCs indicated hard physical work with ADLs and IADLs. The UFCs within their African American families spoke of sacrifice. They noted that the stroke affected the whole family. They not only rearranged their lives, but they also gave up many things. Most did this willingly, but some were resentful (Stack, 1996). Nevertheless, the UFCs were teaching and sharing to and with other family members about the physical and emotional aspects of caring. Actions involved in caring for others in their family that were shown to be useful enough were taught to other family members by the UFCs of persons with stroke (Friedemann, 1995; Schein, 1985). In order to accomplish caring, the UFCs developed ways to organize their own lives and the life of their family. There was a routine to their caring that everyone knew. UFCs used open and direct communication styles as they participated in caring processes (Stack).

Communication also played a part in system change; it was the vehicle for determining if change was needed. Communication also helped them to maintain problem-solving and decision-making skills (Stack, 1996). Along with communication, accommodation made by the UFCs was found in system change targeted at control and growth. These UFCs made accommodations in their lives and environments (Friedemann, 1995). Loss of proximity (e.g., altered sleeping arrangements) between the UFC and the care recipient was mentioned. UFCs also lost personal freedom in that they altered their lifestyle to accommodate the care recipient. For example, one son lived with his mother, caring for her through the night. Other family members provided the caring during the day. In other families, daughters and wives described staying with the care recipients even when this was not convenient. One daughter aptly stated that she adjusted. A wife stated that many adjustments in caring for the person with stroke needed to be made. Caring is complex. The UFCs learned through family role models about caring throughout their lives. Kin support existed, because the UFCs' network was influenced by cultural patterns created and retained from earlier periods in history (McAdoo, 1988).

All UFCs learned in childhood to help one another to survive within their family systems and the environment. Coherence targeted at stability and spirituality was demonstrated as the UFCs worked together as a unit in their family system. They valued being together and supporting one another (Friedemann, 1995). All the UFCs described periodic conflicts of varying degrees of severity that arose related to caring for the person with stroke; however, to survive the situation, the UFCs chose their battles carefully. The majority of UFCs demonstrated good boundaries within their families and were able to communicate and problem-solve with each other all conflicts in a successful and an open manner. They valued mutuality (Chatters et al., 1985; Hines-Martin, 1992; Martin & Martin, 1978; Mitchell & Register, 1984; Price, 1994; Taylor, 1985; Taylor & Chatters, 1986; Stack, 1974, 1996; Wykle & Segal, 1991). For the family with a history of anger and abuse from the care recipient, however, this was not the case. Here the wife and children ignored through suppression most conflicts generated by the husband and care recipient and continued to work together in caring for him. Even in this family, some disagreements were resolved through discussion between the UFC and her children; this strategy was similar to all the other families in this study. Although this care recipient did not act in an appreciative manner, there was a strong and unbroken bond that was highly respected between this mother and her children. All UFCs indicated that they only had each other to depend upon in growing up and that this extended into their adult lives. The UFCs displayed a mutual togetherness in their relationships with one another exhibited as a give-and-take process among the family members (Stack, 1996).

Individuation occurred with learned caring actions for these families and targeted growth and spirituality (Friedemann, 1995). Caring was a learned value by the UFCs in their family systems (Noddings, 1984; Watson, 1988). Growth and, thus, individuation occurred for the UFCs of persons with stroke within their family settings (Friedemann, 1995). One care recipient's son captured the sentiments of the UFCs when he noted, "That's how I was taught and raised when I grew up...[to be caring]." Others told of reading books and learning about stroke. Other UFCs said they learned caring for the person with stroke from health professionals and the media.

Caring family functions located within system maintenance and system change were invclved with stability, control, and growth of self and/or family. Adaptation in families and in caregivers' enforcement of old values were located in system maintenance; adaptation in the UFCs' watchfulness was found in system change; and differences in filial function was centered in coherence.

In system maintenance, adaptation in UFCs' family systems occurred as they became involved in caring for the person with stroke (Friedemann, 1995). They spoke of an altered lifestyle, and yet, they all mentioned that life remained the same for them and their family. In actuality, they made these adaptations so that life could go on as it had in their families. There was an adaptation in the UFCs' enforcement of old values. They would never give up their caring for the person with stroke. Placing the care recipient in a nursing home for these families was equated with the care recipient's death (Kelly, 1994a; Nkongho & Archbold, 1995; Picot, 1995; Stack, 1974, 1996; Wykle & Segal, 1991). However, there were differences in their motives. For the majority of families, the UFCs of persons with stroke stated that caring for the person with stroke in their family and at home was paramount and was based on love and affection. This view had nothing to do with their financial situation or whether they could afford the cost of placement. They stated that they would not like the care recipient to be in a nursing home nor would the care recipient. Over and over again, the UFCs stated that the nursing home was a sure death for the care recipient. Nursing home placement became an option for only one family, when the health of the UFC was deemed at risk. For this family, which had an abusive past, caring in the home was seen as obligation, as they believed there was no one else to provide caring for the care recipient (Stack, 1996). The children loved their mother and helped her in caring for their father.

System change occurred in the past and was incorporated into their lives as the family system was maintained over time. Ongoing system change was occurring within their family systems (Friedemann, 1995). All UFCs displayed adaptation in their sense of vigilance. They were ever-observant of the care recipient (Bowers, 1987). A watchfulness was used by these family caregivers to provide a safe environment for the care recipient. UFCs and other family members changed their lives so that the person with stroke was never alone or, if they were alone, frequent checks were made on their safety.

How the UFCs' family was thought to grow or developed was related to interpersonal relationships among family members and others prior to the stroke event. There were differences in filial function as the UFCs grew and individuated (Friedemann, 1995). All the families were similar in that the members pulled together to provide the needed caring (Adams, 1980; Kelly, 1994a; Kinshef & Yeolin, 1981; Ward & Carney, 1994; Wykle &

Segal, 1991). However, the motives for caring differed. Some UFCs participated in caring out of love and duty, whereas others' motives for caring centered on obligation. These motives were the force behind the relationships that guided the caring situation and were at the root of the differences in how these families functioned. Most UFCs thought that it was like "the whole family had the stroke" and that the stroke event had actually brought family members closer together. Based on love and duty, the families functioned harmoniously and the caring situation was seen as "a celebration of joy." This was not the case for the one family with a history of anger and abuse. The wife explained that she was being used and controlled by the husband, as there was no one else to participate in caring for him. In other families, the UFCs were also controlled by the care recipients and the circumstances of the caring situation. The UFCs' lives were dictated by the needs of the care recipients. There were degrees of these motives, love and duty and obligation, displayed within all the families as they participated in caring. Nevertheless, when there was little love shown between the UFCs and care recipient, the UFCs still worked together in caring due to felt obligations held within the family and love for other family members. There was a sense of duty and obligation as major factors in these African American families' reasons for caring (Nkongho & Archbold, 1995).

The UFCs, while living in the present, were focused either implicitly and/or explicitly with hope for the future that maintained their and the family's caring for the persons with stroke. These were spiritual values deeply felt within their family systems (Gonzalez, 1997; Smerglia et al., 1988; Wykle & Segal, 1991). Some hopes were unrealistic in that many UFCs hoped for gains in the care recipient's functioning that were out of reach. For example, many wanted the care recipient's memory to significantly improve. Improvements for the care recipient were seen by a few UFCs as hopes that their own lives and their families would also improve in the caring situation. Other UFCs were more realistic in their hopes for the future, in that many said they would accept the future with little worry. The future was uncertain for many UFCs' families, but it was important for them to continue caring for the person with stroke. All families hoped that God would get them through the caring circumstances. Some UFCs noted that they were "strong" people, and thus their families were also strong; they were able to tolerate vulnerability and uncertainty (Stack, 1996).

The UFCs avoided conflict situations that were not beneficial in their families while caring for the person with stroke. This too helped maintain stability (Friedemann, 1995). One daughter's comments captured the essence of evasion of conflict to stabilize family relationships. She said,

> When [disagreements] come up; for instance, if my sister wants me to stay over with my mom, sometimes she'll just say it, "I'm not coming." She never comes. So I know somebody has to stay there and I'll stay. Just do what you have to do.... We do have our disagreements. Sometimes we talk them out and sometimes we just blow up and don't say anything for a day or so. It's extremely hard because [Mother's stroke] has changed all of our lives.

Nevertheless, all family members worked together as a team and displayed a filial piety that maintained their family system. This family unity was displayed as a spiritual attitude. Several UFCs commented that they were taught to survive, work together, and keep on going. The UFCs voiced differences related to the fairness of caring for the person with stroke. Some UFCs said that caring was fair for all. Some simply said that they had been taken care of by the care recipient and now it was their turn to reciprocate. Others stated that although they were really not dissatisfied with the caring situation, they were disappointed that other family members did not participate in caring as much as they thought they should. The men were not equal participants in caring for the person with stroke. Still, only one wife in one family expressed that caring was unfair; she had felt used and controlled by the care recipient for years. Now she was caring for him, because there was no one else. Her daughter's comments reflected the predominant view in this family that had a history of anger and abuse by the care recipient. She said,

> [Fairness] better to care to do the best you can do for him [father] than be 6 feet under, cause some people don't have that. I call every day, but I'm not there half of the time.... If he be making it hard on [mother], she could have a stroke, then who to take care of him if she gets sick. I'm not going...to take care of him. I'd take care of her but not him. I will not do that....

A strong motivation for stability was the UFCs concerned love and a sense of duty between caregivers, care recipients, and their families. Caring was carried out with a spiritual attitude voiced as a responsibility, not a choice (Nkongho & Archbold, 1995). Most of the caring was centered in love; if not, it was cold obligation. The comments of one wife said it all:

> I would tell anybody that [caring] is not bad when the person is sick, but I think you got to have love between you all. It's not so hard. It's not a burden, cause you love that person and they love you. Everything you do for them, they are going to be grateful and you don't mind. If there's no love there, it just like a man taking care of a child that he really don't feel is his, that he's just going along with the program. Can't be no bonding like that...no bond in [my] situation....

African American children are traditionally socialized to consider family and obligations to parents, siblings, and other kin as paramount (Sudarkasa, 1988).

Spirituality was highly emphasized and prized by the UFCs of persons with stroke in their African American families. Additionally, cultural maintenance of ethnic patterns occurred with UFCs' beliefs that caring involved Christian piety and purpose. When they became overwhelmed with the caring situation, they turned to God (Gonzalez, 1997; Smerglia et al., 1988; Wykle & Segal, 1991). These UFCs repeatedly stated that God gave them and their family only what they could handle. They used prayer to get through the day and, thus, their spiritual beliefs helped maintain their own sense of self as well as their family situation. Their determination or purpose associated with caring for the person with stroke also helped to maintain their family system. Simple things, such as a smile from the care recipient and help to and from others, were said to give purpose for the UFCs. Caring meant feelings of love, pleasure, growth, and joy to many of the UFCs as well as giving purpose to their lives. These feelings were virtually unsubstantiated in the literature. Spiritual aspects interwoven with daily life were very pronounced for the UFCs and the family.

Culture Transformation

All in all, caring was deeply rooted in culture and strongly maintained. This was evidenced by the values placed on caring for the person with stroke by their families in their homes and on working together as a family to achieve this end. However, some environmental patterns and ideologies conflicted with the patterns grounded in the UFCs' value systems. The result was that families incorporated through individuation some new knowledge about caring and compromised their usual behaviors (Friedemann, 1995). For instance, a small transformation happened when the UFCs accepted help from outside their family for caring. In another example, many women UFCs stated that the men in their families were not taught nor did they help with personal caring that involved ADLs. Their role was to provide money, if possible, and home maintenance repairs. For the men UFCs in this study, this was not true. Their role was transformed. They participated fully in all aspects of caring for the person with stroke from bathing, dressing, and toileting the care recipients to cooking and shopping. Family loyalty was strong and this drove the men to participate in caring. Husbands and sons in caring for their wives and mothers said time and again, "She did for me, now it is my turn to do for her." Family cohesion was a major factor in African American families' ability to care (Luckey, 1994).

With the caring situation, these UFCs of persons with stroke learned survival and new coping skills. Individuation targeted growth with the occurrence of self-development (Friedemann, 1995). All the UFCs thought they had learned new patience and tolerance from the caring situation. As one daughter put it, "[Caring] has learned me patience." In another family, one sister shared, "I'm no different than nobody else; it [stroke] could happen to me.... How would I be if I was in that same shape, how would I act, what would I do, what would I say?.... Caring is teaching me patience, long-suffering, love." Thus, the UFCs accepted new roles in providing for in-home caring for the persons with stroke. These African American families appeared to be supportive across generations and demonstrated a sense of responsibility for caring (Cherlin & Furstenburg, 1986). The new roles taken on by the UFCs reflected this. Men in caring for their wives and mothers with a stroke provided personal caring and participated in taking care of home maintenance needs, such as cooking, cleaning, and shopping. Women in caring for their husbands and fathers also took on paying bills and home repairs that the men were no longer able to do.

For caring to occur for UFCs in their African American families, if one person was not available to help, then (in a serial progression) another person stepped in. The UFCs in their family relied more on each other for emotional support in dealing with the effects of the stroke. They used new patterns of communication for problem solving and decision making (Morycz, Malloy, Bozich, & Martz, 1987). For example, in one family they "walked away" from disagreements with the care recipient. In other families, members ignored confusional episodes of the person with stroke. In both these situations, the behaviors of the care recipients were dictated by the effects of the stroke on the brain in which no cure was possible. One UFC was disappointed that medical technology was not available to make the care recipient better. All UFCs referenced feelings of pain or hurt focused on the care recipients' memory losses. The care recipients had changed both mentally and physically since their stroke. A daughter-in-law of one care recipient said, "You are used to the person being a certain way and then seeing them a different way; it's really hard to adjust.... She understands most of what's goin' on and it hurts her as it hurts me...." In another family, a daughter shared, "My mom was a real go-getter. You could say that she was a workaholic and...the emotional part of that is, her not being able just to get up on her own and go anymore." With the emotional changes for the care recipient, the family members changed, too. One daughter stated that it was "not business as usual" in the family since her mother's stroke. All UFCs felt that the entire family had changed in response to the stroke event. They made compromises in their lives, such as changing work schedules, letting go of conflicts, and giving up social opportunities.

SUMMARY OF CHAPTER

The research questions were answered in this chapter. These findings, drawn to Friedemann's (1995) Framework of Systemic Organization, revealed the experience and meaning of caring for these UFCs in their African American family setting. Cultural themes universally bound to the experience and meaning of caring for these UFCs also were discussed.

Caring as experience was demonstrated by two domains: caring actions and caring family functions. These assistive or enabling actions based on cognitive knowledge and without regard to successful or problematic outcomes occurred between UFCs and the person with stroke in the context of their family system. On a concrete level, families worked toward Friedemann's (1995) abstract systemic targets of stability, growth, control, and spirituality by activating observable actions and functions. The caring actions and caring family functions occurred within Friedemann's four process dimensions of system maintenance, system change, coherence, and individuation for the UFCs within their African American family setting.

The meaning of caring was centered in one domain: caring expressions. The UFCs' caring expressions concerned how they interpreted or explained their caring situation, specifically, how the UFCs adjusted to individual differences, respected each other's opinions, and maintained their relationships with family members. The caring expressions were drawn in the final analysis to the systemic targets of stability, growth, control, and spirituality in Friedemann's (1995) Framework of Systemic Organization.

Cultural patterns were evidenced in the experience and meaning of caring and focused on cultural maintenance that the UFCs and their families developed to survive the caring situation. Culture transformation such as being open to more options could occur only if the UFCs' circumstances changed. For the most part, these UFCs were doing everything in their power to maintain their family system. There was little change for the UFCs and the family. They were stuck, and their culture helped them to survive.

CHAPTER 6

CONCLUSION

Chapters 1, 2, and 3 addressed the research questions, literature review, research design, and data analysis. Chapters 4 and 5 presented and discussed the findings. This chapter presents a theoretical discussion of findings concerning the experience and meaning of caring for UFCs of persons with stroke in their African American family settings linked to Friedemann's (1995) Framework of Systemic Organization. In addition, this chapter clarifies constraints related to the study, describes implications for the discipline, and delineates recommendations for further research.

THEORETICAL DISCUSSION OF FINDINGS

The Framework of Systemic Organization by Friedemann (1995) was supported and explicated by the findings of this study. The framework was found to be an appropriate organizational structure for this ethnographic, qualitative study. In Tables 5 and 6, the experience and meaning of caring, respectively, and the Framework of Systemic Organization picture how the domains of caring can be theoretically arranged. In examining the perceived and observed congruence found within Friedemann's systemic targets for caring, the constructs of the process dimensions were investigated. For the experience of caring and the framework pictured in Table 5, the domains of caring actions and caring family functions were drawn within Friedemann's system maintenance, system change, coherence, and individuation process dimensions of behaviors. The experience of caring was centered in actions used to assist others in the family, in how these actions were incorporated in family functioning, and in how perceived changes in self and the family occurred with these actions. The meaning of caring encompassed how the family reconciled individual differences, respected differing opinions, communicated thoughts and feelings, and reported well-being. For the meaning of caring and the framework depicted in

Table 5

The Framework of Systemic Organization by Friedemann (1995) and the Experience of Caring Domains

		SYSTEMIC TARGETS:			
	Definitions:	**Stability** The maintenance of identity in tradition, values, and cultural beliefs in the family.	**Control** The organizational and regulatory functions of the family with the aim of minimizing or regulating the effect of change.	**Growth** The ability to change through new understanding and examination of beliefs.	**Spirituality** The connectedness and belonging through adjustment of the system's own patterns and rhythms to those of other systems based on values which concern commitment, love, and affection.
Experience Of Caring					
PROCESS DIMENSIONS:					
System Maintenance	Behaviors that are grounded in tradition, refer to the structure and process of the family, and pertain to organizing and operating the family business. According to Friedemann, system maintenance comprises roles, rules, organizational patterns, rituals, decision making, power structure, and division of labor and **targets stability and control**. The capacity for change is also anchored in system maintenance, as readiness for change is a stable pattern rooted in the family's value system.	***Domain: Caring Actions -*** Caring is: **physical work.** **sacrifice.** **taught and shared.** **structured.** **communication.** ***Domain: Caring Family Functions -*** Caring is: **adaptation in families.** **adaptation in caregivers' enforcement of old values.**			

(table continues)

PROCESS DIMENSIONS:	***Definitions (con't):***	***SYSTEMIC TARGETS:*** **Stability**	**Control**	**Growth**	**Spirituality**
System Change	The purposeful alterations of system operations which result in shifts within the traditional family value system, requiring cooperation and agreement of all family members. System change **targets control and growth** in that new information is incorporated and channeled; values and adjustment of beliefs are tested; behavior patterns to concur with new values are adjusted; and new patterns are incorporated into system maintenance by changing or eliminating old ones.		***Domain: Caring Actions -*** Caring is: **communication.** **accommodation.** ***Domain: Caring Family Function -*** Caring is: **adaptation in caregivers' watchfulness.**		

(table continues)

		SYSTEMIC TARGETS:			
PROCESS DIMENSIONS:	***Definitions (con't):***	***Stability***	***Spirituality***	***Growth***	***Control***
Coherence	The emotional bonding and caring relationships among family members and **targets stability and spirituality** of the family.	**<u>Domain: Caring Action -</u>** Caring is: **mutuality.** **<u>Domain: Caring Family Function -</u>** Caring is: **differences in filial function.**			
Individuation	The family's promotion of individual learning and changing attitudes, taking in and incorporating information, and sharing opinions and beliefs. Individuation **targets spirituality and growth,** because the family, through communication, encourages the examination of new values suggested by its members and initiates system change.		**<u>Domain: Caring Action -</u>** Caring is: **learned.**		

Table 6

The Framework of Systemic Organization by Friedemann (1995) and the Meaning of Caring Domain

Meaning Of Caring

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CONGRUENCE
occurs through balancing and reconciling systemic targets in many areas of daily living expressed as well-being or health.

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+SYSTEMIC TARGETS: ↔	***+PROCESS DIMENSIONS:*** **Coherence**	***System Maintenance***	**System Change**	**Individuation**
Stability	***Domain: Caring Expressions -*** Caring is: [a]**emotional burden.** **evasion of conflicts.** **motivation: love and a sense of duty between the caregivers, care recipient, and their families.** [b]filial ethereal value.			
Control			***Domain: Caring Expressions -*** Caring is: **fairness.** evasion of conflicts. filial piety.	

(table continues)

+PROCESS DIMENSIONS:

+SYSTEMIC TARGETS:	System Maintenance	System Change	Individuation	Coherence
Growth		***Domain: Caring Expressions -*** Caring is: **self-development.** self-contemplation. motivation: philosophical introspection.		
Spirituality			***Domain: Caring Expressions -*** Caring is: **filial ethereal value.** **self-contemplation.** **motivation: philosophical introspection.** **filial piety.** **living in the moment and hoping for the future.** **purpose.** **motivation: approval by care recipient.** **Christian piety.** motivation: love and a sense of duty between the caregivers, care recipient, and their families.	

+Definitions for Process Dimensions and Systemic Targets are presented in Table 5.
[a] Bold type denotes primary Systemic Target, as designated by the researcher; [b] regular type denotes second Systemic Target, as designated by the researcher.

Table 6, the domain of caring expressions was connected to perceptions of how growth and enrichment occurred through the caring process via Friedemann's systemic targets of stability, growth, control, and spirituality. Experience and meaning of caring were closely intertwined in healthy families within these processes. Caring assumed a common cultural meaning and led to coherence at the personal and family levels. The person in the family who was coherent was likely to have a healing effect on the family system as a whole.

The experience and meaning of caring arose through the life process of the family system, which is the process of maintaining and transforming culture. By using the Framework of Systemic Organization (Friedemann, 1995) and exploring the process that led to congruence or failed to do so, the researcher entered the realm of the family's culture and detected congruence, health or well-being, along with the roots of fulfillment as well as the pain or grief resulting from failure. Thus, the framework provided a broad theoretical foundation, and yet, specific processes were explicated to describe the experience and meaning of caring from an African American family perspective. The following discussion highlights issues related to caring processes and the framework.

Human life on an individual or personal level is complex. Family life processes, the interpersonal level, are equally difficult due to the intricacy of connectedness and constant motion between individuals and environment within their culture. This study, designed and executed within the Framework of Systemic Organization by Friedemann (1995), is an example of these phenomena: multiple complex processes in continuous movement. The following findings serve to illustrate this point. The caring action of communication was found in two process dimensions: system maintenance and system change (see Table 5). This was due to the content and context components of communication processes. Communication was used to organize caring processes as well as to decide if change was needed. Several caring expressions, filial ethereal value, evasion of conflicts, filial piety, self-contemplation, and motivations for philosophical introspection and love and a sense of duty between caregivers, care recipient, and their families, were also located in more than one systemic target of stability, growth, control, and spirituality (see Table 6). This is expected, because congruence, health and well-being, encompasses all of them. The Framework of Systemic Organization allowed latitude to not compartmentalize or force the findings into a narrow scope.

Qualitative data were indispensable for a comprehensive understanding of these caring processes. Specific interview questions, anchored in the Framework of Systemic Organization by Friedemann (1995), guided the interviews and facilitated an in-depth, moving portrait of caring processes within the African American families. The dialogue was rich and intense as experiences and feelings about caring were uncovered. By using the framework, an exhaustive description of caring for African American families evolved that supported and extended what can be found in the present literature. For example, caring was difficult work and caused emotional burden for caregivers and families as they united to provide the needed caring in their homes (Boaz & Hu, 1997; Chatters et al., 1985; Evans et al., 1992; Grant & Davis, 1997; Hines-Martin, 1992; Kelly, 1994a; Segal & Schall, 1996; Stack, 1974, 1996; Wilkinson, 1993; Williams, 1993; Wykle & Segal, 1991). The findings extend what was known about caring in that the caregivers described their perceived purpose for caring. They told of determination and were very analytical and insightful in finding meaning for caring in cognitive ways. Additionally, the caregivers described in an extensive manner the overwhelming influence that spirituality played in their own lives and in the lives of their families (Gonzalez, 1997; Nkongho & Archbold, 1995; Smerglia et al., 1988; Wykle & Segal, 1991) that went beyond what is currently known. Tremendous strengths were revealed that formed a comprehensive picture of spirituality and caring.

In this study, the density and complexity of caring processes were captured by utilizing the Framework of Systemic Organization (Friedemann, 1995). The result was an aggregate portrait that showed a continuous flow of the experience and meaning of caring within urban, African American family settings.

CLARIFICATION OF CONSTRAINTS RELATED TO THE STUDY

The ethnographic method guided by the Framework of Systemic Organization by Friedemann (1995) was a suitable way to learn about caring from the people involved in the process. A major benefit of using this method was the extensive, vivid delineation of the experience and meaning of caring that emerged from the data. Each person's worldview of caring processes was known (Friedemann; Spradley, 1979, 1980). Nonetheless, all research has constraints. Important limitations for this study include measurability of concepts and transferability of the findings.

Measurability of the Concepts

The domains of caring identified in this study contained a multitude of concepts revealed in the taxonomic analysis related to the experience and meaning of caring. In the data analysis, the concrete caring actions and caring family functions were quickly and easily drawn to the Framework of Systemic Organization by Friedemann (1995). Even with the caring action of communication cutting across two process dimensions of system maintenance and system change, the findings were forthright. A more difficult data analysis process ensued with the caring expressions. This was expected, as the taxonomy of these data and the systemic targets were more abstract in nature. Nevertheless, the data analysis process was arduous, as the caring expressions were drawn to more than one of Friedemann's systemic targets by the researcher and confirmed in final analysis by Friedemann.

The measurement of congruence, health or well-being, was also a difficult undertaking. According to Friedemann (1995), health is defined as the very personal experience of congruence. Health is always present to some degree and has the potential to evolve into something stronger or better; life processes are in constant motion and adjustments to changes from within the environment are continuously occurring. Absolute congruence is impossible to achieve. Thus, a certain amount of incongruence, emotional burden or pain and disappointment, is unavoidable. Experiences of incongruence may be even beneficial, if they encourage people and families to make decisions, solve problems, or find new solutions. Health is not the absence of emotional burden; rather, health is a continuous process that establishes and reestablishes congruence and prevents incapacitating feelings of burden (Friedemann). These constraints made data analysis not unrealizable, but somewhat laborious. Several indicators of health were used to determine congruence: (a) Behaviors related to all process dimensions had to be present; (b) Emotional burden was not perceived to incapacitate; and (c) A balance of the systemic targets had to occur, in that persons had to be reasonably satisfied with themselves, their families, and the environment. Thus the measurement of health was a multifaceted undertaking in understanding the experience and meaning of caring for African American families.

Another constraint connected to measurement of the concepts happened with the discovery of cultural patterns. Cultural conclusions cannot be made clearly without comparisons (Friedemann, 1995; Kaufman, 1990; Leininger, 1991a; Spradley, 1979, 1980). Before any comparisons can be made, there is a need to examine groups and populations in detail. This study did not allow for comparisons of the concepts between or among groups or populations. Rather, this small study of 24 UFCs represents an in-depth, first look at the experience and meaning of caring for UFCs of persons with stroke within African American family settings. Once an examination of larger groups occurs, then beginning comparisons can be undertaken that lead to clear cultural inferences; however, caution must be exercised when making any comparisons. In examining the many variations in the cultural patterns of caring, Friedemann noted two perceivable dangers. First, there is the danger of losing one's self in the details of diversity; caring practices and rituals become the sole reason of research at the expense of a more comprehensive understanding of culture. The other danger is stereotyping; there may be an attitude of "they versus us." Like all designs for research, there are methodological shortcomings of comparative designs to explain the realities of caring. Comparative designs, in which a minority group is contrasted to the majority, gives knowledge as to the differences that exist along the dimensions that have been identified as important for one group. The potential result is that basic caring processes will remain unknown for one group (Gonzales, Gitlin, & Lyons, 1995).

Additionally, there were limitations to arrive at theoretical explanations of the data related to the measurement of concepts in this study. One must question whether the results would be different with similar areas of brain damage from the stroke for the care recipients, with UFCs caring for persons at the same functional level since the stroke, with more men as UFCs, with UFCs caring for family members with other medical diagnoses, with a longitudinal research design, with families without economic constraints, and with more families dealing with anger and abuse issues. The irregular case of the family with a history of anger and abuse was not well supported by the small number of other UFCs participating in this study. In order to discover more about caring and families dealing with anger and abuse (i.e., incongruence), similar families using these parameters as inclusion criteria would need to be examined.

Despite these constraints, the original purpose of this study was met. The experience of caring and the meaning or congruence of caring were discerned for UFCs of persons with stroke within the family system. Nonetheless, with the issues identified in regard to measurability of the concepts, any transfer of the findings from this study to other settings is a decision for other researchers to make.

Transferability

By definition, internal and external validity criteria in all research studies are placed in a trade-off position. If, for the sake of control (i.e., internal validity), strenuous conditions are imposed, then the results are not generalizable (i.e., external validity) to any contexts, setting, or sample, except those that approximate the original conditions (Lincoln & Guba, 1985). In other words, transferability (or generalizability) refers to the extent to which the findings from the data can be transferred to other settings or groups (Polit & Hungler, 1995). A limitation of this study is related to transferability. The setting was a community in northwestern Ohio. All key informants were purposively selected from one rehabilitation hospital setting. General informants were chosen from this hospital environment or from referrals made by the key informants.

Transferability of the research must be reassessed in each case in which transfer is proposed. The person who wishes to make the judgment of transferability needs information about both contexts in order to make a sensible judgment. While the researcher cannot know all the contexts to which another person may wish to transfer working hypotheses, the researcher did include relevant descriptors of the design and data. It is not known if these descriptions provide a sufficient base to permit another to make the needed comparisons of similarity and to enable others interested in making a transfer to reach a conclusion about whether a transfer is possible.

IMPLICATIONS FOR THE DISCIPLINE

Although this study has limitations, knowing the experience and meaning of caring for UFCs of persons with stroke within African

American family systems can benefit society and nursing in general and can specifically benefit individual nurses, UFCs, and care recipients.

Benefits for Society and Nursing

This study was an effort to examine the UFCs' experience and meaning of caring as they influence their capacity to care for persons with stroke and to interact with others in their African American family. At the general or broad scope level, as the body of knowledge in regard to caring for persons with stroke in family settings is developed and researched, nursing has an increased base upon which to build practice decisions. The use of the Framework of Systemic Organization by Friedemann (1995) (which incorporates the findings of this study, the caring actions, caring family functions, and caring expressions) at an applied practice level is beneficial in assisting professionals to understand the needs of UFCs of persons with stroke within a family context. Published literature, for example, the Hastings Center Report ("What Do We Owe the Elderly?" 1994), has indicated that caring in the home may be costly in terms of time, physical health of the caregiver, and money. The results of this study added to this found that caring was an emotional burden as well as a physical one. Health was a delicate balance of patterns, including the domains of caring, relevant caring actions, caring family functions, and caring expressions within the family's environment. Clearly, the UFCs in this study valued caring in the home setting. While caring was hard (e.g., physical work and an emotional burden), there was great pride in being able to continue with caring processes. Their strong sense of spirituality helped in this respect.

The present healthcare delivery system, however, did not support home caring efforts by the UFCs. Healthcare systems are slow to initiate change even though costs would likely be lower. The roots of this inflexibility are two-fold: the structure of the system and the UFCs' mistrust of the system. First, the healthcare delivery system is structured so that access is controlled by physicians who determine eligibility for Medicare and Medicaid services used by these caregivers. Because these services have to be medically prescribed, there is a tendency toward medically related care (Jamieson, 1992). The caregivers did seek medical care for the care recipient; however, the UFCs required more than traditional medical management of the situation. They needed assistance with personal caring needs and home making services. Second, the UFCs voiced a sense of mistrust in the established healthcare delivery system, as they said over and over that the care recipient would die if placed in a nursing home environment. Thus, conventional services, even if available, may not be used by these caregivers.

Healthcare agencies, instead of only providing direct care services, may be more effective if they partner with local neighborhoods and communities and assist them in developing caring networks for personal, respite, and home making needs required by UFCs. Services could include persons trained as personal care assistants to work with the UFCs to relieve the physical work of caring (e.g., bathing and mobility issues), to provide respite for the caregivers as they rested or attended to their personal needs, to facilitate home making chores (e.g., cleaning, laundry, and grocery shopping), and to visit and entertain the person with stroke or simply be available to call on the caregivers. These services would not be covered by traditional Medicare and Medicaid insurance but would be underwritten by government and local grants. Programs could be based within churches and schools and employ neighborhood persons to develop home caring services for the community. A caring network centered within churches or schools would continue to provide spiritual strength and in some respects might reduce the expressed emotional burden related to caring.

These programs directed by professional nurses could ensure that each family was accurately assessed to determine if there were services that they could qualify for through Medicare and Medicaid to provide as much comprehensive support as possible. The strengths of the patterns of caring identified in this study can be built upon by professional nurses as they direct others and interact with UFCs of persons with stroke.

Benefits for Individual Nurses, UFCs, and Care Recipients

At a very specific level, culturally congruent caring can result in benefits and satisfaction for the professional nurse caregiver. This study aided in developing a knowledge base for nurses of the experience and meaning of caring perceived by low-income UFCs as it influenced their capacity to care within their African American family system. Nurses need to view the caring situation from a family perspective, assess the family's situation, and ask questions about the family's systemic process. This is especially important for nurses working with UFCs whose culture, in terms of ethnicity and poverty, plays a significant role in the interpretation and execution of caring. The results of the interactions between nurses and families involved in caring processes affect how well the family will survive the caring situation.

Caring is linked to the nursing assessment and intervention (pictured in Table 7). First, nurses must build their cultural assessment around the domains of caring actions, caring family functions, and caring expressions displayed in Tables 2 and 3. This assessment leads to a sound knowledge of the caring needs for UFCs and their families. Gathering information about caring actions and family functions help to gain a beginning picture of the caring situation. Throughout the assessment of the more concrete caring actions and caring family functions, the more abstract caring expressions are also uncovered by astute questioning and listening by the nurse. Together the total assessment offers direction for caring processes. Specific culturally sensitive assessment questions related to these domains of caring are delineated in Table 7.

The listing of all caring actions, caring family functions, and

Table 7

Domains of Caring and Nursing Assessment and Intervention

- Culturally sensitive **assessment** questions include the following:

Caring Actions

- What are activities of and instrumental activities of daily living?
- What type of sacrifices are made? What has been given up?
- How is caring organized on a day-to-day basis?
- What is being taught and shared with other family members to survive the situation?
- What are the communication patterns being used to operate the day-to-day business of caring and to decide if change is needed?
- How are personal plans changed? How successful are caregivers in accommodation of their needs to those of the care recipient?
- Is a give-and-take process displayed in their relationships?
- How is caring learned (e.g., in childhood, from professionals, from the media)?

Caring Family Functions

- How does family adaptation occur with the caring actions related to the circumstances of the stroke event and the loss of independence?
- How do caregivers maintain a watchfulness (e.g., vigelance) over the care recipient and continue caring?
- How do they maintain caring in the home? Are their role changes related to caring in the home that reflects an enforcement of old values?

(table continues)

Caring Expressions

- Is there evasion of conflicts to maintain relationships or resources?
- Is patience and tolerance expressed? Are feelings of closeness discussed? How is self-development attained?
- Is vulnerability expressed? Are caregivers able to reframe values to make situation acceptable? What is the motivation for looking within self?
- Is fairness expressed in caring? Are they satisfied with the situation?
- Is there emotional burden for the caregivers related to mental confusion and memory loss for the care recipient?
- How is spirituality expressed?
  - Is there an ability to live in the moment while hoping for the future? What will future be like?
  - How does the family work together in caring?
  - What are motivations for caring? Is the approval of the care recipient important? Is caring based on love and/or obligation?
  - Does belief in God help?
  - Is there purpose in caring? What makes caregivers go on with caring?
  - Is there a togetherness displayed in the family as they participate in caring?
  - Are there rewards for caring?

- Specific **interventions**, based on this assessment include the following:

Design and Implement Interventions

- Highlight existing strengths

(table continues)

Design and Implement Interventions

- Encourage use of systemic resources
- Assist in the discovery of new strategies:

  Incorporate the healthy caring strategies outlined in Table 4
- Lead the change process
- Support all efforts

Evaluate Interventions

- Test results of interventions
- Evaluate health:
  - Is there a balance of caring actions, caring family functions, and caring expressions?
  - Is burden incapacitating?
  - Is there growth? Is new learning taking place and being incorporated into caring situations?
  - Is there evidence of spirituality being used to deal with caring circumstances?

caring expressions may be too large to be clinically useful in its entirety. In practice, an assessment by the generalist nurse is limited to the essential problems reported by the UFCs and, most importantly, to the family system's strengths that are most likely to exist when solving problems. While an entire assessment of all parameters is rarely accomplished at one time, an initial assessment may describe the situation at that point in time. For example, the UFCs received more help with caring in the initial period following the stroke, and then it dissipated. Nurses must continually assess the UFCs' needs as they change over time. As patterns evolve over time, the use of these caring actions, caring family functions, and caring expressions contribute to the evolution of a fluid appraisal of these patterns. Assessments may be modified and supplemented as the UFC and nurse work together. Furthermore, assessment questions may serve as interventions as they raise the family's awareness of certain patterns of actions, functions, and expressions. Nurses in advanced practice may utilize a modified assessment; however, they may also want to use the entire assessment in certain situations (e.g., in counseling UFCs who are having major difficulties with caring processes). In addition, the topical interview guide presented in Appendix I may be of use for an on-going and in-depth assessment.

Second, following the assessment of caring actions and caring family functions in conjunction with caring expressions used by UFCs, all nurses can determine if there is a need for change or intervention with caring processes (see Table 7). The nurse conjointly with the UFCs can highlight strengths and discuss areas for growth specific for each family. Together they can determine systemic family resources and bring to light new strategies for caring. The nurse leads the process for this discovery and implementation of interventions. All chosen interventions must be specific to individual UFCs' and their family's needs for caring. The self-maintenance strategies for healthy caring identified by the UFCs and presented in Table 4 can be shared with and tried by caregivers as appropriate. Further, plans for home visits or telephone calls by volunteers could be initiated with community organizations, such as churches or schools; these plans would lend emotional support in addition to helping the UFCs with the physical work of caring. A more generously subsidized formal home caring program is another option. This type of program could increase the length of time that a person with stroke could remain in community family settings and, at the same time, it could decrease the time spent in caring by the UFC. Additionally, this type of program would decrease financial costs over time. It is documented that it is less costly to provide caring in the home than in nursing home settings. However, caring in community family settings is costly in terms of emotional burden and may result in future unhealthy outcomes for the caregivers. These outcomes would need to be evaluated. Examples of other applicable interventions based on caring needs include strategies for conflict resolution and problem solving, strategies for restructuring specific day-to-day overall caring processes, and strategies for using family and spiritual resources over time to their best advantage. When using these strategies in caring situations, professional nurses need to, of course, assess the caregiver's and family's readiness to participate and, finally, evaluate the resultant outcomes.

Finally, all nurses need to test the results of each implemented strategy and evaluate the UFCs' and their family's satisfaction or resultant health (see Table 7). Health is evaluated by determining if a balance exists among the domains of caring and if the person exhibits and/or expresses feelings of well-being. This is expressed as peace within one's self, rewards gained through the caring process, and love within the family. The questions center around determining a balance of caring actions, caring family functions, and caring expressions (e.g., Are the UFCs and their families stable and in control of their caring circumstances and do they demonstrate growth and spirituality?).

Using these approaches of assessment, intervention, and evaluation, it is anticipated that professional nurses can foster, strengthen, and maintain healthy caring for UFCs of persons with stroke within their African American family settings. This results in satisfaction for nurses as well as their clients.

RECOMMENDATIONS FOR FURTHER RESEARCH

Caring is a process, not just a set of services. Research on delivery of services in regard to caring processes needs to be accomplished. Overall, there is a need for research to focus on gaining a greater understanding about how cultural attitudes toward caring influence the quality of caring provided, how family and cultural expectations fit with actual or potential services and need, and how race or ethnic groups actually access available services. More research is needed to determine if changing social trends (e.g., living alone) influence the caring needed by different groups in similar ways. There is much interest in current research that focuses on differences at the individual level. Expanded studies are needed of ethnic community values and the degree of adherence to these values by families. Conducting local studies of minority race or ethnic groups, despite the limits to generalizability or transferability, is valuable. However, research is needed to integrate knowledge of local caring processes and outcomes across communities and with those of national studies.

Further nursing research is needed and the ethnographic method can be an important way to discover not only the experience but also the meaning of caring processes. This method was especially valuable, wherein the experience and meaning of caring in urban African American families for healthcare providers, UFCs, and most importantly, their care recipients was discovered and understood. Replication of this study is indicated, not only with other cultural groups, but also in other geographical areas in urban, suburban, and rural community settings.

Research to discover the experience and meaning of caring for caregivers in these cultures and settings, as well as with larger sample sizes, persons with other diagnoses, and more men as informants would be beneficial, in that the knowledge base about caring would expand. Research is also recommended with caregivers who are at the same point in time in the caring process since the stroke event happened and also with care recipients who suffer either right- or left-brain damage, but not both in the same study. Further research of care recipients' worldviews would also be important to extend the knowledge about the experience and meaning of caring. Also, a longitudinal study would provide for increased understanding of the experience and meaning of caring as an interpersonal process between caregivers, care recipients, and remaining family; would more clearly describe commonalities and differences of the caring actions, caring family functions, and caring expressions for those involved in the caring situation; and would further test explications based on assumptions fundamental to Friedemann's (1995) Framework of Systemic Organization. Although fraught with complications, a longitudinal study could be implemented by making contracts with interested individuals to maintain contact with the researcher throughout the period of investigation. Incentives would need to be built into the contract to maintain the persons' interest in continuing with the project.

Additional nursing research, using appropriate methods, is recommended to augment the caring domains discovered in this study. Triangulation of methods could be considered in examining the experience and meaning of caring. Meshing ethnographic interview and observation/participation data collection techniques with questionnaires to ascertain emotional burden or Friedemann's (1991) instrument for families to estimate the level of their health would be beneficial. Also, tools that measure individual satisfaction, family satisfaction, or well-being, as long as they are consistent with the theoretical tenets, need to be considered.

Other nurse researchers planning studies focused on caring might consider implementing and evaluating the suggested interventions that the UFCs recommended and the personal self-maintenance strategies they found valuable, presented in Table 4, to achieve a healthy experience of caring. And finally, further research needs to determine the consequences of variations in long-term caring for the well-being of African Americans and other minorities (in terms of health) and their families (in terms of the quality of relationships). Insight is needed into the emic perspective of caring on a broader scale. Another component that needs investigation concerns how changes in type and extent of disability within various race or ethnic groups interface with changes in resilience of caring networks in response to the changing disability.

SUMMARY OF CHAPTER

In this final chapter, a theoretical discussion of the experience and meaning of caring for UFCs of persons with stroke within their African American families, relevant to Friedemann's (1995) Framework of Systemic Organization, was presented. The experience and meaning of caring arose through the life process of the family system, which is the process of maintaining and transforming culture. By using the Framework of Systemic Organization and exploring the process that led to congruence or failed to do so, the researcher entered the realm of the family's culture and detected congruence, health or well-being, along with the roots of fulfillment and the pain or grief resulting from failure. Thus, the framework provided a broad theoretical foundation and specific processes were explicated to describe the experience and meaning of caring from an African American family perspective.

Important limitations for this study included measurability of concepts and transferability of the findings. The domains of caring identified contained a multitude of concepts revealed in the taxonomic analysis. The data analysis process was arduous, as the caring expressions were drawn to more than one of Friedemann's (1995) systemic targets. The measurement of congruence, health or well-being, was also a difficult undertaking. A balance of the systemic targets had to occur, in that persons had to be reasonably satisfied with themselves, their families, and the environment. Thus the measurement of health was a multifaceted undertaking. Another constraint connected to measurement of the concepts occurred with the discovery of cultural patterns. Cultural conclusions cannot be made clearly without comparisons. Before any comparisons can be made, there is a need to examine groups and populations in detail. This study did not allow for comparisons of the concepts between or among groups or populations. Additionally, there were limitations to arrive at theoretical explanations of the data. For example, one must question whether the results would be different with similar areas of brain damage from the stroke for the care recipients.

Transferability of the research must be reassessed in each case in which transfer is proposed. It is not known if the descriptions of design and data provide a sufficient base to permit another to make the needed comparisons of similarity and to enable others interested in making a transfer to reach a conclusion about whether a transfer is possible.

Several implications for the discipline were identified. At the general or broad scope level, as the body of knowledge in regard to caring for persons with stroke in family settings is developed and researched, nursing has an increased base upon which to build practice decisions. The use of the Framework of Systemic Organization by Friedemann (1995) (which incorporates the findings of this study, the caring actions, caring family functions, and caring expressions) at an applied practice level is beneficial in assisting professionals to understand the needs of UFCs of persons with stroke within a family context. Nurses with a broader and fuller understanding of caring can find solutions that truly assist families through continuous assessment, intervention, and evaluation of outcomes.

Further nursing research is needed and the ethnographic method can be an important way to discover not only the experience but also the meaning of caring processes. For example, replication of this study is indicated, not only with other cultural groups, but also in other geographical areas. Research with larger samples, persons with other diagnoses, and more men as informants would be beneficial. Further research of care recipients' worldviews also would be important to extend the knowledge about the experience and meaning of caring. Additionally, a longitudinal study would provide for increased understanding of the experience and meaning of caring as an interpersonal process between caregivers, care recipients, and remaining family; would more clearly describe commonalities and differences of the caring actions, caring family functions, and caring expressions for those involved in the caring situation; and would further test explications based on assumptions fundamental to Friedemann's (1995) Framework of Systemic Organization.

APPENDICES

APPENDIX A

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APPENDIX B

Selected Authors' Work on Caring Compared to the Process Dimensions and the Interpersonal System

Author	**Process Dimensions**		
Caring As:	**System Maintenance and Change** Interpersonal System	**Coherence** Interpersonal System	**Individuation** Interpersonal System
Noddings (1984)	A caring relationship is reciprocal; both individuals have potential for enhancement through the caring relationship; human systems are maintained and changed; caring is an end in itself; the relationship is valued over the outcome.		
Mayeroff (1971)	Signifies helping the other grow regardless of the kind of relationship; caring is reciprocal or egalitarian;		Separates mind and body; caring takes place in the mind and refers to the ability to know another individual; a present and future

(table continues)

Author	**Process Dimensions**		
Caring As:	**System Maintenance and Change**	**Coherence**	**Individuation**
	Interpersonal System	Interpersonal System	Interpersonal System
Mayeroff (continues)	human systems are maintained and changed.		orientation is emphasized; space is an absolute and time is directional and linear; caring leads to growth fundamentally for the one receiving care, the one caring grows by enhanced self-knowledge.
Watson (1979, 1988)	Relationship of self and other is characterized by mutuality in the power relationship; both benefit from the relationship and experience enhancement; human system are maintained and changed.	An interpersonal process.	

(table continues)

Author	**Process Dimensions**		
Caring As:	**System Maintenance and Change**	**Coherence**	**Individuation**
	Interpersonal System	Interpersonal System	Interpersonal System
Buber (1965)	"Feeling the address," full receptivity is central to caring (p.11); originates from the ability to be open to the claim of another individual; to engage in a living dialogue; through this dialogue living, systems are maintained and changed; the outcome of this lived dialogue is unimportant; mutuality and reciprocity of awareness prevail in the caring relationship; caring is an end in itself.		

(table continues)

Author	**Process Dimensions**		
Caring As:	**System Maintenance and Change** Interpersonal System	**Coherence** Interpersonal System	**Individuation** Interpersonal System
Friedemann (1995)	Concepts of how maintenance and change occur through the involvement in caring for another person.	The family gains coherence through providing emotional support for one another.	Human interpersonal connection or growth in the interchange with another person; interactional, it may involve systems that are not human, such as the process of finding meaning.

APPENDIX C

Medical College of Ohio

INSTITUTIONAL REVIEW BOARD

MEMORANDUM

TO: Linda Pierce, M.Ed., R.M.
School of Nursing

FROM: Angele McGrady, Ph.D.
Chair, Institutional Review Board

DATE: June 12, 1996

SUBJECT: IRB #96-442 - The Experience and Meaning of Caring for Urban Family Caregivers of Persons with Stroke

---

The above project was reviewed and approved by the chairman of the Institutional Review Board as an <u>expedited review</u>. The full board will review it at its meeting on 1996-06-20.

APPROVAL DATE: 1996-06-12

EXPIRATION DATE: 1997-06-11

It is the responsibility of the Principal Investigator to request reapproval of IRB protocols which are going to continue beyond the approval period. Research and Grants Administration will try to remind the P.I. when these requests are due. However, it is recommended that you have a reminder system in place in your office to initiate the reapproval process at least a month prior to the expiration date shown above.

IF ANY UNTOWARD INCIDENTS OR UNANTICIPATED ADVERSE REACTIONS SHOULD DEVELOP IN THE COURSE OF YOUR RESEARCH ON HUMAN SUBJECTS, YOU MUST PROMPTLY NOTIFY THE INSTITUTIONAL REVIEW BOARD OFFICE AT 381-4251.

AMcG:mt

Medical College of Ohio

INSTITUTIONAL REVIEW BOARD

MEMORANDUM

TO: Linda Pierce, M.Ed., R.M.
School of Nursing
MCO

FROM: Angele McGrady, Ph.D.
Chair, Institutional Review Board

DATE: May 19, 1997

SUBJECT: IRB #96-442 - The Experience and Meaning of Caring for Urban Family Caregivers of Persons with Stroke

---

The above protocol was reviewed and reapproved by the Institutional Review Board at its meeting on 1997-05-15. The project is reapproved for a period of up to one year.

CONTINUING REVIEW DATE: 1997-05-15

EXPIRATION DATE: 1998-05-14

REMINDER: As of December 5, 1996, Federal regulations require that subjects, or their legal representatives, date the informed consent form at the time they sign the form to give consent to participate in the study.

If any changes in procedures, key personnel, or in the consent/assent form(s) for this protocol need to be made, it is your responsibility to request IRB review and approval of those changes by sending a memo and the revised consent documents, if applicable, with the revisions highlighted, to me. Prior approval must be received before making those changes.

It is the responsibility of the Principal Investigator to request reapproval of IRB protocols which are going to continue beyond the approval period. Research and Grants Administration will try to remind the P.I. when these requests are due. However, it is recommended that you have a reminder system in place in your office to initiate the reapproval process at least a month prior to the expiration date shown above.

IF ANY UNTOWARD INCIDENTS OR UNANTICIPATED ADVERSE REACTIONS SHOULD DEVELOP IN THE COURSE OF YOUR RESEARCH ON HUMAN SUBJECTS, YOU MUST PROMPTLY NOTIFY THE INSTITUTIONAL REVIEW BOARD OFFICE AT 381-4251.

Attached please find guidelines for reporting ADVERSE EVENTS and the MCO form to be used for ALL SUCH REPORTS for ALL ACTIVE PROTOCOLS. Make copies of the form for future use. Should you have any questions about the form or its use, contact Kathi Hinrichs, Research and Grants Administration, Block HSB, Rm. 148, Ext. 4252.

Enclosures: A.E. form and guidelines; survey

DHHS MPA #M1358

AMcG/mj

APPENDIX D

Wayne State University
Multiple Project Assurance # M 1261
IRB B03

HUMAN INVESTIGATION COMMITTEE
Room 2238 Gordon H. Scott Hall
540 E. Canfield Avenue
Detroit, MI 48201
Phone: (313) 577-1628
FAX: (313) 577-1941

MEMORANDUM

TO: Linda Pierce, Nursing
413 Loyola Drive
Elyria, Ohio 44035

FROM: Peter A. Lichtenberg, Ph.D., Peter A. Lichtenberg, Ph.D.
Chairman, Behavioral Investigation Committee

SUBJECT: Approval of Protocol # H 07-62-96(B03)-FB; "The Experience and Meaning of Caring for Urban Family Caregivers of Persons with Stroke"

DATE: August 21, 1996

As required under provisions of the Department of Health and Human Service Regulation 45 CFR 46 (as amended) and or other pertinent federal regulations to assure that the rights of human subjects have been protected, **the above protocol and revised informed consent(s)** submitted to/supported by <u>No Funding Requested</u> was approved following **full board review** by the Wayne State University Behavioral Investigation Committee (B03) at its meeting of August 8, 1996.

Since the BIC has not evaluated this proposal for scientific merit except to weigh the risk to the human subjects in relation to potential benefits, this approval does not replace or serve in place of any departmental or other approvals which may be required.

This protocol will be subject to annual review by the BIC.

cc: M. Friedemann/Nursing

Wayne State University
Human Investigation Committee

Behavioral Institutional Review Board
4201 St. Antoine Blvd., 8C
Detroit, MI 48201
(313) 577-1628 Office
(313) 993-7122 Fax

Notice of Protocol Continuation Approval

TO	Linda Pierce Nursing
FROM	Peter A. Lichtenberg, Ph D Peter A. Lichtenberg Chairman, Behavioral Institutional Review Board
DATE	August 14, 1997
RE:	**Re-Approval of Protocol #: H 07-62-96(B03)-FB;** "The Experience and Meaning of Caring for Urban Family Caregivers of Persons with Stroke."

The above protocol, submitted on June 17, 1997, was approved following Full Board review by the Wayne State University Behavioral Institutional Review Board (B03), for the period of August 14, 1997 to August 14, 1998.

This approval does not replace, or serve in place of, any departmental or other approvals that may be required.

Federal regulations require that all research be reviewed at least annually. Approximately two months in advance of the due date you will again receive a Continuation Form to complete. You should be aware that if the report is delinquent it is Federal policy to SUSPEND the study immediately.

All changes or amendments to your protocol or consent form require prior review and approval by the Committee before implementation. You are also required to submit a written description (Adverse Reactions and Unexpected Events Form) for any unexpected, more frequent than expected, more severe than expected, or fatal events to the HIC office and appropriate regulatory agencies with 72 hours of the occurrence.

/la

APPENDIX E

Informed Consent (Interviews) For Key Caregiver Participants

The Experience and Meaning Of Caring For Urban Family Caregivers Of Persons With Stroke

INVESTIGATOR: Linda L. Pierce, RN, MSN

PURPOSE: The purpose of this research study has been explained to me. I am being asked to participate in a study concerning my experience in caring for a person with stroke. The information obtained from this study will be helpful to nurses and other caregivers involved in caring for persons with stroke.

PROCEDURE: If I agree to participate in the study, Linda L. Pierce will conduct three tape recorded interviews, averaging 2 hours in length and 1 week apart, and a fourth meeting, averaging 1 hour in length, with me in my home. During the interviews, I will be asked about my experience in caring for a person with stroke. The discussion will also include how I interpret my situation. During the meeting, I will be asked to review the summary of my responses; I can add or clarify my responses at this time.

RISKS/SIDE EFFECTS: There are no anticipated risks for me. If this study raises questions or makes me aware of problems, I am urged to call Linda L. Pierce at 419/381-5800. If I am too uncomfortable to continue the interview, I or Linda L. Pierce will stop the interview.

BENEFITS: I have been told that the information obtained from this study may benefit nurses in the future by helping them understand caregivers' needs and give better care. I may also learn more about my situation and its effect on my family.

COSTS/COMPENSATION: There are no costs to me for participating other than the time I spend with the investigator. In the unlikely event of injury resulting from this research, I understand that no reimbursement, compensation, or free medical care is available from Wayne State University, Medical College Hospitals, or Linda L. Pierce.

VOLUNTARY PARTICIPATION/WITHDRAWAL: My participation is entirely voluntary. I can refuse to answer questions, withdraw my consent, or discontinue my participation at any time without explanation or penalty.

If I have questions about the study now or in the future, I can contact Linda L. Pierce at 419/381-5800. If I have questions about my rights as a participant in the study, I can contact Dr. Peter Lichtenburg, Chairman of the Behavioral Sciences Research Committee, Wayne State University at 313/577-5174 or Dr. Douglas Wilkerson, Associate Vice President for Research, Medical College of Ohio at 419/381-4251.

Page 1 of 2

CONFIDENTIALITY: All information will remain confidential. The tapes of the interviews, including notes taken by the investigator and any resulting written reports, including quotations, will not contain your name. Tapes of the discussion will be destroyed by fire at the conclusion of the research. Consent forms will be kept in a locked file separate from the interview data and notes so that names cannot be associated with the data. I have been told that the interviews are not legally considered privileged communication.

CONSENT TO PARTICIPATE IN THE RESEARCH STUDY: I have read, or had read to me, all of the above information concerning this research study, including the procedure, possible risks, side effects, and the likelihood of any benefits to me. The content and meaning of the above information has been explained and is understood. All of my questions have been answered. I hereby consent and voluntarily agree to take part in the study. I will receive a signed copy of the consent form.

Participants Signature:____________________Date:__________

Address:____

Telephone:____

Investigator:______________________________Date:__________

APPENDIX F

Informed Consent (Observation-participation Session)

For Key Caregiver Participants

The Experience and Meaning Of Caring For Urban Family Caregivers Of Persons With Stroke

INVESTIGATOR: Linda L. Pierce, RN, MSN

PURPOSE: The purpose of this research study has been explained to me. I am being asked to participate in a study concerning my experience in caring for a person with stroke. The information obtained from this study will be helpful to nurses and other caregivers involved in caring for persons with stroke.

PROCEDURE: If I agree to participate in the study, Linda L. Pierce will meet with me for approximately 4 to 6 hours in my home. During this time, nurse Pierce will observe, participate in, and keep written notes of my caring for a person with stroke.

RISKS/SIDE EFFECTS: This observation-participation session may put stress on my relationship with this person with stroke. If this study raises questions or makes me aware of problems, I am urged to call Linda L. Pierce at 419/381-5800. If I am too uncomfortable to continue the observation-participation session, I or Linda L. Pierce will stop the observation-participation session.

BENEFITS: I have been told that the information obtained from this study may benefit nurses in the future by helping them understand caregivers' needs and give better care. I may also learn more about my situation and its effect on my family.

COSTS/COMPENSATION: There are no costs to me for participating other than the time I spend with the investigator. In the unlikely event of injury resulting from this research, I understand that no reimbursement, compensation, or free medical care is available from Wayne State University, Medical College Hospitals, or Linda L. Pierce.

VOLUNTARY PARTICIPATION/WITHDRAWAL: My participation is entirely voluntary. I can refuse to answer questions, withdraw my consent, or discontinue my participation at any time without explanation or penalty.

If I have questions about the study now or in the future, I can contact Linda L. Pierce at 419/381-5800. If I have questions about my rights as a participant in the study, I can contact Dr. Peter Lichtenburg, Chairman of the Behavioral Sciences Research Committee, Wayne State University at 313/577-5174 or Dr. Douglas Wilkerson, Associate Vice President for Research, Medical College of Ohio at 419/381-4251.

CONFIDENTIALITY: All information obtained will remain confidential. The notes taken by the investigator and any resulting written reports, including quotations, will not contain your name. Notes of the discussion will be destroyed by fire at the conclusion of the research. Consent forms will be kept in a locked file separate from the notes so that names cannot be associated with the data. I have been told that this observation-participation session is not legally considered privileged communication.

CONSENT TO PARTICIPATE IN THE RESEARCH STUDY: I have read, or had read to me, all of the above information concerning this research study, including the procedure, possible risks, side effects, and the likelihood of any benefits to me. The content and meaning of the above information has been explained and is understood. All of my questions have been answered. I hereby consent and voluntarily agree to take part in the study. I will receive a signed copy of the consent form.

Participants Signature:____________________Date:__________

Address:____

Telephone:____

Investigator:______________________________Date:__________

APPENDIX G

Informed Consent (Observation-participation Session)

For General Care-recipient Participants

The Experience and Meaning Of Caring

For Urban Family Caregivers Of Persons With Stroke

INVESTIGATOR: Linda L. Pierce, RN, MSN

PURPOSE: The purpose of this research study has been explained to me. I am being asked to participate in a study concerning my caregiver's experience in caring for a person with stroke. The information obtained from this study will be helpful to nurses and other caregivers involved in caring for persons with stroke.

PROCEDURE: If I agree to participate in the study, Linda L. Pierce will meet with me for approximately 4 to 6 hours in my home. During this time, nurse Pierce will observe, participate in, and keep written notes of my caregiver's caring for me.

RISKS/SIDE EFFECTS: This observation-participation session may put stress on my relationship with my caregiver. If this study raises questions or makes me aware of problems, I am urged to call Linda L. Pierce at 419/381-5800. If I am too uncomfortable to continue the observation-participation session, I or Linda L. Pierce will stop the observation-participation session.

BENEFITS: I have been told that the information obtained from this study may benefit nurses in the future by helping them understand caregivers' needs and give better care. I may also learn more about my situation and its effect on my family.

COSTS/COMPENSATION: There are no costs to me for participating other than the time I spend with the investigator. In the unlikely event of injury resulting from this research, I understand that no reimbursement, compensation, or free medical care is available from Wayne State University, Medical College Hospitals, or Linda L. Pierce.

VOLUNTARY PARTICIPATION/WITHDRAWAL: My participation is entirely voluntary. I can refuse to answer questions, withdraw my consent, or discontinue my participation at any time without explanation or penalty.

If I have questions about the study now or in the future, I can contact Linda L. Pierce at 419/381-5800. If I have questions about my rights as a participant in the study, I can contact Dr. Peter Lichtenburg, Chairman of the Behavioral Sciences Research Committee, Wayne State University at 313/577-5174 or Dr. Douglas Wilkerson, Associate Vice President for Research, Medical College of Ohio at 419/381-4251.

Page 1 of 2

CONFIDENTIALITY: All information obtained will remain confidential. The notes taken by the investigator and any resulting written reports, including quotations, will not contain your name. Notes of the discussion will be destroyed by fire at the conclusion of the research. Consent forms will be kept in a locked file separate from the notes so that names cannot be associated with the data. I have been told that this observation-participation session is not legally considered privileged communication.

CONSENT TO PARTICIPATE IN THE RESEARCH STUDY: I have read, or had read to me, all of the above information concerning this research study, including the procedure, possible risks, side effects, and the likelihood of any benefits to me. The content and meaning of the above information has been explained and is understood. All of my questions have been answered. I hereby consent and voluntarily agree to take part in the study. I will receive a signed copy of the consent form.

Participants Signature:____________________Date:__________

Address:____

Telephone:____

Investigator:______________________________Date:__________

APPENDIX H

Informed Consent (Interviews) For General Caregiver Participants

The Experience and Meaning Of Caring For Urban Family Caregivers Of Persons With Stroke

INVESTIGATOR: Linda L. Pierce, RN, MSN

PURPOSE: The purpose of this research study has been explained to me. I am being asked to participate in a study concerning my experience in caring for a person with stroke. The information obtained from this study will be helpful to nurses and other caregivers involved in caring for persons with stroke.

PROCEDURE: If I agree to participate in the study, Linda L. Pierce will conduct one (1) tape recorded interview, averaging 1 hour in length, with me in my home. During the interview, I will be asked about my experience in caring for a person with stroke. The discussion will also include how I interpret my situation.

RISKS/SIDE EFFECTS: There are no anticipated risks for me. If this study raises questions or makes me aware of problems, I am urged to contact Linda L. Pierce at 419/381-5800. If I am too uncomfortable to continue the interview, I or Linda L. Pierce will stop the interview.

BENEFITS: I have been told that the information obtained from this study may benefit nurses in the future by helping them understand caregivers' needs and give better care. I may also learn more about my situation and its effect on my family.

COSTS/COMPENSATION: There are no costs to me for participating other than the time I spend with the investigator. In the unlikely event of injury resulting from this research, I understand that no reimbursement, compensation, or free medical care is available from Wayne State University, Medical College Hospitals, or Linda L. Pierce.

VOLUNTARY PARTICIPATION/WITHDRAWAL: My participation is entirely voluntary. I can refuse to answer questions or withdraw my consent at any time without explanation or penalty.

If I have questions about the study now or in the future, I can contact Linda L. Pierce at 419/381-5800. If I have questions about my rights as a participant in the study, I can contact Dr. Peter Lichtenburg, Chairman of the Behavioral Sciences Research Committee, Wayne State University at 313/577-5174 or Dr. Douglas Wilkerson, Associate Vice President for Research, IRB, Medical College of Ohio at 419/381-4251.

Page 1 of 2

CONFIDENTIALITY: All information will remain confidential. The tapes of the interviews, including notes taken by the investigator and any resulting written reports, including quotations, will not contain your name. Tapes of the discussion will be destroyed by fire at the conclusion of the research. Consent forms will be kept in a locked file separate from the interview data and notes so that names cannot be associated with the data. I have been told that this interview is not legally considered privileged communication.

CONSENT TO PARTICIPATE IN THE RESEARCH STUDY: I have read, or had read to me, all of the above information concerning this research study, including the procedure, possible risks, side effects, and the likelihood of any benefits to me. The content and meaning of the above information has been explained and is understood. All of my questions have been answered. I hereby consent and voluntarily agree to take part in the study. I will receive a signed copy of the consent form.

Participants Signature:____________________Date:__________

Address:____

Telephone:______________________________________

Investigator:______________________________Date:__________

APPENDIX I

Topical Interview Guide

Demographic information:

Question: 1) Tell me about yourself and your family.

The experience and meaning of caring:

General Questions: 1) What is a typical day like for you in caring for (**insert name of person receiving care**)? Describe the day. 2) Was yesterday a typical day in caring for (   )? If not, what was different?

Probe for the experience of caring:

System maintenance

Questions: 1) What are some caring things (actions) done by you in caring for (   ) on a daily basis; in the day and evening? 2) Who is responsible for caring actions in your family? 3) Who makes the decisions about caring in your family? 4) What caring actions are done to organize/operate the day-to-day business of caring in your family? 5) What gets you through the day and helps in maintaining your life in caring for (   )? 6) If you had in your family of origin experience with caring in the past, is your current way of caring for (   ) done a lot like this? 7) What things about caring are you sharing and teaching other family members? Give examples. 8) What are some ways that your family uses the community, such as organizations, neighbors, or churches, to support caring efforts? Give examples and describe.

System change

Questions: 1) What are some things that have changed in the family since (   ) had the stroke? Describe changes for self; changes for other family members and what steps have you had to take in order to make these changes? 2) What are some new or different recent caring actions you have used with (   ); what causes you to use them; what made you change; and in what ways are they different? 3) If you do something different in caring for ( ), in what way did family members react? 4) In what way do caring activities interfere with the family's normal activities? 5) What do you do about activities or schedules that conflict with caring actions that need to be done for ( )? Give an example and describe. 6) What are some attitudes, beliefs, or ideas that have changed in your family since you have been involved in the caring situation? 7) If family members have changed, in what way does this affect you personally and the way you care for ( )? Give an example. 8) What will the future be like for you and your family?

Coherence

Questions: 1) What are some actions done in caring for ( ) that your family uses to promote togetherness? 2) In what ways do you spend time and energy in the caring situation? Give examples. 3) In what ways do others in the family show that they are caring about you? Give examples. 4) What are some of the things that your family does to help each other in caring for ( ) and in what way does this help you get through the day? 5) What are some of the ways that your family works together as a group in caring for ( )? 6) What are some of the ways that the members of your family help each other to solve problems related to the caring situation? Describe a situation. 7) What kind of concerns, worries, and problems can you share with one another about caring for ( )? Describe examples. 8) What kind of things keep your family from working together in caring for ( ); what are some conflicts? 9) What is upsetting you about other family members?

Individuation

Questions: 1) In what way are there differences in opinions and attitudes of family members about the care of ( ); do they cause difficulties for you? Describe them. 2) Are there disagreements? If yes, how are the disagreements resolved? 3) What are some of the abilities of different family members used in caring for ( )? 4) Basically, is caring for ( ) a good experience or a burden? 5) In what way(s) is caring a learning and growth producing experience for you and your family? 6) What have you learned from caring for ( ) and what have you learned about yourself? 7) What is the situation teaching you? 8) What are your feelings about yourself when you get up in the morning? 9) If you feel like you want to give up, what makes you feel that way and how often do you feel that way? 10) What keeps you going? 11) You give so much, what do you receive back? 12) What are some ways that you take care of yourself? 13) Where do you get the energy to do what you need to do in caring for ( )?

Probe for the meaning of caring:

Congruence

Questions: 1) How satisfied are you with your situation? 2) Describe in detail one caring situation that gave you great satisfaction and one caring situation that was dissatisfying to your family. 3) Have you ever thought about the fairness of having to do all this caring? How often? 4) In what ways do you react or respond (anger or depression) with anyone or yourself to the caring situation and what helps you to get over these feelings? 5) In what way(s) does your caring situation have some kind of meaning or purpose? 6) Is religious belief important to you? If so, what has it taught you in this caring situation and how has it helped you feel better about yourself? 7) What makes you happy about the caring situation? 8) What, if any, rewards do receive from the caring situation and from whom? 9) Is caring worth it and what makes it so?

REFERENCES

Aamodt, A. (1977). The social-cultural dimensions of caring in the world of Papago child and adolescent. In M. Leininger (Ed.), *Transcultural nursing care of infants and children: Proceedings From the First Transcultural Nursing Conference* (pp. 44-50). Salt Lake City, UT: University of Utah College of Nursing.

Ablon, J., & Ames, G. (1989). Culture and family. In C. Gillis, B. Highley, B. Roberts, & I. Martinson (Eds.), *Toward a science of family nursing* (pp. 124-125). Menlo Park, CA: Addison-Wesley.

Adams, J. (1980). Service arrangements preferred by minority elderly: A cross-cultural survey. *Journal of Gerontological Social Work, 3*(2), 39-57.

Allen, W. (1978). The search for applicable theories of black family life. *Journal of Marriage and the Family, 40,* 117-129.

American Heart Association. (1990). *About high blood pressure in African-Americans.* Dallas, TX: Author.

Anetzberger, G. (1987). *The etiology of elder abuse by adult offspring.* Springfield, IL: Charles C. Thomas.

Archbold, P., Stewart, B., Greenlick, M., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health, 13,* 375-384.

Baines, E. (1984). Caregiver stress in the older adult. *Journal of Community Health Nursing, 4,* 257-263.

Baines, E., & Oglesby, F. (1992). The elderly as caregivers of the elderly. *Holistic Nursing Practice, 7*(1), 61-69.

Baldwin, B. (1988). Community management of Alzheimer's disease. *Nursing Clinics of North America, 23*(1), 47-56.

Baumgart, A., & Larsen, J. (1988). *Canadian nursing faces the future: Development and change.* Toronto, ON, Canada: Mosby.

Bauwens, E., & Anderson, S. (1992). Social and cultural influences on health care. In M. Stanhope & J. Lancaster (Eds.), *Community health nursing process and practice for promoting health* (pp. 91-107). St. Louis, MO: Mosby.

Benner, P., & Wrubel, J. (1989). *The primacy of caring: Stress and coping in health and illness.* Menlo Park, CA: Addison-Wesley.

Bevis, E. (1981). Caring: A life force. In M. Leininger (Ed.), *Caring: An essential human need* (pp. 49-60). Thorofare, NJ: Slack.

Boaz, R., & Hu, J. (1997). Determining the amount of help used by disabled elderly persons at home. *Journal of Gerontological Social Sciences, 52B*(6), S317-S324.

Bowdoin, C. (1994). Commentary on new diagnosis: Caregiver role strain. *AACN Nursing Scan in Critical Care, 4*(1), 23.

Bowers, B. (1987). Intergenerational caregiving: Adult caregivers and their aging parents. *Advances in Nursing Science, 9,* 20-31.

Broderick, J., Brott, T., Kothari, R., Miller, R., Khoury, J., Pandoli, A., Gebel, J., Mills, D., Minneci, L., & Shukla, R. (1998). The greater Cincinnati/northern Kentucky stroke study: Preliminary first-ever and total incidence rates of stroke among blacks. *Stroke: A Journal of the American Heart Association, 29*(2), 415-425.

Brody, J. (1988). Virtue ethics, caring and nursing. Scholarly *Inquiry for Nursing Practice: An International Journal, 2*(2), 87-101.

Bronstein, K., Popovich, J., & Stewart-Amidei, C. (1991). *Promoting stroke recovery.* St. Louis, MO: Mosby.

Bruyn, S. (1966). *The human perspective in sociology: The methodology of participant observation.* Englewood Cliffs, NJ: Prentice Hall.

Buber, M. (1965). *Between man and man.* New York: MacMillan.

Bunting, S. (1989). Stress on caregivers of the elderly. *Advances in Nursing Science, 11*(2), 63-73.

Burgener, S., & Chiverton, P. (1992). Conceptualizing psychological well-being in cognitively-impaired older persons. *Image: Journal of Nursing Scholarship, 24*(3), 209-213.

Burns, N., & Groves, S. (1993). *The practice of nursing research.* Philadelphia: W.B. Saunders.

Cameron, C. (1990). *An ethnonursing study of the influence of extended caregiving on the health status of elderly Anglo-Canadian wives caring for physically disabled husbands.* Unpublished doctoral dissertation, Wayne State University, Detroit, MI.

Cantor, M. (1983). Strain among caregivers: A study of experience in the United States. *Gerontologist, 23,* 597-604.

Carlson, R., & Keller, M. (1992). Control over daily life and caregiver burden: Little things do count. *Rehabilitation Nursing Research, 1*(1), 6-13.

Chatters, L., Taylor, R., & Jackson, J. (1985). Size and compositions of the informal helper networks of elderly blacks. *Journal of Gerontology, 40,* 605-614.

Chenoweth, B., & Spenser, B. (1986). Dementia: The experience of family caregivers. *The Gerontologist, 26*(3), 267-272.

Cherlin, J., & Furstenburg, F. (1986). *The new American grandparent.* New York: Basic Books.

Chesla, C., Martinson, I., & Muwaswes, M. (1994). Continuities and discontinuities in family members' relationships with Alzheimer's patients. *Family Relations, 43,* 3-9.

Christensen, B. (1991). Family dissolution and health care crisis. In *When families fail...the social costs* (pp. 67-83). Lanham, MD: University Press of America.

Davis, L., & Grant, J. (1994). Constructing the reality of recovery: Family home care management strategies. *Advances in Nursing Science, 17*(2), 66-76.

Dawson, T. (1987). Be stroke smart. Denver, CO: National Stroke Association.

Dellasega, C. (1991). Caregiving stress among community caregivers for the elderly: Does institutionalization make a difference? Journal of Community Health Nursing, 8(4), 197-205.

Devine, J., & Wright, J. (1993). The greatest of evils: Urban poverty and the American underclass. New York: Aldine De Gruyter.

Deimling, G., & Bass, D. (1986). Symptoms of mental impairment among elderly adults and their effects on family caregivers. Journal of Gerontology, 26, 253-259.

Draper, B., Poulos, C., Cole, A., Poulos, R.,& Ehrlich, F. (1992). A comparison of caregivers for elderly stroke and dementia victims. Journal of the American Geriatrics Society, 40(9), 896-901.

Ekberg, J., Griffith, N., & Foxall, M. (1986). Spouses burnout syndrome. Journal of Advanced Nursing, 11(2), 161-165.

Evans, R., Bishop, D., & Ousley, R. (1992). Providing care to persons with physical disability: Effect on family caregivers. American Journal of Physical Medicine & Rehabilitation, 71(3), 140-144.

Evans, R., Hendricks, R., Haselkorn, J., Bishop, D., & Baldwin, D. (1992). The family's role in rehabilitation: A review of the literature. American Journal of Physical Medicine and Rehabilitation, 71(3), 135-139.

Fanslow, J. (1987). Compassionate nursing care: Is it not a lost art? Journal of Practical Nursing, 37(2), 40-43.

Farran, C., Keane-Hagerty, E., Salloway, S., Kupferer, S., & Wilken, C. (1991). Finding meaning: An alternative paradigm for Alzheimer's disease family caregivers. Gerontologist, 31(4), 483-489.

Folkman, S., & Lazarus, R. (1980). An analysis of coping in a middle-aged community sample. Journal of Health and Social Behavior, 21(9), 219-239.

Folkman, S., Lazarus, R., Pimley, S., & Novacek, J. (1987). Age differences in stress and coping process. Psychology and Aging, 2(2), 171-184.

Forrest, D. (1989). The experience of caring. Journal of Advanced Nursing, 14(10), 815-823.

Friedemann, M.-L. (1989a). Closing the gap between grand theory and mental health practice with families. Part 1: The Framework of Systemic Organization for nursing of families and family members. Archives of Psychiatric Nursing, 3(1), 10-19.

Friedemann, M.-L. (1989b). Closing the gap between grand theory and mental health practice with families. Part 2: The control-congruence model for mental health nursing of families. Archives of Psychiatric Nursing, 3(1), 20-28.

Friedemann, M.-L. (1989c). The concept of family nursing. Journal of Advanced Nursing, 14(3), 211-216.

Friedemann, M.-L. (1991). Exploring culture and family caring patterns with the Framework of Systemic Organization. In P. Chinn (Ed.), Anthology on caring (pp. 169-182). New York: National League for Nursing.

Friedemann, M.-L. (1995). The Framework of Systemic Organization: A conceptual approach to practice and research with families and family members. Thousand Oaks, CA: Sage.

Friedemann, M.-L., & Musgrove, J. (1994). Perceptions of inner city substance abusers about their families. Archives of Psychiatric Nursing, 8(2), 115-123.

Gadow, S. (1985). Nurse and patient: The caring relationship. In A. Bishop & J. Scudder Jr. (Eds.), Caring, curing, coping (pp. 31-43). Birmingham, Alabama: The University of Alabama.

Galarneau, L. (1993). An interdisciplinary approach to mobility and safety education for caregivers and stroke patients. Rehabilitation Nursing, 18(6), 395-399.

Gaut, D. (1986). Evaluating caring competencies in nursing. Topics in Clinical Nursing, 8(2), 77-83.

Gaylin, W. (1976). Caring. New York: Knopf.

Gendron, D. (1988). The expressive form of caring. Toronto, ON, Canada: University of Toronto.

George, L., & Gwyther, L. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. Gerontologist, 26, 253-259.

Giordano, J., & Giordano, G. (1977). The ethno-cultural factor in mental health. New York: Institute on Pluralism and Group Identity of the American Jewish Community.

Given, B., King, S., Collins, C., & Given, C. (1988). Family caregivers of the elderly: Involvement and reactions to care. Archives of Psychiatric Nursing, 2(51), 281-288.

Gonzalez, E. (1997). Resourcefulness, appraisals, and coping efforts of family caregivers. Issues in Mental Health Nursing, 18(3), 209-227.

Gonzales, E., Gitlin, L., & Lyons, K. (1995). Review of the literature on African American caregivers of individuals with dementia. Journal of Cultural Diversity, 2(2), 40-48.

Grafstrom, M., Norberg, A., & Hagberg, B. (1993). Relationships between demented elderly people and their families: A follow-up study of caregivers who had previously reported abuse when caring for their spouses and parents. Journal of Advanced Nursing, 18, 1747-1757.

Graham, H. (1983). Caring: A labour of love. In J. Finch & D. Groves (Eds.), A labour of love, women, work, and caring (pp. 13-30). London: Routledge & Kegan Paul.

Grant, J., & Davis, L. (1997). Living with loss: The stroke family caregiver. Journal of Family Nursing, 3(1), 36-56.

Griffin, A. (1980). Philosophy and nursing. Journal of Advanced Nursing, 5(3), 261-272.

Griffin, A. (1983). A philosophical analysis of caring in nursing. Journal of Advanced Nursing, 8(4), 289-295.

Gwyther, L., & Matteson, M. (1983). Care for the caregivers. Journal of Gerontological Nursing, 9(2), 93-95.

Haase, J., Britt, T., Coward, D., Leidy, N., & Penn, P. (1992). Simultaneous concept analysis of spiritual perspective, hope, acceptance and self-transcendence. Image: Journal of Nursing Scholarship, 24(2), 141-147.

Haggard, E. (1949). Psychological causes and results of stress. In Committee on Undersea Warfare (Ed.), Human Factors in Undersea Warfare (pp. 441-461). Washington, DC: National Research Council.

Helman, C. (1984). Culture, health and illness. Bristol, England: John Wright and Sons.

Hines-Martin, V. (1992). A research review: Family caregivers of chronically ill African-American elderly. Journal of Gerontological Nursing, 18(2), 25-29.

Hinrichsen, G., & Niederehe, G. (1994). Dementia management strategies and adjustment of family members of older patients. Gerontologist, 34, 95-102.

Hirschfield, M. (1983). Home care versus institutionalization: Family caregiving and senile brain disease. International Journal of Nursing Studies, 20(1), 22-32.

Homer, A., & Gilleard, C. (1990). Abuse of elderly people by their carers. British Medical Journal, 310, 1359-1362.

Horn, B. (1978). Transcultural nursing and child-rearing of Muckleshoot people. In M. Leininger (Ed.), Transcultural nursing: Concepts, theories, and practice (pp. 223-239). New York: Wiley & Sons.

Horner, S. (1988). Intersubjective co-presence in a caring model. In Caring and nursing explorations in the feminist perspective (pp. 166-180). Denver, CO: Center for Human Caring, University of Colorado Health Services Center.

Hwalek, M., & Sengstock, M. (1986). Assessing the probability of abuse of the elderly: Toward development of a clinical screening instrument. Journal of Applied Gerontology, 5, 153-173.

Jamieson, A. (1992). Home care in old age: A lost cause? Journal of Health Politics, Policy and Law, 17(4), 879-898.

Jones, P., & Martinson, I. (1992). The experience of bereavement in caregivers of family members with Alzheimer's disease. Image: Journal of Nursing Scholarship, 24(3), 172-176.

Kahan, J., Kemp, B., Staples, F., & Brummel-Smith, K. (1985). Decreasing burden in families caring for a relative with a dementing illness. Journal of American Geriatrics Society, 33(10), 664-670.

Kaufman, D. (1990). Engendering family theory. In J. Sprey (Ed.), Fashioning family theory (pp. 107-135). Newbury Park, CA: Sage.

Kaye, J., & Robinson, K. (1994). Spirituality among caregivers.

Image: Journal of Nursing Scholarship, 26(3), 218-221.

Kelly, J. (1994a). African American caregivers: Perceptions of the caregiving situation and factors influencing the delay of the institutionalization of elders with dementia. The ABNF Journal, 5(4), 106-109.

Kelly, J. (1994b). Caregivers: Managing health care at home. The ABNF Journal, 5(4), 101.

Kinshef, C., & Yeolin, M. (1981). Differential use of informal and formal helping networks among rural elderly black and white Floridians. Journal of Gerontological Social Work, 3(3), 45-59.

Klass, D., & Gordon, A. (1978-79). Varieties of transcending experiences in death: A videotape-based study. OMEGA-Journal of Death and Dying, 9, 19-36.

Knowlden, V. (1988). Nurse care as constructed knowledge. In Caring and nursing explorations in the feminist perspective (pp. 318-339). Denver, CO: Center for Human Caring, University of Colorado Health Services Center.

Kumabe, K., Nishida, C., & Hepworth, D. (1985). Bridging ethnocultural diversity in social work and health. Honolulu, HI: University of Hawaii.

Lazarus, R. (1966). Psychological stress and coping process. New York: McGraw-Hill.

Lea, A. (1994). Nursing in today's multicultural society: A transcultural perspective. Journal of Advanced Nursing, 20, 307-313.

Leininger, M. (1970). Nursing and anthropology: Two worlds to blend. New York: Wiley & Sons.

Leininger, M. (Ed.). (1978). Transcultural nursing theories and research approaches. In Transcultural nursing: Concepts, theories, and practice (pp. 31-51). New York: Wiley & Sons.

Leininger, M. (Ed.). (1981). The phenomenon of caring: Importance, research questions and theoretical considerations. In Caring: An essential human need (pp. 3-16). Thorofare, NJ: Slack.

Leininger, M. (Ed.). (1984). Southern rural Black and White American lifeways with focus on care and health phenomena. In Care: The essence of nursing and health (pp. 133-160). Thorofare, NJ: Slack.

Leininger, M. (Ed.). (1985). Ethnography and ethnonursing: Models and modes of qualitative data analysis. In Qualitative research methods in nursing (pp. 33-72). Orlando, FL: Grune & Stratton.

Leininger, M. (Ed.). (1988). The phenomenon of caring: Importance, research questions and theoretical considerations. In Caring: An essential human need (pp. 3-16). Detroit, MI: Wayne State University Press.

Leininger, M. (1990). Ethnomethods: The philosophic and epistemic bases to explicate transcultural nursing knowledge. Journal of Transcultural Nursing, 1, 40-51.

Leininger, M. (Ed.). (1991a). Ethnonursing: A research method with enablers to study the theory of culture care. In *Culture care diversity and universality: A theory of nursing* (pp. 73-118). New York: National League for Nursing.

Leininger, M. (Ed.). (1991b). The theory of culture care diversity and universality. In *Culture care diversity and universality: A theory of nursing* (pp. 5-68). New York: National League for Nursing.

Leininger, M. (1993). Culture care theory: The comparative global theory to advance human care nursing knowledge and practice. In D. Gaut (Ed.), *A global agenda for caring* (pp. 3-18). New York: National League for Nursing.

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry.* Newbury Park, CA: Sage.

Lindgren, C. (1990). Burnout and social support in family caregivers. *Western Journal of Nursing Research, 12*(4), 469-487.

Lindgren, C. (1993). The caregiver career. *Image: Journal of Nursing Scholarship, 25*(3), 214-219.

Luckey, I. (1994). African-American elders: The support network of generational kin. *Families in Society: The Journal of Contemporary Human Services, 75*(2), 82-89.

Lyden, P. (1997). Magnitude of the problem of stroke and the significance of acute intervention. *Proceedings of the National Institute of Neurological Disorders and Stroke, USA,* 1-4.

Malinowski, B. (1922). *Argonauts of the Western Pacific.* London: Routledge.

Markson, E. (1979). Ethnicity as a factor in the institutionalization of the ethnic elderly. In E. Gelfand & A. Kutzik (Eds.), *Aging and ethnicity* (pp. 341-356). New York: Springer.

Martin, B., & Belcher, J. (1986). Influence of cultural background on nurses' attitudes and care of the oncology patient. *Cancer Nursing, 9*(5), 230-237.

Martin, E., & Martin, J. (1978). *The black extended family.* Chicago: University of Chicago.

May, R. (1969). *Love and will.* New York: Norton & Co.

Mayeroff, M. (1971). *On caring.* New York: Harper & Row.

McAdoo, H. (1993). *Family ethnicity: Strength in diversity.* Newbury Park, CA: Sage.

McCrae, R. (1982). Age differences in the use of coping mechanisms. *Journal of Gerontology, 17*(4), 454-460.

McFarlane, J. (1976). A charter for caring. *Journal of Advanced Nursing, 1*(5), 187-196.

Mercer, R. (1989). Theoretical perspectives on the family. In C. Gilliss, B. Highley, B. Roberts, & I. Martinson (Eds.), *Toward a science of family nursing* (pp. 9-36). Menlo Park, CA: Addison-Wesley.

Miller, B. (1987). Gender and control among spouses of the cognitively impaired: A research note. Gerontologist, 27, 447-453.

Minuchin, P. (1985). Families and individual development: Provocations from the field of family therapy. Child Development, 56(2), 289-302.

Mitchell, J., & Register, J. (1984). An exploration of family interaction with the elderly by race, socioeconomic status, and residence. The Gerontologist, 24(1), 48-54.

Montgomery, R., Gonyea, J., & Hooyman, N. (1980). Caregiving and the experience of subjective and objective burden. Family Relations, 34(1), 19-26.

Montgomery, R., Stull, D., & Borgatta, E. (1985). Measurement and the analysis of burden. Research on Aging, 7, 137-152.

Morse, J., Bottorff, J., Neander, N., & Solberg, S. (1991). Comparative analysis of conceptualizations and theories of caring. Image: Journal of Nursing Scholarship, 23(2), 119-126.

Morycz, R., Malloy, J., Bozich, M., & Martz, P. (1987). Racial differences in family burden: Clinical implications for social work. In R. Dobrof (Ed.), Gerontological social work with families (pp. 133-154). New York: Haworth Press.

Musolf, J. (1991). Easing the impact of the family caregiver's role. Rehabilitation Nursing, 16(2), 82-84.

Neundorfer, M. (1991). Coping and health outcomes in spouse caregivers of persons with dementia. Nursing Research, 40(5), 260-265.

Nkongho, N., & Archbold, P. (1995). Reasons for caregiving in African American families. Journal of Cultural Diversity, 2(4), 116-123.

Noelker, L., & Poulshock, S. (1982). The effects on families of caring for impaired elderly in residence. Washington, DC: Administration on Aging.

Noddings, N. (1984). Caring: A feminine approach to ethics and moral education. Berkley, CA: University of California.

Nolan, M., & Grant, G. (1989). Addressing the needs of informal carers: A neglected area of nursing practice. Journal of Advanced Nursing, 14(11), 950-961.

O'Neill, C., & Sorensen, E. (1991). Home care of the elderly: A family perspective. Advances in Nursing Science, 13(4), 28-37.

Orem, D. (1995). Nursing: Concepts of practice. St. Louis, MO: Mosby.

Payne, M. (1988). Utilizing role theory to assist the family with sudden disability. Rehabilitation Nursing, 13(4), 191-194.

Pearlin, L., Mullan, J., Semple, S., & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. Gerontologist, 30, 583-591.

Pepin, J. (1992). Family caring and caring in nursing. Image: Journal of Nursing Scholarship, 24(2), 127-131.

Periard, M. (1989). Perceptual factors in the caregiver-care receiver relationship: Impact on caregiver strain. Unpublished doctoral dissertation, Michigan State University, Lansing, MI.

Periard, M., & Ames, B. (1993). Lifestyle changes and coping patterns among caregivers of stroke survivors. Public Health Nursing, 10(4), 252-256.

Periard, M., & Rempusheski, V. (1986). Caring for the frail elderly at home: Toward a theoretical explanation of the dynamics of poor quality family caregiving. Advances in Nursing Science, 10(2), 59-72.

Phillips, L., & Rempusheski, V. (1986). Caring for the frail elderly at home: Toward a theoretical explanation of the dynamics of poor quality family caregiving. Advances in Nursing Science, 8, 62-84.

Picot, S. (1995). Choice and social exchange theory and the rewards of African American caregivers. Journal of National Black Nurses Association, 7(2), 29-40.

Pierce, L., Ader, K., & Peter, P. (1989). Caregiver burden and coping strategies. The American Journal of Alzheimer's Care and Related Disorders & Research, 4(5), 36-41.

Pierce, L., & Salter, J. (1988). Stroke support group: A reality. Rehabilitation Nursing, 13(4), 189-190, 197.

Pillemer, K. (1985). The dangers of dependency: New findings on domestic violence against the elderly. Social Problems, 33, 146-158.

Pillemer, K., & Finkelhor, D. (1989). Causes of elder abuse: Caregiver stress vs. problem relations. American Journal of Orthopsychiatry, 59(2), 179-187.

Polit, D., & Hungler, B. (1995). Nursing research: Principles and methods. Philadelphia: J.B. Lippincott.

Poulshock, S., & Deimling, G. (1984). Families caring for elders in residence: Issues in the measurement of burden. Journal of Gerontology, 39, 230-239.

Pratt, C., Schmall, V., Wright, S., & Cleland, M. (1985). Burden and coping strategies of caregivers to Alzheimer's patients. Family Relations, 34(1), 27-33.

Price, M. (1994). African American daughters' attitudes about caregiving to frail, elderly parents. The ABNF Journal, 5(4), 112-116.

Rabins, P., Fitting, M., Eastham, J., & Fetting, J. (1990). The emotional impact of caring for the chronically ill. Psychosomatics, 31(3), 331-336.

Rabins, P., Mace, N., & Lucas, M. (1982). The impact of dementia on the family. Journal of the American Medical Association, 248, 333-335.

Ragucci, A. (1977). The urban context of health beliefs and caring practices of the elderly women in an Italian-American enclave. In M. Leininger (Ed.), Transcultural nursing care of the elderly: Proceedings from the Second National Transcultural Nursing Conference (pp. 33-51). Salt Lake City, UT: University of Utah College of Nursing.

Reed, P. (1982). Well-being and perspectives on life and death among death-involved and non-death involved adults. Unpublished doctoral dissertation, Wayne State University, Detroit, MI.

Reed, P. (1987). Spirituality and well-being in terminally ill hospitalized adults. Research in Nursing and Health, 10, 335-344.

Roach, M. (1992). The human act of caring: A blueprint for health professions. Toronto, ON, Canada: Canadian Hospital Association.

Robinson, B. (1983). Validation of a caregiver strain index. Journal of Gerontology, 38, 344-348.

Robinson, B. (1989). Predictors of depression among wife caregivers. Nursing Research, 38(6), 359-363.

Scharlach, A. (1987). Role strain in mother-daughter relationships in later life. Gerontologist, 27, 627-631.

Schein, E. (1985). Organizational culture and leadership. San Francisco: Jossey-Bass.

Segal, M., & Schall, R. (1996). Life satisfaction and caregiving stress for individuals with stroke and their primary caregivers. Rehabilitation Psychology, 41(4), 303-320.

Sexton, D., & Munro, B. (1985). Impact of husband's chronic illness (COPD) on the spouse's life. Research in Nursing and Health, 8(1), 83-90.

Silliman, R., Fletcher, R., Earp, J., & Wagner, E. (1986). Families of elderly stroke patients: Effects of home care. Journal of the American Geriatrics Society, 34, 643-648.

Smerglia, V., Deimling, G., & Baresi, C. (1988). Black/white family comparisons in helping and decision-making networks of impaired elderly. Family Relations, 37, 305-309.

Smith, H. (1969). The reach and the grasp: Transcendence today. In H. Richardson & D. Cutler (Eds.), Transcendence. Boston: Beacon Press.

Smith, C. (1994). A model of caregiving effectiveness for technologically dependent adults residing at home. Advances in Nursing Science, 17(2), 27-40.

Smith, K., & Bengston, V. (1979). Positive consequences of institutionalization: Solidarity between elderly parents and their middle-aged children. Geronotolgist, 19(5), 438-447.

Spector, R. (1991). Cultural diversity in health an illness (3rd ed.). Norwalk, CT: Appleton & Lange.

Spradley, J. (1979). The ethnographic interview. New York: Holt, Rinehart, & Winston.

Spradley, J. (1980). Participant observation. New York: Holt, Rinehart, & Winston.

Spradley, J., & McCurdy, D. (1988). The cultural experience: Ethnography in complex society. Prospect Heights, IL: Waveland Press.

Stack, C. (1974). All our kin. New York: Harper.

Stack, C. (1996). Call to home. New York: Basic Books.

Stone, R. (1987). Exploding the myths: Caregiving in America (Publication No. 99-611). Washington, DC: House Subcommittee on Human Services.

Stone, R., Cafferata, G., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. Gerontologist, 27(4), 616-626.

Sudarkasa, N. (1988). Interpreting the African heritage in Afro-American family organization. In H. McAdoo (Ed.), Black families (pp. 27-43). Newbury Park, CA: Sage.

Taylor, R. (1985). The extended family as a source of support to elderly Blacks. The Gerontologist, 25, 488-495.

Taylor, R., & Chatters, L. (1986). Patterns of informal support to elderly black adults: Family, friends, and church members. Social Work, 31, 432-438.

Tripp-Reimer, T. (1980). Appalachian health care: From research to practice. In M. Leininger (Ed.), Transcultural nursing care: Teaching, practice and research. Proceedings from the Fifth National Transcultural Nursing Conference (pp. 48-59). Salt Lake City, UT: University of Utah College of Nursing.

U.S. Bureau of the Census. (1990). Statistical abstract of the United States. Washington, DC: U.S. Government Printing Office.

U.S. Bureau of the Census. (1991). Poverty in the United States: 1990. In Current population reports (Series P-60, No. 175). Washington, DC: U.S. Government Printing Office.

U.S. Department of Health and Human Services. (1994). A report of the NINR priority expert panel on long-term care. Bethesda, MD: Author.

Vezeau, T., & Schroeder, C. (1991). Caring approaches: A critical examination of origin, balance of power, embodiment, time and space, and intended outcome. In P. Chinn (Ed.), Anthology on caring (pp. 1-16). New York: National League for Nursing.

Vitaliano, P., Young, H., Russo, J., Romano, J., & Magana-Amato, A. (1993). Does expressed emotion in spouses predict subsequent problems among recipients with Alzheimer's disease? Journal of Gerontology, 48(4), P202-P209.

Wacquant, L., & Wilson, W. (1989). The cost of racial and class exclusion in the inner city. The Annals of the American Academy of Political and Social Science, 501, 8-25.

Ward, D., & Carney, P. (1994). Caregiving women and the U.S. welfare state: The case of elder kin care by low-income women. Holistic Nursing Practice, 8(4), 44-58.

Watson, J. (1979). The philosophy and science of caring. Boston: Little, Brown & Co.

Watson, J. (1988). Nursing: Human science and human care. Norwalk, CT: Appleton-Century-Crofts.

Weiss, C. (1988). Model to discover, validate, and use care in nursing. In M. Leininger (Ed.), *Care: Discovery and uses in clinical and community nursing* (pp. 139-149). Detroit, MI: Wayne State University.

What do we owe the elderly? Allocating social and health care resources. (1994). *Hastings Center Report, 24*(2), S1-12.

Wilkinson, D. (1993). Family ethnicity in America. In H. McAdoo (Ed.), *Family ethnicity: Strength in diversity* (pp. 15-59). Newbury Park, CA: Sage.

Williams, A. (1993). Caregivers of persons with stroke: Their physical and emotional well-being. *Quality of Life, 2*(3), 213-220.

Williams, M., Oberst, M., Bjorklund, B., & Hughes, S. (1996). Family caregiving in cases of hip fractures. *Rehabilitation Nursing, 21*(3), 124-131.

Williams-Burgess, C., & Kimball, M. (1992). The neglected elder: A family systems approach. *Journal of Psychosocial Nursing, 30*(10), 21-25.

Willoughby, J., & Keating, N. (1991). Being in control: The process of caring for a relative with Alzheimer's disease. *Qualitative Health Research, 1*(1), 27-50.

Wilson, H. (1989). Family caregiving for a relative with Alzheimer's dementia: Coping with negative choices. *Nursing Research, 38*(2), 94-98.

Wolf, R. (1988). Elder abuse: Ten years later. *Journal of the Geriatrics Society, 36,* 758-762.

Wolf, R., Strugnell, C., & Godkin, M. (1982). *Preliminary findings from three model projects on elderly abuse.* Worcester, MA: University of Massachusetts Medical Center, Center on Aging.

Wykle, M., & Segal, M. (1991). A comparison of black and white family caregivers experience of dementia. *Journal of National Black Nurses Association, 5*(1), 29-41.

Zarit, S., Reever, K., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist, 20,* 649-655.

Zarit, S., Todd, P., & Zarit, J. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *Gerontologist, 26,* 260-266.

ABSTRACT

THE EXPERIENCE AND MEANING OF CARING FOR URBAN FAMILY CAREGIVERS OF PERSONS WITH STROKE

by

LINDA L. PIERCE

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Co-Advisor: Dr. Marilyn Oberst

Co-Advisor: Dr. Marie-Luise Friedemann

Major: Nursing

Degree: Doctor of Philosophy

This ethnographic study examined the experience and meaning of caring as it influences urban family caregivers' (UFCs) capacity to care for persons with stroke within African American family systems. This study was executed within and supported the Framework of Systemic Organization (Friedemann, 1995), according to which families as open systems strive for congruence, a dynamic state of equilibrium, evidenced as health. In trying to achieve this state, each family's style of function is different, depending on the family's emphasis on Friedemann's process dimensions: system maintenance, system change, coherence, and individuation. The major research questions were the following: (a) What is the experience of caring?—What are the perceived and observed caring actions related to Friedemann's process dimensions? (b) What is the meaning of caring?—What are the perceived and observed personal and family congruence related to caring? and (c) What expressed caring actions and what expressions of congruence are universal or cultural bound? A purposive sample of 8 UFC key informants and 16 UFC general informants from a community in northwestern Ohio participated in interview and observation-participation field techniques. Domains of caring revealed that the experience of caring involved eight caring actions (i.e., caring is physical work, sacrifice, taught and shared, structured, communication, accommodation, mutuality, and learned) and

structured, communication, accommodation, mutuality, and learned) and four caring family functions (i.e., adaptation in families, in caregivers' enforcement of old values, in caregivers' watchfulness, and in differences in filial function). The meaning of caring concerned 13 affective caring expressions (i.e., emotional burden; evasion of conflicts; motivations concerned with love and a sense of duty, care recipients' approval, and philosophical introspection; self-development; fairness; filial ethereal value; self-contemplation; filial and Christian piety; living in the moment and hoping for the future; and purpose). Cultural patterns were maintained and transformed within the domains of caring actions, family functions, and expressions for these UFCs in African American settings. The findings aid in understanding the concept of caring as an interpersonal process, place the concept of caring in a family system context and examine cultural patterns and diversity as well as common trends, and test the propositions underlying the Framework of Systemic Organization.

AUTOBIOGRAPHICAL STATEMENT

NAME: Linda L. Pierce

EDUCATION:

- 1964, Diploma in Nursing, The Toledo Hospital, Toledo, Ohio
- 1982, B.S.N. and 1986, M.S.N., The University of Akron, Akron, Ohio
- 1998, Ph.D., Wayne State University, Detroit, Michigan

PROFESSIONAL POSITIONS:

- 1964-1967,1969-1970, 1972-1982, Staff Nurse, Elyria Memorial Hospital, Elyria, Ohio
- 1967, Staff Nurse, Allen memorial Hospital, Oberlin, Ohio
- 1982-1989, Lorain Community Hospital, Lorain, Ohio
  - 1982-1984, Clinical Nursing Supervisor
  - 1984-1986, Staff Development Instructor
  - 1986-1989, Clinical Nurse Specialist
- 1989-1994, MetroHealth Medical Center, Cleveland, Ohio
  - 1989-1990, Associate Director
  - 1990-1994, Clinical Nurse Specialist
- 1986-present, Medical College of Ohio School of Nursing, Toledo, Ohio
  - 1986-1989, Adjunct Instructor
  - 1989-present, Assistant Professor

PROFESSIONAL MEMBERSHIPS: Sigma Theta Tau International, Delta Omega and Zeta Theta Chapters; Association of Rehabilitation Nurses, North Coast Chapter; American Heart Association, National Stroke Council

HONORS AND AWARDS:

- Graduated Magna Cum Laude, The University of Akron, 1982.
- Distinguished Nursing Alumni Award, The University of Akron College of Nursing, 1990.
- Outstanding Research/Scholarship Faculty Award, Medical College of Ohio School of Nursing, 1995.
- Student Scholarship in Cerebrovascular Disease, National Stroke Council, American Heart Association, 1996.
- Research Award, Delta Omega Chapter, Sigma Theta Tau International, 1997.
- Scholarship, Zeta Theta Chapter, Sigma Theta Tau International, 1997.
- The Dean's Award For Teaching Excellence, Medical College of Ohio School of Nursing, 1997.
- New Investigator Award, Association of Rehabilitation Nurses, 1997.

PUBLICATIONS:

- Pierce, L., & Salter, J. (1997). Family systems theory: A multicultural perspective. In K. Johnson (Ed.), *Advanced practice nursing in rehabilitation: A core curriculum* (pp. 42-50). Glenview, IL: Rehabilitation Nursing Foundation.
- Pierce, L. (1997). The framework of systemic organization applied to older adults as family caregivers of persons with chronic illness and disability. *Gastroenterology Nursing, 20*(5), 168-175.
- Pierce, L. (1994). Fear held by caregivers of people with stroke: A concept analysis. *Rehabilitation Nursing Research, 3*(2), 69-74.