THE LIVED EXPERIENCE OF AFRICAN AMERICAN FEMALE CAREGIVERS
IN A COMMUNITY-BASED SUPPORT PROGRAM:
A HEIDEGGERIAN HERMENEUTIC STUDY

A DISSERTATION
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BY

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To the Associate Vice President for Research and Dean of the Graduate School:

I am submitting herewith a dissertation written by Penny Wolfe Moore entitled "The Lived Experience of African American Female Caregivers in a Community-Based Support Program: A Heideggerian Hermeneutic Study." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Health Education.

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The Musings of a Thankful Heart

[You've]given me so many things intangible and dear, I couldn't begin to count them all or even to make them clear.

I only know I owe so much to people everywhere And when I put my thoughts in here it's just my way to share

The musings of a thankful heart, a heart much like your own, For nothing that I think or write is mine and mine alone. . .

Helen Steiner Rice, 1984, p. 62

Interpretive research turns on the participants involved. "Thank you" to the seven women who shared with me important and intimate aspects of their lives.

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I am blessed with a wonderful family who have been extremely supportive. I am especially grateful for a mother who programmed me since before birth to value education. Mother, this one is for both of us. I love you.

ABSTRACT

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The purpose of this phenomenological study was to describe and interpret the lived experience of African American female caregivers. Through this process common meanings embedded in the experience were uncovered (recovered) and new possibilities for understanding were presented. A purposeful sample of seven (N=7) caregivers was interviewed using an informal conversation style. Interviews were audio-taped and transcribed. Data were analyzed by the researcher and a team of three interpretive researchers. Common themes and descriptive elements were identified using the seven step hermeneutic process. A constitutive pattern, centeredness, and four themes emerged: tradition, maneuvering, religion, and leaping-in/leaping-ahead. The practice of centering presented as the major finding of the research. This pattern exemplified how maintaining a balance became pervasive in the lives of the caregivers and linked the other relational themes. Other new understandings included the denial that caregiving is a burden. Another word, obligation, that is found in caregiving literature was not reflective of feelings and attitudes of these participants. Further research with underrepresented groups is needed to determine how to support caregivers in a culturally sensitive method. These findings should warn researchers to validate labels such as burden, problem, and obligation with participants before assuming such labels describe groupings or clusters of data.

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CHAPTER 1

INTRODUCTION

Many older African Americans are involved in extended family arrangement (Hays & Mindel, 1973; Johnson & Barer, 1990; Taylor & Chatters, 1991). This system provides assistance, exchange of goods and services (Cantor, 1979; Mutran, 1985), child rearing (Burton & Dilworth-Anderson, 1991), and family closeness and satisfaction (Taylor & Chatters). This "family" arrangement is often inadequate to provide the health care support needed. The extent of actual health service needs among African Americans is unclear. Ethnocentric bias in research is partially to blame for this lack of information (American Psychiatric Association, 1994; Krause & Wray, 1991). Underrepresented groups have not been appropriately recruited as participants in clinical studies. Valid research could address issues of ethnic diversity, but the lack of research perpetuates the possible misconception that the problems of older persons within underrepresented groups are related only to the "culture of poverty." Research actually tends to reinforce stereotypes rather than identify needs (Kellogg Foundation, 1995).

Between 1990 and 2030, the older White population is projected to increase by 93%. During this same period, ethnic minority older persons are expected to increase by a staggering 328% (Bureau of Census, 1994). Data from 1985 indicate 35% of African

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Americans over the age of 65 remain below the poverty level (U.S. Department of Commerce, 1986). Despite these statistics, little research focuses on the African American community caregiving experiences.

Dementia is a prevalent problem among older persons (Gonzales, Gitlin, & Lyons, 1995). In spite of this knowledge only one study (Segall & Wykle, 1988-89) examines the unique components of caregiving for the African American population with dementia. Specific information about the caregiving process and support for African Americans is thus sparse.

Social gerontologists have long recognized the influences of culture on the lives of older people. Keith (1990, p. 91) has argued that research investigating social and cultural influences on aging has two important goals: first, the location of the aging experience in specific social, cultural, and subjective contexts and, second, interpretations of the mechanisms through which these contexts influence the experiences of aging. For example, culturally based prescriptions and proscriptions influence patterns of family care for the elderly by defining appropriate behaviors for each gender (Montgomery & Kamo, 1989).

Systems to support family caregivers are slow in developing and have many needs to address. The basic maintenance/custodial supports that can assist older persons to meet their goal of living at home as they age are frequently unavailable and/or unaffordable (Harrington, et al., 1991; Koff, 1988; Sharp, 1992). Current home care systems often lack the structure to provide services and involvement of family and community (Benson &

McDevitt, 1989). Communities are beginning to recognize that custodial/maintenance care and the coordination of care are critical if their older members are to remain in the community. The Living at Home/Block Nurse Program (LAH/BNP) is a program designed to provide the community support system that aging constituents and their caregivers need.

The LAH/BNP, which is being introduced to Texas for the first time (Hall & Butcher, 1996), is modeled after 14 existing programs in three other states. The LAH/BNP is a volunteer-driven, neighborhood organization dedicated to providing a range of services that allows older citizens to remain in their homes. The central principle is "neighbors helping neighbors," where consent, caring, and mutual respect are the basis for all relationships (Jamieson, 1995). This type of community support should enhance the lived experience of those involved in caregiving.

Heideggerian phenomenology provides a way to study experience (Heidegger, 1962). This process helps to disclose and understand the meanings embedded in the everyday world of lived experience (Dreyfus, 1987). Heideggerian phenomenology strives to derive the nature and meaning of Being by understanding some of the possible meanings of Being through personal experience of the world and one's own being within it. Everyday experience as it is lived is the focus of attention with Heideggerian phenomenology. These everyday lived experiences are where meaning resides. Yet because lived experience is everyday and seems so ordinary, much of the meaning is

hidden. Heideggerian phenomenology seems particularly appropriate for studying the lived experiences of African American caregivers.

Purpose

The purpose of this study was to describe the shared experiences and common meanings of African American women who provide care to an older (65 years of age or older) person with the support of the LAH/BNP. There is no problem in interpretive research, only a quest for new understanding.

Interviews based on Heideggerian hermeneutics (Weber, 1986) were conducted by the primary researcher in each caregiver's home. From these interviews thematic analysis, constitutive patterns, and paradigm cases were presented according to hermeneutic procedures (e.g., Diekelmann, Allen, & Tanner, 1989). Excerpts from the narratives were provided to allow the manuscript reader to participate in validation of the findings. A team of three interpretive researchers conducted validation reviews.

Research Questions

For this interpretive research, specific study questions were developed to guide in obtaining information needed to explore the lived experiences of African American female caregivers:

1. What are the interpersonal concerns, feelings, cultural influences, and background meanings involved in the caregiving experience?

2. Do those concerns, feelings, cultural influences, and background meanings change with community support?

3. How is the LAH/BNP embedded into the lived experience of the caregiver?

The Heideggerian interview format did not include asking questions from a formal list. "The very act of posing a question is disclosure, for to question is to sketch in advance the context of meaning in which a particular inquiry will move" (Heidegger, 1969, p. 269). The process was one of conversation with some guidance from the researcher. Each conversation was begun with, "Please share with me what caregiving is like for you." The conversation led beyond the everyday notions of interviewing to the "between" that reveals understanding (Weber, 1986). Conversation sessions continued until the researcher considered the information sufficient to answer the research questions.

Definitions

Five terms were defined for more consistent understanding of the study: (a) caregiver, (b) care recipient, (c) Living at Home/Block Nurse Program, (b) background meanings, and (e) community support. Caregiver for this study was female, provider for at least one-half of the care given to an older person who was considered homebound by the LAH/BNP, and African American. The care recipient was 65 years of age or older, homebound (difficulty in mobility, leaves home rarely and for short periods), and received services from the LAH/BNP. The LAH/BNP was a

well-defined program operated jointly by the specified communities and a health care facility. Background meanings are meanings of life that are everyday, ordinary and thus hidden. Community support is specifically that support provided by the LAH/BNP.

Assumptions and Limitations

Hermeneutics as a methodology and Heideggerian phenomenology required several assumptions. These assumptions included:

1. Human beings are social, dialogical beings.

2. Understanding is always with us in shared backgrounds made up of our societies, cultures, language, skills, activities, and in our intersubjective meanings.

3. We are already in a hermeneutic circle (Hoy, 1978) of understanding.

4. The researcher, on the basis of common background meanings given by culture and language, has a preliminary understanding of the human action being studied.

5. There is no Archimedean point from which one could have a "privileged," foundational view of the world that is atemporal and ahistorical (Benner, 1994, p. 55).

6. The researcher has the expertise to conduct a Heideggerian conversation (interview) for data collection.

7. The team of interpretive researchers who conducted validation reviews are competent and conscientious.

Limitations of this study were:

1. Hermeneutic phenomenology does not aid in prediction.

2. Not all persons, whether potential researchers or participants, are willing or able to participate in this type of research.

3. The framework of understanding, including preconceptions and biases, can prevent the researcher from remaining true to the participants' lived experience.

4. If an interpretive account loses its contextuality and temporality and operates beyond its original context, it may be reduced to what Dreyfus (1991) refers to as "leveling to banality."

5. Content validity may be threatened in a hermeneutic study by social desirability and by the ambiguity inherent in language.

6. The researcher conducting the conversations (interviews) is not of the same cultural background as the participants.

7. The LAH/BNP's prime goal is to keep older adults in their home as long as possible not primarily to support caregivers.

The sample chosen for this study was deliberately diverse so there would be a broad base of experiences on which to draw. Therefore, age or gender of the care recipient, and the amount or kind of service provided by the LAH/BNP were not seen as limitations.

Significance

The intent of this study was to add to understanding by describing the everyday lived experiences of female African American caregivers. Their participation in this research was a part of their personal, ongoing, hermeneutic process of consciously reflecting on their lived experience and interpreting meanings that disclose new possibilities for their being-in-the-world (existence). Heidegger referred to this process as "entering the circle" (Heidegger, 1962). In this way the research has benefited the participants.

A review of literature supports the position that culture plays a role in caring for persons who are older. Underrepresented groups have not been recruited in appropriate numbers as research participants. This research helped fill that void by concentrating on one of the underrepresented groups in society.

Community support systems are becoming increasingly valuable to the care of older adults. One of the LAH/BNP involved in this study was the first in Texas. This study provided valuable feedback related to the service this LAH/BNP provided. The second LAH/BNP in this study was in Alabama and has been serving its neighborhood for eight years. They have included information from this study in their own program evaluation.

CHAPTER 2

LITERATURE REVIEW

The purpose of this study was to describe the shared experiences and common

meanings of African American women who provide care to an older (65 years of age or

older) adult with the support of the Living at Home/Block Nurse Program (LAH/BNP).

Topics that guided the literature review were (a) caregiving, (b) community support

programs, and (c) Heideggerian phenomenology and hermeneutic analysis.

The literature pertaining to caregiving was voluminous; however, studies specific

to African American caregiving were rather sparse. Qualitative/interpretative research in

the area or caregiving was scarce. Criteria for caregiving literature inclusion in this review

were (a) recent (since 1990), (b) pertinent to understanding African American caregiving,

and/or (c) information from non-African American caregiver literature that addressed

obvious deficits in African American-specific research.

Caregiving

Older adults receive most of their care from female family and friends. The impact

of providing this care has been researched from several different perspectives. The burdens

or adverse implications for the caregivers were addressed by McKinley, Crawford, and

Tennstedt (1995). Two other recent studies (Kahn & Eaves, 1996; Nkongho & Archbold,

1995) indicated many positive aspects of caring. A combination of negative and positive aspects of caregiving were reported by Able and Nelson (1990) and Fisher and Tronto (1990).

McKinlay, Crawford, and Tennstedt (1995) examined the impact of caregiving and the effect on the care recipient within the conceptual framework of a stress process. Data were taken from the Massachusetts Elder Health Project (Aneshensel, Pearlin, & Schuler, 1993; Pearlin, Mullan, Semple, & Skaff, 1990; Tennstedt, Crawford, & McKinlay, 1993), a 7-year longitudinal study tracking a representative sample of older (70+) people with functional limitations and a need for assistance with daily activities of living. A stratified random sample of 5,855 people over 70 years of age was drawn from the local census lists of 19 cities in Massachusetts. Telephone interviews were conducted with the entire sample in 1984-1985 (with in-person interviews conducted as required), with three follow-up interviews at 15-month intervals through 1991.

The data were analyzed by principal components followed by varimax rotation. Three factors, or major types of care, were found at each interview: (a) in-home care, (b) out-of-home care, and (c) linkage care. Four areas of negative impact were identified: (a) personal impact (sleep, health, leisure, privacy, financial situation, household chores), (b) family relationships (marriage, children), (c) employment (quit or did not seek), and (d) job structure (change in job, number of hours worked, change in shift).

The greatest impact was on the caregivers' personal life (sleep, health, leisure, privacy, financial situation, household chores). This personal life impact persisted over time and was not relieved by assistance from other sources.

Of significance in contrast to the negative impacts found in other research were findings that identified positive aspects or benefits of caregiving (e.g., Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Long, 1991; Wright, Lund, Caserta, & Pratt, 1991). Some of the benefits described in these studies included self-satisfaction, mastery, improved relationship with the care recipient, and a decline in negative self-feelings and loneliness.

Kahn and Eaves (1996) concurred with the idea of positive outcomes with caregiving. They conducted an ethnographic study of caregiving in African American "elderly dyads." The specific aim of the study included obtaining a rich description of these experiences from the perspective of the elders. The influence of contextual elements such as ethnicity and history of loss made this study particularly important. Ethnographic interviews were conducted with 14 pairs of African American elders who met the criterion of at least one of the pair requiring regular caregiving activity. Interviews and participant observation occurred over a 2-year period. A traditional hermeneutic analysis was used to develop data texts, exemplars, themes, and a final narrative description of the informants' experiences.

Kahn and Eaves' (1996) findings were summarized:

One interesting theme in the findings was the seemliness or transparency of the experience of caregiving for those elders who were taking care of the other. In contrast to the vast literature about caregiver burden, primarily derived from research on middle-class European-Americans [sic], these elders did not talk about burdens of caregiving as part of their everyday life. Instead, caregiving was taken for granted, was something that they had been doing for others most of their lives, and was not a new, unusual, or particularly important or salient experience. (p. 29)

Nkongho and Archbold (1995) also found that African American caregivers focused on the positive aspects of their role in the family. These researchers conducted focused interviews with 17 African American caregivers of old, ill relatives regarding their reasons for caregiving. The sample included both male and female caregivers, age range 35 to 81, mean income $16,958 per year, and an education range of 4 to 16 years. The sample represented a broad range of caregiver characteristics with both typical and atypical experiences. This method of sampling increases the meaningfulness of the data obtained. Each interview was about 2 hr long. The data were analyzed following the steps for qualitative research identified by Corbin and Strauss (1990), which included open, axial, and selective codings.

Reasons for caregiving that emerged from the analysis were (a) familial (duty, maintaining family integrity, and role modeling), (b) relational (reciprocity, affection, and respect), and (c) personal (beliefs, values, and attitudes). All of the caregivers noted belief in God and caring for one's own family as important reasons for caregiving. Also a sense of duty or obligation was a strong influence in the decision to provide care.

Able and Nelson (1990) presented a review of literature in the introductory essay of their book <u>Circles of Care</u> that included both positive and negative aspects of caregiving. The description "labor of love" was accurate if both "labor" and "love" were considered. Able and Nelson made several cogent observations: (a) Society enshrines the virtue of independence, (b) society defines instrumental work as superior to emotional work, and (c) society devalues the activities of women. More than 70% of caregivers to the elderly were wives and adult daughters (therefore women). These observations led Able and Nelson to consider the feminist movement. Socialist feminists argue that, for most women, caregiving is not a freely chosen activity; a variety of forces pushes them to provide care. A second group of feminist scholars, asserts that the intense emotional involvement of many women in caregiving activities suggests that they are not simply assuming assigned role but that caregiving is meaningful and fulfilling to most women. This group of feminists argue that the experience of providing care is humanizing.

Able and Nelson (1990) conclude that the views of both groups are inadequate. The first strips caregiving of any sentimentality and robs it of the most vital and distinctive aspects of caregiving. The second view, with emphasis on the personal fulfillment women derive from caregiving, serves as a rationale for women's inferior position (p. 7). Only by exploring caregiving within specific context can understanding of its meaning in women's lives develop. Therefore the need for situated interpretive inquiry to gain better understanding about what it means to care is evident.

their shortsightedness, and the elders agreed to share the fruits of their labors and joined

the tribe once more (Wallis, 1993).

The legend of the two old women was more than an oft-told tale of the ways of

Alaskan times past. It was a powerful reminder that when a tribe abandons its old ones,

the people lose far more than they gain.

Communities everywhere have learned the valuable lessons of the Alaskan legend.

Consortiums have sprung up in communities all over the United States to provide the

support needed to keep their elders at home.

McKnight's (1995) work contrasted the effectiveness of programs that develop

through community association and community development with the frequent failures of

the traditional service system. He reports that failed systems tend to emphasize a model of

regulation and control. McKnight saw community building as an effort motivated by

caring and carried out through consensus of the individuals in the community. Rather than

being directed by experts, community associations were constructed with neighbors

helping neighbors and offered a place for everyone to participate. The emphasis was on

the strengths of each community member, rather than making an effort to catalog, classify,

and address their inadequacies.

Three such programs are presented here: (a) the Healthy Seniors Project,

(b) Interfaith Volunteer Caregivers, and (c) the Living at Home/Block Nurse

Program. These programs were chosen because they function in several areas of the

United States and each represents a slightly different approach to elder care.

The Healthy Seniors Project is a neighborhood-based nurse case management model. It is directed by the Community Nursing Organization. There are award-winning sites in Arizona, Illinois, New York, and Minnesota.

> The mission of the Community Nursing Organization is to design and implement a nurse-managed health care delivery system that assures quality, access, and affordable services for Medicare beneficiaries. This system sets forth a new structure for the delivery of selected community and ambulatory services and incorporates strategies to maximize continuity, care coordination, and active consumer participation. The Community Nursing Organization model provides an effective infrastructure for building consumer-oriented and cost-effective managed care networks. (National Dissemination Conference, p. 1)

This project is a partnership between community health nurses and an established health care facility. They work together to establish health care services in a specific neighborhood to serve the Medicare population. The community is involved through volunteer recruitment and training. Some services are included that Medicare does not reimburse, such as wellness care, respite care, custodial/maintenance services, and friendly visits/phone calls.

The National Federation of Interfaith Volunteer Caregivers coordinated the upstart of Interfaith Volunteer Caregivers all over the United States. A toll-free call to headquarters in Kingston, New York will provide any "church" group (regardless of religion) the information, support, and materials needed to start their own program.

Members of the church volunteer to be partnered with a person needing help. Services are provided to all age groups, without regard to insurance, religion, or specific need. The primary focus is support services (lawn work, baby-sitting, transportation,

shopping, etc.) but when health care professionals are among the volunteers they participate in some direct care activities.

Rosalynn Carter has been active with the Interfaith Volunteer Caregivers and writes (National Federation of Interfaith Volunteer Caregivers, Inc.):

> Sandra Wolfenbarger, who cares for her seriously ill husband, speaks for millions of others who also feel terribly isolated: "I had no one I could call or talk to. I had no one for support. I had no one for advice. I had no friends, and I stood alone."
>
> The Interfaith Volunteer Caregivers concept was designed to help people like Sandra Wolfenbarger and her husband [sic].
>
> In a study conducted by the Rosalynn Carter Institute for Human Development, only 10% of family caregivers said they received support from their religious institutions, and more than two-thirds of those surveyed said that their church was providing inadequate assistance. . . .
>
> The power of an organized Interfaith Volunteer Caregiving effort can change a community [sic].
>
> Who are Interfaith Volunteer Caregivers? Simply people of all ages. . . who wish to put their faith into action through volunteer work.
>
> It is the first time that many have volunteered for anything. Motivated by faith, the volunteers quickly develop a lasting relationship with the people they serve and often become family to one another. They receive training by professionals so that they are comfortable, confident, and competent when called upon to provide assistance. They do not replace formal service providers in the community but, rather, fill in the gaps. (inside cover [Brochure])

The Living at Home/Block Nurse Program has many aspects of the Healthy Seniors Project and the Interfaith Volunteer Caregivers project. The LAH/BNP, which is being introduced to Texas for the first time, is modeled after 14 existing programs in three other states including the Woodland program in Birmingham, Alabama. The Texas and Alabama programs were selected for this study since they serve African American communities.

The LAH/BNP starts with a steering committee from within the community whose members discuss and define the needs and capabilities of the community. These include (a) values, attitudes, common bonds, and relationships; (b) needs and capacities of the elderly as seen by community members; (c) availability and use of health and long-term care in the community; (d) availability of informal linkages and networks in the community including a senior center, churches, volunteer groups, and others; (e) community leaders from whom support is essential for organizing the program; (f) communication systems such as newspaper, radio, and television that could be used in the community; (g) civic and social groups that might welcome a speaker regarding the needs of seniors; and (h) organizations in the community that could be home base for the program (Jamieson, 1995).

Next, a board of directors is formed, again from within the community. No new agency is created. A partnership with a local health care facility (i.e., Harris Methodist Health System in the Texas program and the Jefferson County Health Department in the Alabama program) is established and a LAH/BNP is born.

The focus of the LAH/BNP is to provide the coordinated care that would meet the individual needs of each senior in the designated "block" (community). This typically includes early social support, health education, prevention-oriented intervention, support for daily living needs, and custodial-maintenance care. This essential care is provided regardless of entitlements or the ability to pay. Enhancing the ability of the family to meet

the needs of its own members and organizing community support when the family is not available are cornerstones of the LAH/BNP.

The community coordinator, volunteers, and block nurses work together to organize and support the family in its utilization of its current resources. Where the family has become a central support to a senior, the LAH/BMP (a) assures that family members maintain a positive supportive role, (b) provides respite from constant caregiving, and (c) averts family burnout.

Evaluating the services that the LAH/BNP provides is a challenge. Caregiving is a personal experience, one that does not lend itself to quantitative techniques. A qualitative approach seems most appropriate.

Heideggerian Hermeneutics

Central to Heidegger's philosophy was his phenomenological view of the person. He viewed a person as a self-interpreting being who does not come into the world predefined but becomes defined in the course of living. Over time people acquire a culturally skilled habitual body which is so taken for granted that it is most often completely unnoticed (Benner & Wrubel, 1989). Heidegger referred to this concept as the embodied intelligence. When embodied intelligence works well, it is rapid, nonconscious, and nonreflective. When embodied intelligence breaks down it loses its essential taken-for-granted quality and becomes conscious. Smoothly functioning intelligence is difficult to notice, much less study. Examples of smoothly functioning intelligence are

recognition of familiar faces, maintaining posture, driving, typing, and the trade of our everyday labor. All of these functions come from "background meaning" (p. 46).

Background meaning, according to Heidegger (1962), is what a culture gives a person from birth; it determines what is real for that person. Background meaning is a shared, public understanding of what is. Background meaning is a way of understanding the world. An analogy of background meaning is the light. You do not see the light, you see what it illuminates, and without it, you would see nothing.

Embodiment allows people to live in the world and understand it in relation to themselves, and background meaning provides the content of what is understood. Another aspect of what it is to be a person is that "things matter." This involvement was called "concern" by Heidegger (1962).

Concern is a key characteristic of the phenomenological view of the person. Although embodied understanding and background meaning can account for how the person can be in the world and grasp meaning directly, concern accounts for <u>why</u>. Because concern is qualitative (i.e., a meaning term), how concern is lived out can be discussed. Heidegger (1962) talked about two types of concern: (a) the kind of solicitude that leaps-in and takes over and (b) the kind of solicitude that leaps-ahead not in order to take away care but rather to give it back authentically (pp. 158-159). The second kind of solicitude is a form of advocacy and facilitation. It empowers the care recipient to be all that he or she can be.

Because of concern, people are involved in a context. They inhabit their world, rather than live in an environment. Because of embodied intelligence, background meaning, and concern, people understand a situation in terms of its meaning for the self. This is what is meant by phenomenology. Because people live in their worlds in an involved way, people are constituted by their worlds. To understand a person's behavior or expressions, one has to study the person in context, for it is only in their context that what a person values and finds significant is visible.

Persons are fundamentally self-interpreting beings for whom things have significance. Understanding human action always involves an interpretation by the researcher of the interpretation being made by those persons being studied. This interpretive approach is called hermeneutics.

The goals of hermeneutics are to understand everyday skills, practices, and experiences; to find commonalties in meanings, skills, practices, and embodied experiences; and to find exemplars or paradigm cases that accurately embody the meanings of everyday being. In hermeneutics the primary source of knowledge is everyday activity and the individuals involved in that activity. Human behavior becomes a text analog that is studied and interpreted in order to discover its hidden or background meaning. This meaning is hidden because it is so pervasive and taken for granted that it goes unnoticed. It is often through breakdowns that the researcher achieves flashes of insight into the lived world.

Packer and Addison (1989) offered an interpretation of the hermeneutic circle as being constituted by a forward arc of projection and a return arc of uncovering. This circle is the constant process of interpretation and evaluation through dialog. The forward arc of the circle is the understanding that leads to the projecting of possibilities. Packer and Addison refer to this as the researcher's perspective or point of view that makes understanding possible. The reverse arc of uncovering provides for evaluating an interpretive account. Heidegger (1962) warned that:

> Projecting has nothing to do with comporting oneself towards a plan that has already been thought out; rather, it is what is always already understood in the background practices that makes our pressing into possibilities possible; that is, our possibilities in any given situation were shaped by the person or family's background history, culture, society, and language. (p. 185)

Heideggerian hermeneutic phenomenology as a research methodology is well suited for studying health and health-related practice and activities in families. Hermeneutics is an appropriate methodology because it strives to understand the significance of practical activities in our everyday lives.

CHAPTER 3

METHOD

The purpose of this study was to describe the shared experiences and common meanings of African American women who provide care to an older (65 years of age or older) adult with the support of the Living at Home/Block Nurse Program (LAH/BNP). Person was conceptualized as a self-interpreting being who was continuously defined in the course of living. As such, Being was studied as it presented itself in the everyday world of practices and lived experiences.

The method used in this study was presented under the following headings: (a) Participants, (b) Instruments, (c) Procedure, and (d) Analysis. Since Heideggerian phenomenology grounded the entire research, it and hermeneutic analysis were covered thoroughly in the review of literature.

Participants

The population of interest was African American women who provided care to an older (65 years of age or older) adult and who were also served by the LAH/BNP. Geographically, this population resided in two different areas. One was in the eastern half of the Fort Worth, TX, zip code 76104. This community had a total population of 17,670 of which 1,564 were women over 65 years of age, 854 were men over 65 years of age,

and 11,759 were African American (Census tracts, 1994). The other community was located in Birmingham, AL, zip code 35212. This community had a total population of 7,465; 713 were women over 65 years of age, 361 were men over 65 years of age, and 244 were African Americans.

There was a population of 10 caregivers from which to draw a sample. The sample was purposeful and drawn to include wide ranges in length of time in caregiving, number of services provided by the LAH/BNP, severity of the care recipient's disabilities, and age of the caregiver. The number of caregivers selected for this study was guided by saturation (no new data were noted in the information provided by caregivers). Saturation was reached with 7 caregivers. Informational adequacy was ensured by saturation or completeness of concepts rather than by the number of participants. "The representativeness of the sample is replaced by the representativeness of the recurring themes and patterns identified by the study, consistency replaces reliability"   (Leonard, 1989, p. 53).

Sampling was completed in a two-step procedure. First, a representative of the LAH/BNP contacted African American female caregivers who provided care for an older adult with their help. The representative shared a letter from the researcher which explained the project and requested information necessary to accomplish the second step of sample selection (Appendix I). Next, the letters returned to the researcher from the first step were reviewed to identify possible participants who would provide a wide range of caregiving experiences.

Selected respondents were invited by the LAH/BNP representative to participate and appointments were made. The researcher went to the homes of those individuals who agreed to participate and explained the purpose of the study, the methods used, and gave assurances of confidentiality. The participants were asked to give informed written consent and were given a copy of the consent form (Appendix II). The topic of the interview was explained as an effort to obtain each caregiver's personal story of the caring experience. The consent form also requested permission to audio-tape the sessions.

<div align="center">Instruments</div>

Hermeneutic interviews are not conducted; rather they are participated in, since the person being interviewed both shapes and is shaped by the interview (Diekelmann, 1994). It becomes a conversational relationship between two people. This process develops trust and commitment; both contribute to the validity of the narrative obtained. Participants are free to lead in the conversation as it makes sense to them. As stories are told, they become alive; there is an awareness by both the investigator and the participant of new meanings. This is the emancipatory aspect of hermeneutic studies. Subject and researcher become co-participants in the research process.

Each conversation began with a brief review of the purpose of the research. Open-ended, probing statements, such as (a) tell me more about that, (b) and that felt . . ., (c) what happened next, and (d) where did that leave you, were used to explore areas of potential deeper meaning. Interview questions were formulated only as a guide and were

seldom asked directly. As the narratives were analyzed these questions were answered retrospectively.

1. How long have you been the caregiver?

2. Tell me a story about a specific caregiving situation you have encountered.

3. How has the LAH/BNP impacted your life?

4. What are your main concerns about caregiving?

5. Why do you continue to provide this care?

6. What needs do you have that are not being met?

Validity was addressed again during the narrative analysis. The narratives and interpretations were validated with the participants. A team of three interpretive researchers were recruited. The research team reviewed the narratives for indications of interviewer biases. They also verified the narrative interpretations. The criteria for participating on the research team were (a) qualitative research experience, (b) previous knowledge of Heideggerian hermeneutics, and (c) willingness to participate. The team was (a) Carolyn Cagle Ph.D., RN, (b) Sharon Murphy ACSW, CISW and (c) Rick Zamarripa-Zoucha Ph.D., RN.

Carolyn Cagle and Sharon Murphy (as well as the primary investigator) have attended the Institute for Heideggerian Hermeneutical Studies at the University of Wisconsin-Madison conducted by Nanacy L. Diekelmann, Ph.D., RN, FAAN. This was a

two week (80 hour) course on theory and application of Heideggerian interpretive research. Carolyn Cagel's research emphasis is qualitative with a population of women and children. Sharon Murphy is conducting interpretive research dealing with abuse of Native American women. Rick Zamarripa-Zoucha has conducted qualitative research on health behaviors of Mexican American clinic clients.

Reliability and validity were further promoted by the researcher's experience and expertise. The principal investigator conducted all the conversation sessions. The researcher's credentials encompassed 20 years of nursing experience, including 15 years of actual home health visitation. Therapeutic communication skills were among the skills the investigator practiced and taught at three universities in the South. She has attended the Institute for Heideggerian Hermeneutical Studies at the University of Wisconsin-Madison.

Procedure

The team of three interpretive researchers assessed the research questions and procedure. A pilot study was then conducted. The data were analyzed by the principal researcher and verified by the research team. No changes were indicated and the remaining conversations were conducted and interpreted.

Conversation sessions (about 1 hr each) were conducted with all 7 participants. All conversations were private and took place in the participants' homes. The sessions were audio-taped, transcribed, and the data were interpreted by the primary researcher and a team of three other interpretive researchers. It was discovered that saturation of information had occurred at 7 participants. A sample size of 10 was projected at the

development stage of the study but was adjusted based upon the quality of the texts and the way that the lines of inquiry were reshaped by the participants (Benner, 1994). Saturation was determined by the researcher and the research team. Multiple conversations with the same caregivers provided richness and redundancy so meanings and patterns were more visible, producing increased confidence about understanding the practical worlds of the participants.

Follow-up conversation sessions were used as needed to verify the transcriptions of the previous session and the interpretations that had resulted. The final conversation session was used to establish closure.

<p align="center">Analysis</p>

Analysis of the conversation narrative transcriptions took the form of interpretations and was carried out by a team of researchers that included the principal investigator and three experienced interpretive researchers. The narratives were interpreted according to the seven-stage hermeneutic method described by Diekelmann, Allan, and Tanner (1989).

Stage one: The entire set of seven narratives was examined as a whole by each member of the research team to obtain an overall understanding of the narratives.

Stage two: The narrative of each conversation was summarized by each member of the team with possible themes identified. The summary required identification of key words, verbalized feelings, and a list of possible unspoken feelings and other areas to

investigate at the next conversation session. Written interpretations were supported with excerpts from the interviews. The research team discussed the interpretations of each interview. Team members discussed analysis and narrative evidence with group consensus being the ultimate goal.

Stage three: In further independent analysis, each team member's interpretation was compared with the investigator's for similarities and differences. Any discrepancies in the interpretations were clarified by referring to the narrative and by additional conversation sessions with the participants to clarify and validate.

Stage four: Material generated in previous stages was reread and studied to determine if similar (common) or contradictory meanings were present in various narratives. The purpose of this stage was to identify relational themes arising out of common meanings, which cut across all narratives. Extensive documentation provided support for the identification of common themes.

Stage five: During this stage of analysis, a constitutive pattern emerged. Constitutive patterns are present in all narratives and express the relationships among relational themes. Constitutive patterns are the highest level of hermeneutical analysis.

Stage six: The purpose of this stage was to validate the themes and constitutive patterns with the conversation participants. This conversation session provided an opportunity to achieve closure with the participants.

Stage seven: The last stage was the preparation of the final report, using sufficient excerpts from the interviews to allow for validation of the findings by the reader.

The purpose of the multiple stages of interpretation was to expose contradictions, conflict, and inconsistencies by allowing for reappraisals and comparisons. Multiple interpretations at every stage of the analysis also served as bias control, exposing unsubstantiated meaning and inaccurate or unwarranted interpretations not supported by the narratives. The open, conversational nature of the inquiry increased understanding by a constant revising of the interpretations and was a strength of the method. All interpreters attempted to be "true" to the narratives and not read into them any meaning which the evidence did not support.

The outlined stages of analysis represented the interpretive process beginning with new perspectives and insights from the "whole." This new understanding was used to examine the parts of the whole, and then the researcher and the research team reexamined the whole in light of the perspective gained from the parts. The interpretive process followed this part-whole strategy until the researcher was satisfied with the depth of understanding.

CHAPTER 4

DATA ANALYSIS

The philosophy of Heideggerian phenomenology and hermeneutic analysis was employed to identify four relational themes and one constitutive pattern in the texts of caregivers. A purposeful sample of seven caregivers was interviewed using open-ended conversational style questions. Data were gathered using audio-taped conversation sessions that were subsequently transcribed and interpreted. Demographic data were collected during the conversations. The interpretations examined the seven texts for salient common and not-common meanings either implicit or explicit in the African American women's lived experience as caregivers. Although the specific steps of the Heideggerian hermeneutical method used were explained in Chapter 3, Chapter 4 will include a review of how the process was specifically applied in this research.

Each member of the research team received a copy of each of the texts with a first draft interpretation. Each interpretation included excerpts to support all interpretive claims. Each team member reviewed the text and the initial interpretation. They each stated if they found the interpretation warranted (i.e. supported by the text) and if found not warranted a rationale was presented. Each team member also provided additional ideas for interpretation with particular attention to developing themes. The team's

comments were incorporated into the interpretation as appropriate and the second draft of the interpretation was sent to each team member. This process continued until all team members agreed completely with the interpretation.

The entire set of interpretations was then studied by each research team member to determine common and contradictory meanings. The purpose of this stage was to identify relational themes that cut across all narratives. Themes were always kept open and changed frequently as new meanings emerged in the ongoing hermeneutic process. Each common theme was supported by extensive documentation. As themes were identified a constitutive pattern emerged. The constitutive pattern was seen in all narratives and expressed a relationship among the relational themes.

As the constitutive pattern emerged the participants were contacted again and the interpretation of their story was shared with them. After the interpretations were verified as reflective of the participants' true experience the final report was written incorporating the contribution of all persons involved in the interpretive process. During this process the study was shared with the Living at Home/Block Nurse Program (LAH/BNP) directors in both the Fort Worth, TX and the Birmingham, AL locations. Feedback from the LAH/BNP was reflected in the findings.

The analysis was written with the input of all involved, researcher, team members and participants. It was written using sufficient exemplars from the stories to allow the reader to participate in the interpretation. The purpose of this research report was to provide the

reader with a wide range of explicated text so that common practices and shared experiences can be recognized.

A paradigm story emerged through the interpretive process. This was a story that engaged the reader in the practical world of the participant and moved the reader closer to the lived experience. The text became meaningful because it flowed from multiple traditions, particular language, a set of social practices, and a variety of experiences. These things came together to form community and culture (Benner, 1994). Once this paradigm case was selected by the researcher and the research team, other cases followed with specific references to how they compared/contrasted with the paradigm case. The paradigm case was used as a scheme of perceptual apperception and awareness during the research process and as a presentation strategy for this report.

Chapter 4 presents the paradigm case, each of the remaining caregivers' stories, and findings about the LAH/BNP. Chapter 5 presents the themes, constitutive pattern, research questions, and comparisons with the findings presented in the review of literature.

Description of the Sample

The total population of participants that met the criteria for this study (African American, female, providing care for an adult >65 years old, who receives services from the LAH/BNP) was 10. There were five in the Birmingham, AL LAH/BNP and five in the Fort Worth, TX program. Of these 10, 7 participated in conversation sessions which was sufficient to obtain saturation of data.

The caregivers ranged in age from 42 to 73 years of age. The care recipients ranged from 65 to 101 years of age. Several caregivers cared for more than one individual but this age range represented the elder upon which the stories centered. Two caregivers worked outside the home in addition to their caregiving responsibilities. Two care recipients continued to live alone while the caregiver came to them to provide needed services. Formal education of the caregivers ranged from "some grammar school" (grade completed not known or not shared) to "some college." No care recipient was confined to bed. Two required diapering at times, maximum assistance with bathing, dressing, and hands-on assist with ambulation but were able to feed themselves. Three care recipients required supervision with bathing, dressing, and ambulation but were usually independent with toileting and eating. All five of these required assistance with medication administration. Two care recipients were independent with all activities of daily living except driving, major cooking, major cleaning, yard work, shopping, and home repairs. They required careful monitoring for medication compliance, safety practices, and signs of illness or physical/mental deterioration. There were men present in five homes. Three care recipients were men. Each caregiver chose a name to be used in this study.

Paradigm Story: Mary

Mary is a caregiver for several people including an Aunt. Auntie was a difficult person in some ways. "I know sometimes, Auntie is good at rubbing people the wrong way. Ah, that is just saying something out of place or some times she doesn't remember or whatever." Auntie lives in the "old neighborhood" where she used to live next door to

Mary's parents and participated in their care when Mary was a child. Actually Mary is not

sure the woman she cares for is an aunt but that makes no difference. Fiction kin is

common in the African American culture (e.g., Gelfand, 1994, pp. 122-125). "I really

believe you are supposed to care for people regardless what they are cause I remember

what they had done for me when I was small or growing up. So we are all in this

together." Is this an "obligation to care" or is it the "reciprocity of caring" in this family?

She says,

> My mother, she has passed, she passed in 1994, seeing as though when we stayed
> on Georgia Row where Auntie lives, she would go around, I guess that is what
> they did during that time, they went to the people that was sick and cared for
> them. Auntie have a mama there she would go over there and stay with her and do
> whatever for her mama and then when anybody in the neighborhood was sick or
> even sometime, we call stray people, or say they had a drinking problem, she
> would prepare food and send them a plate, you know, send them something to eat
> and things like that. I do whatever I have to do if she has a need. My nephew go to
> the store. . . .my brother he tends to see about the yard. . . .the niece takes her to
> the restaurant and some cooking. . . .there are 5 or 6 of us that goes and sees
> about her.

Being-in-this-together is part of Mary's background. It is "everydayness" for her. It is just

a family thing, a tradition.

Tradition establishes our differences. Bellah, Madsen, Sullivan, Swidler, and

Tipton (1985) explain more about tradition and its relationship to culture.

> These differences derive from a historical past of which none of [us]. . . is entirely
> aware. . .our cultural tradition, in its several strands, is still very much present. . . .
> So long as it is vital, the cultural tradition of a people - its symbols, ideals, and
> ways of feeling - is always an argument about the meaning of the destiny its
> members share. Cultures are dramatic conversations about things that matter to
> their participants. (p. 27)

Culture is those patterns of meaning that any group or society uses to interpret and evaluate itself and its situation. Language is an important part of culture. Since culture always has a history, it frequently takes the form of tradition. Culture is a constitutive dimension of all human action. It is not an epiphenomenon to be explained by economic or political factors. Caregiving is just one traditional strand that when combined with many other strands becomes culture (Bellah et al.,1985).

Caregiving is not always an easy thing. It is often accompanied by a sense of tension. To provide care is to make oneself vulnerable. The word vulnerable stems from the Latin word vulnus, meaning "wound" (Skeat, 1982). Vulnerability carries with it the notion of being wounded or becoming more prone to injury. Confronted with the realities of aging (with its sufferings) caregivers sense the helplessness and vulnerability of isolation, illness, and loss, and the fear of one's own destiny that comes in caring for persons experiencing threats to their physical, emotional, and spiritual well-being. Mary experiences many of these vulnerabilities.

> They want to be talked to. It seems they don't want you to go, they be lonely. She just told me, "put that so and so down and come in here and talk to me," you know. . . .They want the doctor to talk to them, a lot of the things they complain about come with age. . . .They [old people she has cared for] are not remembering . . . .they want a lot of attention. . . .they want to have their own way. . . .they're not in touch with reality. . . .She is fearful and stays up at night listening for sounds and things.

Perhaps Mary expressed this vulnerability of seeing herself grow old in the people she cares for (coming face to face with her own mortality) when she said,

I don't think they understand that as we grow older that our bodies deteriorate, I see, I use to tell my mama "do you ever be well" and she say "LIVE ON, CHILD." You know, you are always be saying this, but I was young and flighty, you know, but you JUST LIVE ON.

Mary seems to have learned that rather than approaching the pain of vulnerability as something to be avoided at all costs, it is important to recognize that when one makes a commitment to care for others, one is committing to a relationship that renders one vulnerable and open to experiencing pain. A portion of this pain is probably related to the dis-ease with the aging process (or is that dys-ease?) Mary experiences. The discomfort and the risk that come with allowing vulnerability may lead one to question whether it is worth the pain. George (1990) reminds us that risking vulnerability to achieve genuine relationships with self and others is worth the risk. "We will not go through life unbitten. But if we don't take the necessary risks, we can go through life untouched by human tenderness" (p. 47).

Mary protects herself some from the vulnerability she is open to by being tentative in her approach. "And then, basically that, on some days I just stay here [her own home] when I'm feeling bad and don't feel like I want to exert that extra pressure or whatever and then some days I just go on and take it." Mary has some advice for a niece who was "burned out." She says,

Don't go everyday. You know, go certain days and days, you know, you can maneuver but when you go have something else going and say you cannot stay long cause if you don't have something else on the back burner they going to try and take up all your time. It is real time-consuming, very much so.

Mary has an intuitive knowing about her limits and how vulnerable she is willing to become. "You got to know yourself when to go and back off."

Religion is important to Mary. Is that another protection against the pain and uncertainty of vulnerability? Mary says,

> And sometime when things are not true you try to correct them and then they get angry with you and start saying so and so, you just let them think the way they want to think and you just try to be real patient, ask God to just give me patience and strength. . . .She go to complaining about this or that or something hurting her here or there or "I ain't got nobody" or she go on these sentimental moods, "I don't want nothing to eat cause I can't fix it, I ain't got nobody to do nothing for me." So, you know, she say "nobody love me" and I say "now listen to the devil talking, the devil is saying just what the devil wants to say." I do like that so she will stop feeling real sentimental. I say "you 93, you mean to tell me you don't think God, He don't bless you?" You know, stuff like that, so you have to be kind a patient with them. . . .I just ask God to give me help and strength, to go and do this. . . .God will let us know when it is time to start spending the night. . . . And she is praying to God that He will just take her when she's asleep. . . .She really doesn't want to go to a nursing home. . . .She say "I don't know why God got me here all this time, I don't know why I'm still here.". . .I took Mrs. XXX [auntie] to see her son but he was not a Christian, I don't know if that had anything, but I notice that when people are non-Christian. He was in the hospital and he was real, like something was fighting, or he was fighting, or something was at him. Even though he was comatose stage or half way. It was always like someone was jerking him or pulling him, or he fighting somebody.

The church, as a major community institution, is probably most important among African Americans (Gelfand, 1994). Two-thirds of African American adults are church members and view the church as a vital element in the community (Chatters & Taylor, 1989). Hatch (1990), in an analysis of national data suggests that involvement in church social events helps older African American women maintain an informal support network that extends beyond family members. The use of prayer as help-seeking behavior is

stronger among African American women than it is among men. Prayer may also

contribute to the lower rate of suicide among African Americans (Gibson, 1986). The use

of religion and turning to a higher power for help is not a surprising practice for Mary. It

is perhaps another strand of her culture, another tradition.

Mary's story includes efforts to preserve Auntie's dignity. She shows

extraordinary sensitivity to Auntie's self-esteem. When Mary was asked to tell a story

about a visit to the doctor with Auntie, Mary tells how the doctor tends to talk to her

instead of Auntie.

> Well, ah, I can sum it up with about three people I have taken, that I have noticed with the three people. If you take them to the doctor and this is with Auntie too, they want the doctor to talk to them. They are saying as though you might not think that I have any sense, you know, and you talk to me not so and so and so and so, usually that's me. And it is as though they are being DISRECOGNIZED. And a lot of the times I notice that what they complain about even though I'm not old, old I am not young, young but a lot of things they complain about comes with age and the doctor can only do so much and usually the doctor notice, they seem to hear them and they don't hear them. And they don't address the question they ask, like talk to them. Like they be trying to get us to talk to them at home then but they don't miss no doctor appointments even if it is just something, probable just going back to get prescriptions that's all. . . .But basically they want to be talked to just like I'm talking to you, they want the doctor to talk, to look directly into their face. They don't want him to take me aside and go over her and tell me something cause they think they are telling me something bad behind their face.

Is this the practice of hearing? Mary's practice of hearing is very different from this

doctor. The doctor's hearing comportment is one that disrecognizes the aged patient while

Mary maneuvers in a way that presences Auntie back into the room and gently reminds the

doctor who the patient is. "I said, 'Mrs. XXX [auntie] do you hear what he [the doctor] is

saying'? I tried to turn it back so she wouldn't think he is trying to talk to me as an

individual about her case." What an astute and thoughtful maneuver, one that can only be made by a person who is in tune with and cares about another!

Caring involves stepping out of one's own personal frame of reference into the other's. When a person cares they consider the other's point of view, the desires, needs and self-esteem of the other. Attention is turned to the cared-for, not self.

Another story about preserving dignity deals with the loss of short-term memory experienced in aging.

> We were suppose to go to the doctor. I got there [auntie's home] . . .and she was still asleep. So I say "well mama I'm going to go ahead and fix you some cereal". . . . .So she got up and when I had the breakfast ready she say "you said you were going to cook some grits, some grits and salmon." "You want to go to the doctor smelling like salmon." So she got angry. I say, "mama, I did not tell you I was going to fix you some grits, I said cereal." And you know how some time you go back and forth [maneuvering, dancing] until something hits you like that [hits own fist into her hand in demonstration]. I say [to myself] "what you doing, you know she not remembering." I say "OK, you want some grits? I will prepare you some grits," and she didn't say anything so that was a answer that she wanted some grits.

Another issue challenges dignity in Mary's story. The dissonance that is found in the technological society can be overwhelming. Who among us has not stood before a new specimen of technology and felt the wave of intimidation? Mary realizes Auntie has a lack of understanding, even a fear of new technology.

> They are not in touch with reality today because I don't think they could survive with the computer age, the banking age you know, how, you know, the bank here in [home town] they usually, they used to have a passbook, and when they stopped the passbook for the savings account they didn't like that because they give you just the deposit slip to keep up. I think, you are probable more familiar with that, but they were not, they liked it back with the passbook where they could see all

their money and see how it grow. I had a time, sometimes, I do all Auntie's banking and she oversees her bankbook now. . . .and another thing, when it is time for the interest they say "the bank didn't give me my interest. They think they got to go when the quarter end, right there on the first of the month to get it. I say "you don't get it today but whenever we go they going to bring it up to date and give you your interest, it is already there" but they don't understand that. They think someone is trying to take something from them I guess. . . .Auntie does not have her money in CDs, she just have straight passbook savings, checking and that's it and probably somewhere in her house, you know. And, but they make one wonders, it is fear.

Heidegger (1966) does considerable thinking about technology. A major portion of a memorial address given in 1955 at Messkirch on the occasion of the 175th birthday of the composer Conradin Kreutzer was devoted to technology. Here are some relevant excerpts.

> No single man, no group of men, no commission of prominent statesmen, scientists, and technicians, no conference of leaders of commerce and industry, can brake or direct the progress of history in the atomic age. No merely human organization is capable of gaining dominion over it.
>
> Is man, then, a defenseless and perplexed victim at the mercy of the irresistible superior power of technology? He would be if man today abandons any intention to pit meditative thinking decisively against merely calculative thinking [this illuminates Heidegger's love for interpretive vs. scientific research]. . . . Meditative thinking demands of us not to cling one-sidedly to a single idea, nor to run down a one-track course of ideas. Meditative thinking demands of us that we engage ourselves with what at first sight does not go together at all.
>
> For all of us, the arrangements, devices, and machinery of technology are to a greater or lesser extent indispensable. It would be foolish to attack technology blindly. . . . We depend on technical devices; they even challenge us to ever greater advances. But suddenly and unaware we find ourselves so firmly shackled to these devices.
>
> We can use technical devices, and yet with proper use also keep ourselves so free of them, that we may let go of them any time. We can use technical devices as they ought to be used, and also let them alone as something which does not affect our inner and real core. We can affirm the unavoidable use of technical devices, and also deny them the right to dominate us, and so to warp, confuse, and lay waste our nature. (pp. 43-57)

Although Heidegger was 66 years old in 1955 when he spoke these words there is a
generation of older adults who have not had opportunities to acquire technical literacy. To
these people much of today's advances are not positive changes. Feelings of fear and
inadequacy are very likely. Mary understands this and works (maneuvers?) around it.

Mary understands leaping-in and leaping-ahead. The time has not come to leap-in
and do everything, leaping-ahead to empower Auntie is still appropriate most of the time.

> My sister said she was going to spend the night [with auntie]. She had told Auntie
> she was going to spend the night with her. She was going to start coming over to
> spend the weekend. Well she had the sores on the foot and when I got my sister to
> myself I said "No, don't you do that, now it is going to come a time that we are
> going to have to spend the night but right now do not spend the night because
> once you start something you got to continue, God will let us know when it is time
> for us to start spending the night but right now no."

Mary has had the experience of needing to jump in.

> The only thing with her [her terminally ill mother] is she was complaining about
> pain which the doctor did not give her any medicine because of the damage to the
> liver and, I don't know, I don't know the doctor figured she might be able to
> recoup or if he though she might be able to live but I gave it to her anyway, you
> know. Because he had already told her in so many words she was dying, so why
> not make people comfortable.

The practice of maneuvering is a theme in Mary's story. This is the practice she
uses to accomplish much of her caregiving including the leaping-in and leaping-ahead.
"Maneuver" conveys movement within perimeters, some of which are semipermeable.
There are negative and positive blockades but with persistence Mary reaches her goal.
"About 5-6 of us go and see about her, we maneuver. . . .when she be in the back room I

can maneuver a little bit better." Mary sees the practice of maneuvering in others, "I think she miss her freedom of maneuvering." Sometimes the practice is interrupted "She has an awful sore too, on the bottom of her foot, and she has boots on her foot and, you know, and lamb wool, but she still can maneuver." Mary's "maneuvering" is evident in the way she manages communication in the doctor's office, how she deals with Auntie's memory loss, the way she selectively ignores when necessary, and how she reorientates Auntie.

Story Two: Paula

Paula tells a story of African American female caregiving that reveals the everyday family connections that sustain caregiving across generations of women. It is a family thing. "My mother did it, my grandmother, and I. My mother is not a burden, NO, she never will be. Not my mom, I wasn't to her. My grandmother wasn't either. You know down through the years my mother was always there for me, and I will always be." Paula's world is the meaningful set of relationships, practices, and language that she has by virtue of being born into a culture. Caregiving for Paula is a tradition as it is for Mary (our paradigm case). Her world has always included caring and she does not even entertain the idea of that changing. It is part of the fabric of her life.

> Busy knitting the seasons,
> she changes colors often.
> Yarn flying, Grandmother crochets love,
>   tying in treasures;
>   miles of vibrant tapestry
> finery feathered and furred,
> jeweled with pine pitch,

dried moss, emerald lake.
Seashore foam she flings into spirit,
swirled in her white-pine hair.
On wet sand,
in wolf prints,
she marks the way. (Sanderson, 1996, p. 93)

Describing her experiences with her elderly mother, who remains in her own nearby home, Paula tells of learning to care.

> I enjoy taking over for Mom, sometimes she will listen and sometime she won't but I try to find ways to, you know, kind a get around her and make her think she is doing the things she got to do. I mean I love my mother. It was kind of trying at times but I'm getting use to it. I have to think about it, I am growing old too you know so I have learned to deal with it and learn how to get myself into a position to try not to be bothersome. She is not like that. I'm learning to work with her.

In learning to care Paula has learned to "get around" Mother. A kind of circling, or a figurative embracing that provides support for negotiating, almost a dancing with Paula in the lead gently guiding Mother. This is a process very similar to the one Mary repeatedly describes as "maneuvering." In this learning process caring for Mother belongs with how Paula's mother cared for her mother. Recalling this experience, Paula describes what it was like as a young adult to help care for her grandmother.

> I was working a full-time job at the time so I would get off of work and get a couple hours of sleep then I would let her [Paula's mother], you know, rest a little. I remember one night I worked full time and my mom was so tired and she [grandmother] wanted to leave, she wanted to go back home. So we had to stay awake 24 hours cause she gonna get up and leave if you didn't. I was so sleepy I taken the chair and put it in front of the door, you know, and was asleep. I look at that she wasn't knowing what she was doing.

The meaning of this experience for Paula is about being there for one another.

This is my kind, my grandmother and my mother have always been there for me. I never had to worry about where's my mom or where's my grandmother and then I say now it is my time, you know, to treat them like they treated me and with that I have no problem with it.

The practices of fidelity and the reciprocity of caring resonates in this account. As Mary expressed it, "I really believe you are suppose to care for people regardless what they are cause I remember what they had done for me when I was small." Paula tries "to do like she did me, she care for me, and ah, I take care of her." But it is not easy to care for her mother and her husband with diabetes as well. Mother is maintained in her own home. Paula describes how difficult that is. There is an "alarm system" and Paula keeps "close watch." She watches closely her mother's medications.

> Mom has to have some medication or something, even if I have to work late I always check on her. Every day I call her and see if she needs anything. It is the last thing I do before I go to bed at night.

Paula, recovering from stomach surgery herself, calls on a neighbor woman for help in sweeping and mopping the floor. She recruits a young man to make changes in the house and expands the space in the house available to her mother. But it is Paula who takes her mother shopping. She recalls an incident that was difficult for her when her mother forgot her cane at the store.

> Something happened Saturday. I guess I was so tired, you know, we went to the grocery store and I usually watch her. She uses a cane. But like I said, I was so tired I didn't realize she didn't have it and when we got home she said, "where's my cane"? I said, "Oh, my God." So I takes off and I go back to Kroger and they said they hadn't seen it but someone said "just walk around where she was and probably it will be somewhere." And I did, she had left it standing in the center of the aisle, it is one of these three-legged canes, people had just been going around it. She had tears in her eyes. I told her it was all right, I know how she feels, she is

just old. And she felt so bad, I told her it is easy to forget things. I said "I am younger than you and I forget things all the time." But she felt so bad that I had to turn around and go back. But that does not bother me, like I said, when you are tired like I was, you know, all these days so constant, I might have frowned which I so much never let her see me do and I probably did when she said, "Where's my cane" and then that hurt her.

Mother is sensitive to Paula's "frown" and cries when she had left her cane in the food store. There is breakdown in caring that shows itself in the ordinary experiences of this daughter caregiver. Paula reaffirms that her mother is not a burden and she never will be.

At one point in the text, Paula says "my mom will never be a problem to me. . . .I don't care what happens she won't ever be a problem." Paula never labels this caregiving or her mother as a "problem" which is done all the time by health professionals. The problem with taking the path of identifying problems is that then you are bound to find solutions; the problem health care professionals then face (in the current health care field) is measuring the outcomes to the problem solution; and the problem with this is trying to figure out how you measure outcomes such as those Paula relates of "benefiting" or "feeling better." It is meaningless to ask "show me your feeling better." The alternative to this problem-centered approach is in this narrative, for Paula does not see her mother as a problem to give care for, rather her comportment of caregiving for her mother is of "doing." "So basically, I try to do like she did me, she cared for me, and, ah, I take care of her." Caring is doing, and doing is "I being there for." "She has always been there for me and I don't mind." Paula, with her mother always there for her, learns to be there for her mother. And she "be's there" by "doing". Heidegger's term for "being there" is Dasein,

the word he uses to discuss human existence (whether generally or individually). So that Paula, in the *doing* of her *being there*, is simply existing. Her giving care for her mother is existence. It is fundamental to human being (and not a problem). Heidegger did say that Dasein, understood ontologically, is care. Doing is caring for Paula, this is not doing in the common sense of engaging in an activity, rather it is a pervasive, an integral, or even beyond that, it *is* how Paula care gives.

Paula extends her caring to others. She tells of comporting herself in a caring way with neighbors.

> I have this lady right down here, Mrs. XXX, Saturday I was so tired. I was back in my recliner and she called me about 11:15 and said "can you take me down to the multi purpose center"? And I wanted to say "No." I said "Mrs. XXX, is it important"? She said, "yes, I believe they can help me." And I just got up and carried her down there. But she is 91 years old and you just don't say "No." You know, I came back here to the house and stayed until she called me and I went back and got her. So I guess I got it from my grandmother who got it from her grandmother. I never did know my great-grandmother but I think back in those times it was about the same with neighbors helping each other.

Paula cared for a brother, "My brother died in '72. He got off into drinking and had cirrhosis of the liver, and I was right there with him when he was sick." She cared for her stepfather, her grandmother, and now her mom. It is a family tradition at least for the women. It seems Paula has an intuitive knowing that comes with her closeness to and experiences with her mother. "You just don't do like you used to when you are 83, I have to accept that. . . . I try to understand why she is doing what she does and that's it, I try to keep her happy, doing things for her you know."

Benner (1984) explains,

Intuitive grasp is direct apprehension of a situation based upon a background of similar and dissimilar situations and embodied intelligence or skill. Intuitive grasp is never "blind" as in a wild guess, but relies on perceptual capacity based upon prior experience. Intuitive grasp should not be confused with mysticism, since it is available only in situations where a deep background understanding of the situation exists, based upon a broad base of knowledge and experience. Intuitive grasp makes expert human decision-making possible. It allows a gestalt or holistic understanding that by-passes building the situation up element by element and then grouping or synthesizing the elements into a conclusion of whole picture. Intuitive grasp is not possible without a sufficient background and experience with many similar and dissimilar situations. (p. 295)

This description applies to Paula and explains her ability to deal intuitively with Mother.

Paula's reliance on religion is not as strongly emphasized as in Mary's story. Paula says, "I go to church, I really love my church, and go there with my mother. I go to Sunday school and I go to church. That's about all I go." In comparison with Mary's story Paula does not offer as much evidence of vulnerability. She does repeatedly mention being tired. Her vulnerability is seen to some degree in the breakdown that occurred when Mother left her cane in the grocery store. Paula regrets her "frown" and is vulnerable to her mother's tears. In that story there is the practice of preserving dignity, "I might have frowned which I so much never let her see me do. . .and then that hurt her, you know." Paula reflects on her own aging process (one aspect of vulnerability). "I have to think about a lot, I am growing old too, you know, so I have learned to deal with it and learn how to get myself into a position to try not to be the extent that I am bothersome." There is little in Paula's story that gives insight into any problems with technology. Paula does

not specifically mention self-talk as a tool she actively employs (perhaps she just does not call it that).

As in Mary's story, practices of leaping-in and leaping-ahead are documented.

We just watch her and see what she is doing wrong and then I find a way to get her to do without her thinking I'm bossing her. That's been, now that's been kind a hard for me to learn, how to do without making her feel like I am telling her and running her life. . . . I wanted my mama to be able to do the things that she can do. I don't want to take over, you know, I don't want that. I watch her to see how she acts and what happens. I have to get on her and be firm [sometimes].

Paula's "intuitive knowing" is conveyed more extensively than in Mary's story but the practices both share are based upon more than objective data. Decision-making that is easy, quick, and usually accurate comes from more than conscious analysis.

Story Three: Sue

This story involves the extended family picture. Sue is 67 years old. She cares for her 85 year old aunt. Sue's "baby daughter" and her 2 young children live in the same small, cluttered home. Caregiving is not new to Sue, you cannot even say she was called to it, she is care. As a small child she and her cousins spent everyday of our lives we had to take care of my father. Cause he got down with tuberculosis. And we had to take care of him cause all the adults back then be working. That was our grandmother and us we take care of him. . . they laid him out on a cot and we had to fan flies to keep the flies off him all day. We had to fan him when he got hot, too hot, stuff like that. Other caregiving experiences in her life included caring for an ill daughter. "And then my daughter, I've

been like a nurse to her cause sometimes she be so sick I would be up in the bed with her

trying to help her breathe. And I be familiar with sick folks all my life.

Caring is so embedded in her background, it is tradition, it is everydayness, that to

not provide needed care would be distressful to her. So is caregiving an obligation for

Sue? By strict definition it probably is but during a validation conversation Sue says "no."

> [Auntie's] only sister, my mother, had always been her fall back but they all gone
> now. There's nothing left but us children, you know. Everybody is in Detroit
> except my sister. I got one sister here and her husband is sick, she taken care of
> him and can't be no help. And I can't take her [auntie] there so I just have to be
> the one. Everyday is about the same and I don't see no way out of it. I'm not
> going to just throw her away. This is all the home we have. It is not much but it is
> paid. I get so worried some time thinking what the best thing to do. Yes, I guess
> I've been giving care all my life. I know how to give tender, loving care.

In establishing Home from a less than adequate house Sue has consigned herself to

a life without many taken-for-granted freedoms. She does this in a most natural, positive

way. This self-imposed consignment is a decision that she does not seem to regret. After

all, home is more than a building and freedom is more than the physical ability to move.

The home is a very special space experience which "has something to do with the

fundamental sense of our being. Home has been described as that secure inner sanctity

where we can feel protected and by ourselves" (Van Manen, 1990, p. 102). Being

consigned to home is something all people do. Residing in our lived space can make home

where we find ourselves. Thus, stories of prisoners who maintained both physical and

mental health in spite of the ultimate consignment are well known. Sue does not find her

consignment stressful.

> Yesterday morning I was gone and my daughter stayed with her and she [auntie] got so sick. She knew I wasn't here and she got so sick cause I wasn't here. I talked to her [the daughter] and I said "go ahead and call the paramedic." She had pain in her chest, she couldn't breathe, her back was hurting. So the children said [to auntie], "OK, Mama said to go ahead and call the paramedics, they can take you to the hospital." She said "no, no", she didn't want to go to the hospital. She said "I want Ma here, please, don't takes me to the hospital till she come." And I say "Lord have mercy." I come here and I say "What you doing up? I thought you about to die, and go to the hospital." And she said "I just want you to come home." She's got spoilt to me waiting on her.

This story was shared without a hint of frustration. It was almost a brag, something similar to a grandparent telling about a "rotten" grandbaby.

Later in Sue's caregiving story this theme reoccurs. Again it is without any suggestion of bitterness or regret. Sue tells these parts as though it proves her worth and contribution to the family.

> The childrens go to the concert or the store or church and I says "why do I have to be the one whose always left"? [she laughs loudly] She [a daughter] say "Mama, she can't go." She can go but it takes so long to get into the car and so long to get her out. I just feel like it's not fair to her to make her do that. It takes three people to pull around on her to get her in there. Once she be in there she is all right. But that is just hard to do. I say "she older than I am and I know that hard." I bring her in here [the living room] and her and I watch television until they get back. We sure do. And I just, like my mother and all the others, I just try to take care of her. . . . I just brought her here and I love her and she can stay here. It is her home like it is mine.

When consignment inside the home gets too stressful Sue moves to the perimeter to get a taste, breath of the other side. "I goes and sits on the front porch for awhile. . .It gets to the place I can almost cry but God gives me strength, He must give it to me cause all I'm doing." Sue also turns to her religion for strength and support.

Hints of personal vulnerability can be found in Sue's story.

> Now I'm working now trying to get her into a home cause I just not sure of myself, I'm just not able to do it but since I don't have anybody else I just have to do it. It ain't no easy job. . . . You know, you don't never know what kind of shape you going to get in. To look at me you would think I'm the picture of health but you know, you just don't know, you can't never tell.

Knowing when to act on Auntie's behalf and when to step back is a dance (a maneuver) most caregivers learn. Sue tells about that dance with her auntie.

> Whenever they [LAH/BNP] start aggravating her I'm going to tell her to go. . . Kinda stay out of it, let it alone, let it ride. I feel like that the best way to do it. Just deal with each day as you see it. . .She takes her own wash up cause we don't have a shower. . .I ask her 'why you don't eat' and she say "I'm going to eat." We all just get out and leave her alone. I say go back in about 4:00 in the evening and she done clean that plate. She eat it. I don't know if her appetite come back to her or her mind, I really don't. . .When she pull them off [her clothes] she is going to pre-wash them before she let you wash them. I kinda like to let her have her room to herself. . .She sit back there without the fan on. I use to fuss with her but she say she is just cold so I leaves her alone. I always tell her to raise those window so she have flow through. But that keeps her cool enough.

This also illustrates the leaping-in and leaping-ahead identified in Mary's story and some of the intuitive grasp in Paula's story. An element of preserving Auntie's dignity can also be found. "I don't try to confuse her. If she thinks something happened I let her go ahead on and think it cause the worst thing I could do is get her confused or get her to thinking she is losing it cause she has been a proud person all her life."

Conflicts with technology and the understanding of the technical aspects of disease processes are found in Sue's story.

> A man, one of their workers [from the oxygen supply company] is suppose to come out here and check the thing out cause the other nurse told me to not use the thing no more till I got it checked out. I've been waiting for him to come, I don't

know how often they come. But I'm waiting on him to come back again and check it out. When you turn it on it shakes and water flies. She know how to turn it on but it had not been on in about a month.

Sue describes a stroke as "it drained, the fluid, it caused the fluid to drain onto her brain," and "her kidneys break down and she can't hold her water." From the equipment to the disease the technical aspects are not well understood but that does not seem to concern Sue.

Sue does not describe self-talk as Mary did in the paradigm case. Reciprocity of care is missing except that which is provided from one generation to the next and then that enters the arena of obligation by textbook definition.

<div align="center">Story Four: Pat</div>

Pat is the primary caregiver for her husband who has respiratory problems requiring supplementary oxygen all the time. This limits his mobility but also restricts Pat's daily activities. Pat recalls, "In the beginning it was [stressful], you know, 'cause I didn't want to be, just up, staying home all the time though. Like I said it grows on you, part of you, every day. . .it is really routine to me." Caregiving has developed an "everydayness" to Pat. "I, it, it, I, do it because it just comes natural now, like I said. . . It don't seem like it is a burden. . .It's from the heart."

This caregiving is everyday comportment for Pat. Dreyfus (1991) points out the everyday comportment is not deliberate action but neither is it a mechanical behavior such as that of a robot.

To get the ontology right Heidegger introduces his own term for the way human beings relate to things, Verhalten, translated as "comportment." Comportments have the structure of directing-oneself-toward, of being-directed-toward. Heidegger uses "comportment" to refer to our directed activity, precisely because the term has no mentalistic overtones. . . . He thus takes comportment or intentionality as characteristic not merely of acts of consciousness, but of human activity in general. . . . Comportment includes "circumspection," a mode of awareness. Heidegger actually uses the term experience in saying that in the mode of everydayness. . .something has already been experienced ontically. But this experience can be characterized only as openness. Comportment is adaptable and copes with the situation in a variety of ways. Carpenters do not hammer like robots. Even in typing, which seems most reflex-like and automatic, the expert does not return to the home key but strikes the next key from wherever the hand and fingers are at the time. In such coping one responds on the basis of a vast past experience of what has happened in previous situations or, more exactly, one's comportment manifests dispositions that have been shaped by a vast amount of previous dealings, so that in most cases when we exercise these dispositions everything works the way it should. (pp. 63-68)

Pat gives us evidence of her past experience in caregiving. Her mother died when she was 3 years old and she was raised by a great-aunt.

An aunt raised me and she was my great-aunt, she was kind of elderly and I had to do some for her comin' on up. She was large and I had to iron her clothes. . 'cause it looked like to me it was hard. But I would do it over again if I had to. She died when, let's see, when I was about 15, 'cause I married early, I married when I was 16. I keep my grandchildren too, you know. She's [her daughter] off today I think but she hadn't brought them down here. I'll have them until she gets off. Some times she has a swing shift. She goes at different times. And I have. . she has three [children].

Pat had participated in caregiving from an early age. It was a position consigned to her by an unpredictable set of circumstances, the early death of her mother. That position is now relived in her role as caregiver for a husband and grandchildren.

Caregiving is not always easy for Pat. She even admits "he can get on my nerves."

Pat tells of many nights (two or three times a week) when her husband

weren't providing care to your husband and your grandchildren?", she responds "Umm, I have to find a life, I guess [she laughs], I don't know." Pat, like other caregivers, seems to have created a home that is enclosing upon herself while establishing "home" for another.

Is there an element of obligation in Pat's caregiving? Do the marriage vows include such an obligation or are they entirely reciprocal? What are the motives that spur an individual to provide care to another? Walker, Pratt, Shin, and Jones (1989) delineate two caregiving motives. Obligatory motives are based on need that imposes a responsibility on family members. Social forces place women in the position of family caregiver. Relational and situational obligation are both motivators. Included in obligatory motivators are moral beliefs (a kind of obligation bestowed from God), cycle of life (it is my turn in the family), and coercion. Discretionary motives are based on affection and interdependence built over the history of an intimate relationship. This includes feeling of compassion and love. A person can have both types of motives which indeed most do. All the participants in this study would have relational obligation as defined by Walker et al. When they were asked in follow-up sessions about their "obligation" that was not a word they would have chosen. Is "obligation" a middle-class White person word? Perhaps the word carries a negative connotation that is somehow unacceptable to many caregiving people.

Obligatory or discretionary doesn't make a lot of difference to Pat. "It just comes natural now. . . . It's from the heart."

Religion is found in Pat's story. "The church right next door. . . . So I basically goes right here most the time, you know, nice pastor. . . . I likes his sermons, you know. He comes over here and prays with me and [husband] 'cause he don't try to go to church anymore." Religious references are not found throughout like are found in Mary's narrative however.

There is an absence of reference to self-talk or special efforts to preserve dignity. Pat does spend time talking about the "attention-getting" behaviors of her husband. Other participants discussed these maneuvers of care recipients but Pat dwelled on that aspect in some detail.

> You got to have patience. Calls me 50 times a day to do nothing. Yeah, he wants this, he wants that, especially when I'm looking at my story. But he get on my nerves then. . . . When we get interested in something, he goin to want a glass of water. I keep a pitcher of water but he's goin to want something. A sandwich, a piece of cake with ice cream. I have to get up when I'm looking at something that's real interesting to me. I don't know what it is but he come in here and sit on that bed right yonder and he see me just sitting down and lookin like I comfortable. I guess he goin to call. That's the way it seems to me. . . . He was real bad on time. I be ready to be goin somewhere. Look like the minute, the closer I get to walking out the door, the more he be wantin. "Do that before you go," "do this before you go," it be too late to go anywhere. But now he's gotten better with that.

Most of the story Pat tells indicates a jumping-in or a doing for. She does not relate situations where she plans to help her husband do for himself. She appears to have assumed a very dependent role even though as caregiver she is the more physically capable of the two. The maneuvering that Pat does is primarily that which is directed by the husband care recipient.

Is Pat vulnerable? She expresses fear when her husband "hollers" out at night. She feels the urgency when the oxygen tubing becomes disconnected. She loses sleep since she is up with her husband many times during the night and cares for grandchildren during the day so that naps are impossible to obtain. As for her own health she says, "Oh, it's pretty good. Been a while since I had a check up - I know I need one. But I takes my Centracid and my vitamins, my blood pressure pills, I have diabetes too. I take a couple of aspirin."

People, participants and researchers, differ in their ability to participate in interpretive research. Pat did not find sharing her story easy. The experience required a lot of researcher input and a lot of effort on Pat's part.

Story Five: Diane

Diane tells a story of providing care to her great aunt. She provides care because "there was nobody else to take her but me 'cause my children work and she's the last sister of [my mother], I think there was seven." Auntie is 101 years old. Auntie goes to the Senior Citizen Center almost every day. Preparing for that trip causes concern for Diane.

Bathing and dressing, two important daily activities have become difficult to manage. Whenever possible Diane is accommodating but sometimes safety concerns require more intrusive caring. Auntie loves to dress so she likes to dress up and go there [Senior Center]. Oh yes, she loves to dress. She got to have those earrings and beads and pins and something pretty and white. And she won't let nobody see [her hair], she wants to wear a mingled wig. . .She loves to pull out her clothes and look at them, and picks an outfit for tomorrow and, you know. . .She likes to put on too many clothes. She'll

wear two pair stockins all the time, two pair of panties, three slips she does and all that kind of stuff. Its too hot to wear all that. I have to check her and if I catch her, you know what I mean, cause most times she's up and out there waitin' [on the porch, waiting for her ride to the Senior Center]. . She always like the clothes. But she no want old folks clothes [laughter]. Like shoes, she wanted heels. She can't no more. She always wanted them though. . .She took out a pair of shoes yesterday with a little heels about like [holds up her fingers to measure about 1.5 inches] that because they white. She says "I'm tired of wearing these old block buster shoes. Will you get my white shoes and put stretching in them 'cause everybody's wearing white shoes and socks." . . .I'm going to put the stretchers on them, but I still don't think that she should wear them. . . Yea, but she likes to dress like a fool, she a old woman but she don't want to look like an old maid, you know. I bought her some [she goes off and brings back a pair of slippers with sparkles on them, with a low heel]. For some reason she likes these. I try, but I have to watch what she wears. She put on somethin'. She is tiny and petite. She wants to look like that with her belt tight about her waist. Yes sir.

Diane is accommodating, obliging, interposing, intruding, constantly maneuvering and scheming. Like a dance that works best, is most beautiful, when one leads and the other follows. When the partners are not in sync the rhythm is broken and dys-harmony results.

Sometimes caregiving for Diane takes on a hint of "to do battle" rather than "to dance." Bath time has become a struggle.

Now I have to bathe her and boy, that's my big problem. She's afraid she's gonna fall. I notice where now she was doing it herself, she, as soon as she was in the water, she was out. And I found out now what she was doing was just getting in there, washing her legs and get out. That's the main thing is her bathin'. . .She thought she could bathe herself and I found out she couldn't, you know, she wasn't able to bathe herself. Oh, sometimes she cry 'cause I scrub her good, you know. She cried and she started to get out the tub. She doesn't want me to help her. She wants to do it herself. She got a way that she puts one foot out and hold the side of the tub, you know. But, see, I can just pick on that arm and the fact is she only weigh 100 pounds and she's afraid that I might have her fall. So it's kind of hard. That's the big problem. And I can't let her try to do it by herself 'cause

she really might fall, you know? Be there to help. That is our big thing. She be shaking and saying "Lord, Lord," you know, "let me do it myself."

This caregiving act (bathing) becomes more intrusive than accommodating.

Becoming consigned to the home environment in a restrictive manner is life for Diane.

Well, I can't go places. I have to be sure that she's all right - that somebody's here. I guess I just can't go and come as I want to because of her. She can never stay at my daughter's. I got two daughters, but, uhm, she never stay because they have steps and she's afraid of falling.

Diane's story deviates from all the others in this study regarding the circumstances surrounding the decision to provide care. Auntie is a person whom Diane did not find especially pleasant when she was a child growing up.

She never had a child of her own. She raised a boy but, uh, I mean, she thought you ought to been like, uh, an, uh, adult. "You sit in this chair, don't sit anywhere else. Don't touch this, don't touch that." She had some rocking chairs that we had to sit in and nothing else but those rocking chairs. I remember this well, all, even my children on up. Going to her house we had to sit in that rocking chair, she just too, too perfect. She had a beautiful house though until she got to where she wasn't as stable. . .[regarding the boy Auntie raised], He was five years old when she got him. Sometimes, I wonder about him, 'cause she was so strict. She was that way, you know. Well, he did fine though. He would come to see her, oh, about three times a year before she got here. He knows she's in good company or somebody really care for her and see about her so, that's the way I feel, 'cause he don't come [anymore].

This part of the story is hard for Diane, she cries intermittently.

"Auntie, now you know you got him on your will and he gets half of what you have. Why don't you go stay with him some, you know, and let me, give me a rest." She say, "what do you think, I'm not going there and let him put me in no nursing home." She knows there's nobody else. Now he doesn't even call, write her, ah, but once a year. . .he sending her flowers for Mother's Day. And he's able

to do. He works for United. But the minute he sends those flowers, know what she'll say? "Call him," I say "for what?" She say, "I just want to let him know I got the flowers." That means so much to her but, [laughs] to me, it feels like [long silence, tears, unable to finish]. Now that's what I really get upset about. All I have to do, diaper her sometimes, bathe her, feed her, everything. I don't mind it, I mean, but for her to think that he is really.....you know, and I'm supposed to do it. I don't mind it at all. I don't have anything planned. . . I really don't mind. It's kind of lonesome with the children away, you know. And now, there was no one else. So you just do what you have to do. As I say, I, ah, once in awhile, that's not very often, when I get upset with her I think about it, what's on her mind. She's not thankful that I'm here to do this for her, these things for her. 'Cause otherwise, she would be in a nursing home. I know she wouldn't last 'cause she couldn't dress and go. But she couldn't take that.

There is more of Diane's story that affects this relationship. Competition between

Auntie and Diane's mother is evident.

Cause before I brought her down here, she was, ah, kind of, somethin' wrong. And I went and got her. And she was spending her money like everything and the neighbors asked her "why you doing this?" She say 'cause she didn't want me to have a thing she had. So one day she was eatin, and we were on the porch laughing and talking and I told her about it. She said, "I sho' said it." I said, "well, all right, Sister." But, ah, that is no surprise 'cause with her husband being a railroad man, she always lived better than my mama. My dad worked in a steel plant and, ah, she with no children, there were just two of us, I had a sister, and she had what she wanted, more or less. But she never, never wanted for a thing. My mama bought a sewing machine and whatever else. If she [the aunt] already had one she would go and buy two.

Diane has assumed a subservient role which is a continuation of the way these two

family branches have operated for years. Even though the casual observer would think that

Diane has a choice in the matter of providing care for Auntie the greater truth may lie in

that she does not have such a choice. Within herself there is only a finite number of

options and to not provide care to a family member is not one of those choices. Her

background determines her possibilities. Diane did not actually observe caregiving of

extended family in her childhood. The practice of caregiving seems to have been so firmly embedded within her family that she did not have to "see it," she "knew it." Caregiving is transmitted within the families of all our participants. This "transmission" is not as visible with Diane as in the other stories. Diane says,

> My mother used to go with the neighbor but ah, I was married and away at the time, I don't know, just the lady lived across the street and she would go every day and see about her. Then she would go to the hospital and stay with her every day until she passed.

Diane's mother had the practice of caring and that was transmitted to Diane without direct role modeling. How does that happen? Does the way a mother interacts with a daughter make a statement about the value and practice of caring? If caregiving is embedded as an important value during childhood then perhaps as an adult the knowing of caregiving as a practice is one from the inside out.

An element of Diane's story that parallels others' stories is the need to have patience and use self-talk.

> Oh, I pray for that! 'Cause sometimes it just, well, I guess I shouldn't say that. Stupid things, you know. And I know, then I think about what I said, you know. "Why did you do this", and "why did you do that," Then I say "now, what would I do if I was that age?" I probably, I know I wouldn't be as well as she's doin'. I just don't believe I could 'cause she's a strong person. I step in her shoes. Well, not, what would you do if you were a hundred?

Diane's story is one of the more tragic stories because there has never been that element of mutual respect, trust, and appreciation other stories exhibit. There is a kind of love but a stressful one. One has to ask "Why." Why does Diane continue in this situation? The term commitment is often use by social scientist to measure or describe what is

important to people. Heidegger uses "concern" to discuss what it is that matters to a person. Concern is a key component of the phenomenological view of the person. "Although embodied understanding and background meaning can account for *how* the person can be in the world and grasp meaning directly, concern accounts for *why*" (Benner & Wrubel, 1989, p. 48). Because concern is qualitative we can talk about how the concern shows itself in the lived experience. Auntie matters to Diane. Auntie is Diane's concern and that is *why* caring for Auntie is part of Diane's lived experience. Choosing to ignore a matter of "concern" would produce stress perhaps greater than what Diane is dealing with in providing care. Does this place Diane in a special bond (or bondage) because of what she cares about?

This situation certainly increases the vulnerability that Diane experiences. Diane's story includes elements of devaluation, non-appreciation, and being used. Diane certainly feels wounded at times. The pain of the wound brings tears to her eyes as she recounts parts of a somewhat dehumanizing story.

In comparing Diane's story with the paradigm case (Mary) the difference that is prominent centers around motive. Diane's motives are primarily of the obligatory type. "There was nobody else to take her." Reciprocity in the caring situation is almost non-existent. Another difference is found in how Diane acquired the practice of caregiving. Mary says "My mother, she would go around, I guess that is what they did during that time, they went to the people that was sick and cared for them." Diane did not see, only knew about her mother's caring of people outside the home. Vulnerability is

pronounced in Diane's story. Very little about religion can be found in Diane's story. She does say about patience, "Oh, I pray for that!"

Amazingly, in spite of the circumstances surrounding Diane's childhood experiences with Auntie and her motive for caregiving, Diane still actively protects Auntie's dignity. Some examples include, "I let her buy what she want or whatever. And give her the money." Auntie wanted to wear her "heels." Even though Diane thought that was not a good idea she "put the stretchers in" as Auntie wanted. To negotiate a safe solution Diane purchased a pair of flat shoes with extensive decoration that pleased Auntie (a maneuver to preserve dignity?). This is also an example of Diane's intuitive knowing about when to leap-in or leap-ahead. This knowing is demonstrated in the way she deals with bathing.

> I can't let her try to do it by herself 'cause she really might fall, you know? Be there to help. . . . But I'm going up, maybe this week and get her a rail so she can have a safety net. I can bathe her and not bother trying to help her out as much. That, I know that would help.

Diane has had to leap-in but is making plans to leap-ahead by changing the environment so Auntie will be empowered to meet more of her own needs.

Diane does not share any information about trying to deal with technology in her practice of caring. She does say that if Auntie's care becomes technical she will have to go to a nursing home. "I don't uhm, know much about nursing care, not a thing, you know. So if I see where she would have to have that kind of help, then there's nothing to do but

put her in a nursing home." Some might argue that Diane knows a lot about the essence of

nursing, the part she may be lacking is in the area of skills.

Story Six: TV

TV (a childhood nickname) is 73 years old and provides care for her father who is

97 years old and her 51-year-old son with a "mental illness" that requires instructing him

"like a child." TV's story resonates with frustration. Frustration resulting from "being

tired," "getting older," poor personal health, and unresolved issues with her siblings.

TV says she does "about everything. I take care of the household here. I do

laundry, shopping, cooking, and cleaning. I take him to the doctor. . .to get a hair cut." Is

all this almost too much for TV? "Yes, yes, yes, I have no alternative." There appears to

be elements of obligation but does TV regret her caregiving choice?

> It is hard, and I am tired but I wouldn't have it any other way. I give all the praise
> to God. I know that if it weren't for Him I couldn't do anything. I think everyone
> has a purpose in life, I think this is my purpose and I will if He let me do it.

Two issues stand out in this one rich statement by TV. Her faith is strong and

sustaining and she feels called to care. TV was asked directly, "Do you feel you have been

called to care in some special way?" She responds,

> Yes, yes, that has always been my role in the family. My brothers and sisters are
> good people but they don't do the care like I do. I am just getting older and I'm
> tired. But God gives me the strength so I carry on with His help.

Caregiving gives meaning to TV's life and TV gives meaning to giving care. The practice

of caring is a value TV acquired at some point in her life, but can it be called a part of her

culture? Would not her siblings have the same culture having been reared in the same

home as TV? Perhaps each person's culture is made of many strands and while many of those strands are shared with other family members some are not universal to any group of people. Being the family member designated in some way as the caregiver is a pattern throughout TV's story.

> One thing that worries me is I can see before my eyes my mother doing the same thing, deteriorating slowly. I am the only one in the family that was with them both. . .when I was married, things would happen in the family, with my mother and my mother would always call me and I lived in the Southeast, quite a ways from where she lived, and I had two brothers that lived right by her but she always called me to come and see about her mother and take her to the hospital and things like that.. .when Mother got sick, she was diagnosed with cancer. I left my job and moved in with Mother and stayed with her until she died. I was the one who came in and take care of her. Yes, I'm the one, anytime something happens in the family I've been there for them.

> Vulnerability is an inevitable consequence of the call to care. Lashley (1994) says,

> Vulnerability involves risk-taking. These risks are inherently ontological, as persons come to experience the self-alienation, redefinition, and discovery that comes when they are faced with events that lie beyond human understanding. Responses to vulnerability involve a dynamic flux between arming oneself and entering into places of nakedness. Disclosure of the tensions inherent in this flux are illuminated in the context of a spiritual discourse, which may allow one to speak more directly to the personal meanings of vulnerability for oneself and others and to respond to the call to care in the midst of an environment fraught with ambiguity and uncertainly. pp. 43-50

Since TV is the one family member who was called and/or responded to the call to care she experiences uncertainty and ambiguity. This is reflected in the dissonance evident between TV and with her siblings.

> My brothers, they say they could do it but he not living with them 24 hours a day, 7 days a week, 365 days a year, you know [verbalizing consignment], having the brunt of all the misery. . . My brother, he is a professional, he comes by and says "hi" and tells me what to do but coming by and staying 2-3 hours so I can get out,

nobody does that. . .I tell them, "you all can give me a hand" but then they say, "when you need it let us know" and I don't see why I have to ask them when they know what I'm under. This is their father like he is mine. Why should I have to ask them? My brother says "if you need someone to come in and clean we'll pay for it." things like that but I don't bother. . .My brothers and sisters are good people but they don't care like I do.

The wisdom in TV's last statement "they don't care like I do" may hold the key to the lack of understanding the siblings seem to have. Responding to the call to care as described by Lashley (1994) performs an act of metamorphosis upon an individual. A depth and type of meaning evolves which is not intuitively understood by another. But TV thinks her siblings should know intuitively, "Why should I have to ask?" TV wears shoes in which her siblings cannot walk. Understanding cannot be theirs. TV perceives that it would be a "bother" to make the necessary changes so her siblings could be different. In fact, TV probably could not produce those changes in her siblings since they have not responded to the "call to care" and they have not gained access to the essence of caregiving and its language.

> We human beings, in order to be who we are, remain within the essence of language to which we have been granted entry. We can therefore never step outside it in order to look it over circumspectly from some alternative position. (Heidegger, 1971, p. 63)

In a very special sense TV has been granted entry into language that her siblings do not have. Dryfus (1991) explains more about Heidegger's views on language.

> Once one has been socialized into a community's practices, as long as one dwells in those practices rather than taking a detached point of view, words are simply heard and seen as meaningful. Only dwelling in our linguistic practices reveals their

sense. This source of meaning is just what is inaccessible to [those persons] detached. (p. 219)

TV's siblings might be considered among the "detached" who find meaning inaccessible.

There is some reciprocal caring in the household. TV says, "I don't get him his bath, my son does that, I get him into clean pajamas." TV's son requires care and supervision. In a unique way TV's dad contributes to his grandson's life.

> My son idealizes him [TV's dad]. He always wanted to emulate a man. His father did not have time for him. He idealizes my father. . . I think he [dad] is grateful cause XXX [grandson] does everything he can for him. Gets him up, gives him a bath, he jumps up for him more than me, you know. They get along pretty good.

Frequently TV refers to God and her faith as strength.

> With the help of God I keep going, you know. . .I know that according to God's Word we are suppose to honor our father and mother and I'm doing my job as a daughter to take care of what he cannot take care of hisself. . . I keep going, thanks to God, I keep going. . .I'm grateful that I'm here and God lets me do what I'm doing. . .I'm a Christian woman, I go to church, I believe in God, I try to live, to love other people. . .I give all the praise to God. I know that if it weren't for Him I couldn't do anything. . .God gives me the strength so I carry on with his help.

At times in TV's story it sounds like the care she provides flows from duty alone (obligatory). But other times it becomes obvious that there is also enduring love.

> Not that I mind. I love my mother and dad. . .I love my dad, I don't want this to sound like it is a morbid situation. . .I have always been close to my father. Even when I was married I was always close to my dad. All in all I love him very much . . .I've always loved them, done to them and shared with them.

TV has watched her mother "deteriorate" and die. She has been providing care to a "deteriorating" Father for 22 years and a mentally challenged son for 23 years. TV is 73. Given this background TV was asked, "Do you have any fears for yourself as you are

getting older?" Without hesitation she answered, "Yeah, I fear what will happen to my son if something happens to me. . . It worries me cause there is no family that would take him. That's my biggest worry." Never a mention of her own future of deterioration or of seeing in her parents' story a story for herself.

TV, like other caregiver stories in this study, has a way of working around Dad.

> He gives me trouble about cleaning up behind him, things like that. He will go to the bathroom, he will mess the toilet. . .I know he don't mean anything by it but it is hard on me, cause I try to keep it up. . . . I tell her [the doctor] the things that he is doing and sometimes he [dad] denies some of the things I'm saying but we both [TV and the doctor] understand.

This is another example of the never-ending maneuvering that was shared by Mary in the paradigm case.

Another similarity with Mary's story is how TV learned to care. TV was asked, "Did you see a lot of caregiving going on as a child, like did your mother provide care for her mother or an aunt. . .?" TV answered,

> Ah, yes my mother did and well, my mother wasn't too well and her mother came to live with her. There was a time when my mother she dedicated herself to her mother all the time. My mother finally got to where she wasn't well. It is a long story. God forgive me for what I'm fixing to say but Mother didn't provide care like I think is right. I'm trying to do things for my father that she didn't do for her mother. I am like my mother in that I want things clean around here cause that's the way it's suppose to be.

It is interesting that TV learned both how and how not to provide care from her mother. Perhaps her siblings learned only the "how not" lesson.

Throughout the stories preserving dignity, maneuvering, and leaping-in/leaping-ahead are tied together. The same sections of the narrative seem to support each theme. Perhaps the movement or action implied by "maneuvering" and "leaping" produces the intervention needed to preserve dignity. For example, TV says,

> Like Dad, he use to take care of the yard. The other day he said "that yard needs mowing, if XXX [grandson] starts up that mower I'll do the work." Why, there be no way he can do that! He walks to the front door and back and that's about all. Sos I have to bring him back to reality. I says, "Dad, it is too hot out there for any of us. We'll have to wait till it is a little cooler." And then I makes sure XXX is out there in a day or two to do the yard.

This is a caring maneuver that TV practices. It is also a leaping-in, a "no, you cannot do that. It would be dangerous for you. I will take over here." But TV artfully puts this together in a way that protects Dad's dignity.

TV does not share information about difficulties with technology. This may well be an area where TV's sister and brother intervene but that information was not elicited. TV does not mention self-talk. One interesting finding is the narratives that are the strongest in the area of religion, with many references to talking to God, are the weakest in self-talk. Perhaps the "talk to another" but not another "person" is practiced in several ways.

Story Seven: Ann

Ann's story is about the reciprocity of caring. She cares for her 90-year-old father who in turn contributes to Ann's welfare. They live together in the family home of more than fifty years where "Daddy" pays the utility bills. He is still able to cut the grass and "he

vacuums for me. Now if something big, like a roof or something then I would have to do that. . .I feel like we are helping each other."

The reciprocity of caring in Ann's story goes beyond finances and household chores. There is more than mere mutual exchange. Reciprocity is a policy by which advantages or privileges are granted by each to the other. This kind of reciprocal caring is in Ann's story; caring for each other as individuals with needs.

> Daddy doesn't like for me to go out at night. It's not that he doesn't want me to go, he say, "you shouldn't be out at night, you don't never know, now lock your car doors," he is really being more careful than telling me to not go someplace.

> In turn Ann goes to great lengths to protect Daddy's dignity.

> When he go to the bathroom he doesn't go all in the toilet, he goes all over the toilet bowl. So I talk to myself about it. He is doing the best he can. . .but Daddy, sometimes I don't think he sees it, I don't know but instead of asking "don't you see that?", I just go clean it up, I just go wipe it up. . .Don't say anything. Act like you didn't even see it. That keeps his pride, you know. . . So, this is just home, I stay here, he takes care of me and I take care of him.

Ann tells a story of being *nested*, a story of availability, of nurturance and support but not entrapment; maybe not even consignment. Her place feels comfortable.

How did care come to be like this for Ann and her daddy? Ann relates that when her mother passed at an early age, she was 63, her last words were, "Take care of Daddy." So we are still at that [obligatory caring], we take care of Daddy. . .that's the way we were raised. A lot of this has to do with how you were raised. My mother went to work and there was nobody at home and I was raised by my grandmother and grandfather. So we were use to all that.

In the process of "being raised" rituals were prominent in Ann's life. These rituals become family traditions. Even now these traditions are evident. Caring is one of those traditions.

> She [Ann's mother] was always doing for other people. So we were always raised to help others cause we never know when I'm going to get to that same point. . . When my grandmother got a little incapacitated she [mother] would go over and see about her. . . My mother always kept other people. . . My cousins would come from the country and they would stay with us. Mother always say to them "you come to my house you go to school," you know, that sort of thing.

Another "ritual" from Ann's childhood that contributes to her caring background involves Sunday mornings. The family didn't "have much money" so Mom would put Ann and her siblings in a taxi to go the Sunday School. Afterwards the children "little children, 6-7 years old" would walk home. Grandmother's house was on the route and the children would stop where "she would always have pies and cakes, we would spend a couple of hours there and then we would go on home. See that was our ritual, that was something we were brought up with."

The forming of rituals has not ended. Ann tells about her dad, "everyday he gets up, it is almost like a ritual, he gets up, if he feels all right he goes (to the Senior Center). He walks, he walks every morning." The rituals of the past have prepared Ann and her dad for the present and future.

> Grow old along with me!
> The best is yet to be,
> The last of life, for which the first was made:
> Our times are in His hand

Who saith 'A whole I planned,
Youth shows but half; trust God: see all nor be afraid!
(Browning, 1996, cover-page)

Things besides rituals sustain Ann and her dad, herbs and God. A strange

combination? Not to Ann. She does what she can and she depends on God for the rest.

> We see that he takes his herbs, so he doesn't have a lot of illness. He is living long, most of his friends have passed. . .It took us a long time to get my daddy to take herbs. I take them too. I take maybe 10 pills every morning and I really feel that enhances my health. It enhances my living while we are living. People wouldn't have to be in bad condition if they would take herbs. It is sometimes hard for them to take that. . .Now, naturally we are Christians and I ask God to take care of him, especially when I am not with him, you know. Cause that could be rough. . .I have been really blessed.

Ann says her Mother was a Christian woman and Ann is following in that ritual also. The

story of convincing Dad to take herbs demonstrates Ann's ability to guide, maneuver,

(dance with?) Dad. It is part of leaping-ahead. Keeping Dad well keeps him in control and

empowered.

As reciprocal as Ann and her dad's relationship seems to be it is not all easy. Ann

has learned the steps required to work around her dad.

> We couldn't get him to go to the Senior Center. It took us a little while to make him realize he should go there. And when we once got him to go it was not a problem. . .I find that with elderly people, myself included, you can get frustrated with them, to some extent, you have to, because I have to sometimes, they have their own ways and they going to do it their way. So I sometimes I have to talk to myself, I'll call my Sister and cry, "I'm so tired of my daddy, he just fuss at me, he just. . ." She say "just calm down, that's just the way when they get older," you know. And I find myself talking to myself and putting myself in his situation and I say I may be worthless when I get to his age and he is not. I try not to say anything.

Ann is not immune to feelings of vulnerability even though her story is one of "OK-ness." Ann tries to protect herself from the hurt and vulnerability by self-talk. She protects her dad by the practice of "not saying." Is she able to "not say" because she does "self-talk"? This is how Ann positions these talks in her story.

> Sometimes I find he has had an accident with, you know, his clothes. He will not say anything to anybody. He will not say one word. So I have learned to use my eyes. And look for signs of that. I don't say anything, I just go in the room and get all the things, clothes and wash them. . .I have found if you don't say anything to him it works better. I've said "why didn't you come tell me, this is what I would have done," "why didn't you say something," "why didn't you do that," you know. I say [to myself] "just don't say anything.". . . Its hard for me to do that now. I have to consciously talk to myself, you know, "don't say anything, don't say anything. He is doing the best he can."

Maneuvering (this time with the eyes as well as other action), self-talk, and no-talk are the interventions Ann has used to preserve Dad's dignity. It is interesting that Dad also practices the "not say anything to anybody. . .he not say one word." The educated professional might see this as poor communication but that is not the sense Ann conveys. Perhaps this is a strand of their culture, an embodied use of language.

After this part of Ann's story she was asked, "Would you say that anything you do for your father is a burden?" Ann responded without a moment's hesitation.

> NO, I don't look at it as a burden. Cause I know, I guess I would say it like this, since I'm not a social person, I don't want to party all the time, and do things like that, I don't look at it as a burden, I look at it as part of my everyday life.

Heidegger might have said that Ann has terrific insight. Caring is part of "everydayness" for Ann. It is part of her history, her today, and her tomorrow. The hermeneutic understanding of the historical gives us a "sense of an underlying ground-rhythm of

intelligibility in which we participate and which we constantly reshape and transform in our decisions" (Guignon, 1983, p. 80). From this point of view "history is not merely a story; it is a mode of understanding which can affect the order of life itself" (Guignon, 1983, p. 249).

Ann's story does not include information on technology. Her story pictures caregiving as less restrictive than even those caregivers whose care recipients do not share their home. Ann's story is very strong on the reciprocity of care but there is still an element of obligation.

<p style="text-align:center">Living at Home/Block Nurse Program</p>

Two participants shared their story of caregiving without even a mention of the LAH/BNP. Could this be an indication of how completely embedded into the lived experience that program had become or was it an indication of insignificance? The remaining participants were asked directly, "Tell me about the block nurse program, how does that work for you?" Two areas were identified as helpful. One involved verification of health status. "Sometimes he think he has a fever and he don't have it and then when she comes and take his temperature, he find out he hasn't gotten one. It is helpful cause it keeps up with his blood pressure. She knows how to do things like that. Most of the time she have a question for her. She asks a lot of questions. I don't hardly know all the questions."

The second outcome of the LAH/BNP identified as helpful is a "peace of mind" issue. "Keep me from worrying so much, you know, about how he's doing or whatever.

Anytime somebody go to see her it takes, helps us cause then we know she is all right cause they usually they will call us if they find so and so out." Another participant responded, "When they call to talk to her she is radiant. You know, she feel like that is special." A third participant adds, "That make me feel a lot better. Knowing that there are people who care for your mother."

One aspect of both the physiologic and emotional support is education. One participant reports,

> I know while the block nurse come and take her diabetes, you know, blood sugar, that makes a lot of difference cause I was trying to get her to not to eat all that, not to put all that sugar in her coffee. Like she put three teaspoons of sugar and she likes sweets, she likes pork or she wouldn't listen to me about, you know, the way she is eating. Now since the nurse coming she has made a difference she will hear her.

Community leaders from both the Fort Worth, Texas and the Birmingham, Alabama sites were asked about the low participation of older adults with caregivers in their programs. At the Fort Worth site it was reported that there is difficulty "getting the word out." In Birmingham it was thought that caregivers may not always find the block nurse especially helpful as many times they come with the message that something should be changed or with suggestions to do something different. The message might actually increase the work related to caregiving. One participant, Sue, made a comment that adds some support to that thought. "I told her [auntie], 'If they [LAH/BNP] get on your nerves, if you don't want them, or if they bother you or makes you tense when they come I will tell them don't come back no more." This message to Auntie reflects Sue's position

on medical health care, "I don't like nothing in a white coat. I can do for myself and my children won't let anybody get too close cause they be always there, you know."

Able and Nelson, (1990) reports that there is at least some evidence suggesting that the most critical issue for community agencies may be recruiting a sizable clientele. Brody, (1985) argues that the resistance of adult daughters to formal services stems from emotional problems. Because they are over-involved with their parents, she contends, they assume that they are uniquely equipped to minister to them. There is evidence in the participants' stories that they feel uniquely equipped to provide care, even called to be the one to do so. There is no specific reason to conclude "emotional problems" from this part of the participants' texts. Able and Nelson (1990) continues to expand.

> Many elderly people and their friends and kin share with most other Americans the belief that dependence on any social services is a sign of personal failure. Having absorbed a value system which glorifies self-sufficiency, they may be unable to rely on others even when they are desperately needy. . . . Some elderly people also may cling to housekeeping chores as a way of separating themselves from their more severely impaired counterparts. An ability to manage routine tasks may serve as a source of self-esteem, especially for those who have suffered numerous other loses. (p. 80)

While Able and Nelson are talking about the older adult, the participants in this study have made caregiving such an integral part of their lives that it is part of their self-image. Only two participants identified the desire for some relief in their caregiving. Both of those individuals turned to other relatives for help, in both cases without success.

The LAH/BNP is having much more success at serving the community members who are aged and WITHOUT caregivers. These people have fewer choices and are more

willing to receive services from neighbors than from other social service agencies form the "outside." For example, the Birmingham LAH/BNP serves 42 individuals, only 5 of those have any other caregiver at all.

Chapter 5

THEMES AND CONSTITUTIVE PATTERN

"Theme analysis" refers to the process of peeling off layers to discover (recover) themes that are embodied in the participants' narratives. Phenomenological themes may be understood as the structures of experience. Van Manen (1990), likens themes to "knots in the webs of our experiences, around which certain lived experiences are spun and thus lived through as meaningful wholes" (p. 90). In determining the essential themes the researcher's concern is to discover aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is.

Several themes were identified as the narratives in this study were interpreted. Some of the themes were found in all the narratives and others where evident in a limited number of them. These themes and how they were represented in each story are presented in Table 1. The themes of TRADITION, RELIGION, MANEUVERING, and LEAPING-IN/LEAPING-AHEAD were selected as the most essential ones; themes that represented qualities that make the caregiving phenomenon what it was for those seven participants.

Burden was a controversial word for the participants of this study. Based on the study by McKinley et al. (1995), which reported burdens of caregiving (see Chapter 2: Literature Review) and the later studies by Kahn and Eaves (1996) and Nkongho and

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Archbold (1995) which indicated many positive aspects to caregiving, each participant was asked to tell the "burdens" of caregiving. Six of the seven caregivers said "No." The experiences they had were not burdens. Four of the six "no-burden" caregivers were emphatic, repeating in several ways that there were no burdens. The one caregiver, Diane, who listed "burdens" did so reluctantly. After several seconds of thought she said, "Well, I can't go places. I have to be sure that she's all right - that somebody's here. Just to be sure she is all right."

Other caregivers had similar things to say. Paula said, "My mother is not a burden, NO, she never will be. Not my mom, I wasn't to her. My grandmother wasn't either." Ann shared, "NO, I don't look at it as a burden. 'Cause I know, I guess I would say it like this, since I'm not a social person, I don't want to party. . . I don't look at it as a burden I look at it as part of my everyday life."

This information supports Kahn and Eavers'(1996) findings:

> . . .these elders did not talk about burdens of caregiving as part of their everyday life. Instead, caregiving was taken for granted, was something that they had been doing for others most of their lives, and was not a new, unusual, or particularly important or salient experience. (p.29)

The themes of OBLIGATION and VULNERABILITY were both included in all participants' stories but they were excluded as themes for several reasons. While both of these concepts applied to this study's participants, when specifically asked in follow-up conversations the participants did not agree with the words "obligation" and "vulnerability." Paula said, "Mom is my best friend, there is nothing I'd rather be doing."

Mary said, "This is my responsibility, it is not an obligation, I am filling a need, that is not an obligation, I have a choice." TV shares the same thoughts, "This is in my heart, I know it pleases God but I do it of my own free will. I am a free spirit and being the way I am I do it for love. If there was any obligation in the whole thing it would be to God." These comments and those of the other participants fall under obligatory motivation according to Walker et al. (1988); but even with an explanation of the two broad categories of motives (obligatory and discretionary) and examples of each, participants still said that obligation does not describe their caregiving motives.

Table 1: Themes

	Mary	Paula	Sue	Pat	Diane	TV	Ann	Totals
Obligation	X	X	X	X	X	X	X	7
Reciprocity	X	X	O	X	O	X	X	5
Tradition	X	X	X	X	X	X	X	7
Vulnerability	X	X	X	X	X	X	X	7
Religion	X	X	X	X	X	X	X	7
Dignity	X	X	X	O	X	X	X	6
Maneuvering	X	X	X	X	X	X	X	7
Self-talk	X	O	O	O	X	O	X	3
Technology	X	O	X	X	O	O	O	3
Leaping	X	X	X	X	X	X	X	7
Consignment	X	X	X	X	X	X	X	7

Vulnerability is an inherent part of the caregiving relationship (perhaps it is embedded into all relationships) and will be discussed with the theme of caregiving as a tradition. Tradition also includes the "everydayness" of caregiving for the participants.

Tradition

Besides "burden" Kahn and Eaves' findings suggest caregiving as a tradition for their participants (African American elderly dyads). This caregiving tradition was part of their everydayness. The findings of this study are supportive of the tradition of caregiving. Dreyfus (1991) examines Heidegger's thoughts about care and its relationship to culture.

> In a conversation with Heidegger I pointed out that "care" in English has connotations of love and caring. He responded that that was fortunate since with the term "care" he wanted to name the very general fact that "sein geht mich an," roughly, that being gets to me. Thus all ontic senses of caring are to be included as modes of ontological caring. Care is the "formal existential totality of Dasein's ontological structural whole" (Heidegger, 1962, p. 192). "The transcendental 'generality' of the phenomenon of care and of all fundamental existentialia is . . broad enough to present a basis on which *every* interpretation of Dasein which is ontical and belongs to a world-view must move" (Heidegger, 1962, pp. 199-200). This is Heidegger's answer to total cultural relativism. There is a common structure to ways of being human. Every culture is a different self-interpretation, but *an* self-interpreting was of being has the disclosedness-structure called care. p. 239

Sorge is the word Heidegger uses for this type of underlying, always present source of the will that connects us to the world. This is why being-in-the-world (Dasein) in an important sense *is* care. However, how this care is interpreted is culturally influenced and traditions make many of the strands that are one's culture. There is no doubt that the participants in this study were products of caring as a tradition handed down from generation to

generation primarily by the women. Wisdom Women by C. B. Follett (1996) captures this process very well.

> Old women, you were the lattice
> for new growing vines, used to tell
> how fire was kindled, blazed,
> how the years turned and seasons
> swelled with new growth.
> Dark eyes nearly hidden you kept the secrets. Waited.
> Planned when to fish, plant,
> harvest the tall grain. You
> instructed girls in the mysteries
> of blood and sex,
> birth, children. . . .
> You chanted our histories,
> how we moved
> across land and stream bed to come here,
> and when we moved from here, as spring
> heated the land, this too would you braid
> into the story, spinning it out
> in thick plaits. . . .p. 170

Reverby (1987) also connects caring and the person's past.

> Caring is not just a subjective and material experience; it is a historically created one. Particular circumstances, ideologies, and power relations thus create the conditions under which caring can occur, the forms it will take, and the consequences it will have for those who do it. p. 5

Heidegger calls this form of caring "ready-to-hand." When the person is actively involved in the situation actions become transparent or unnoticed, an extension of the body. When a person is healthy, his or her own body is ready-to-hand, unnoticed. This best describes the reason caregiving is everydayness in this study. Heidegger offers two other ways to be in situations (Benner & Wrubel, 1989).

> In "unready-to-hand" smooth functioning breaks down. In the condition of unready-to-hand, the situation is altered, and the person loses the maximum grasp

that was available during the ready-to-hand condition. Because the unready-to-hand is more noticeable than the ready-to-hand condition, this state is the one most often studied by scientists. It is a situation that is "problematized" by the breakdown.

The "present-at-hand" is the most detached objective view of the situation. Here, the person stands outside the situation and looks on. From the Cartesian tradition, this stance is the closest to "truth" because it is more objective and less involved. Relational aspects of the situation cannot be adequately studied from this stance, nor can the actual lived experience because the present-at-hand analysis can only provide static snapshots at given points in time. p. 81

Using Heidegger's terms "ready-to-hand," "unready-to-hand," and "present-to-hand" a person's level of involvement in a situation may be described. For example, TV's caring for her dad is "ready-to-hand", she says, "I just do it." It comes natural and has all her life. "I'm the one anytime something happens in the family I've been there for them." TV's brother and sister have a "present-at-hand" involvement with Dad's caregiving. "My sister, she is pretty well off, she come by and be in and out. My brother, he is a professional, he comes by and says 'hi' and tells me what to do but coming by and staying 2-3 hours so I can get out, nobody does that." The participants' unwillingness to call any aspect of caregiving a burden or an obligation demonstrates how everyday and "ready-to-hand" their caring is.

Wrubel, Benner, and Lazarus (1981) offer another explanation for the participants' objection to the word "obligation." "Caring cannot be controlled or coerced; it can only be understood and facilitated. Caring is embedded in personal and cultural meanings and commitments" pp. 80.

Vulnerability comes with this level of intimate involvement. The old saying "You always hurt the one you love" might well read "The one you love can always hurt you." Being in a relationship opens up the possibility for hurt, pain, and regret. This concept was explored well with the narrative interpretations. It belongs here as a prelude to the next two themes, religion and maneuvering.

Religion

Religion for some African Americans provides an escape from the harshness of life. One participant said, "I take the brunt of all the misery." The church is a mechanism to provide support, maintain self-esteem, and a curator for maintaining the culture. "The Black church, regardless of denominational faith, has become synonymous with the Black life experience" (Giger & Davidhizar, 1991, p. 62).

If Giger and Davidhizar are right then any study of the lived experience of African Americans should find the church an integral part. In fact that was the case with this study. Every participant mentioned church, faith, God, and/or prayer to some extent. This reference to spiritual things was almost universally tied to an identifiable vulnerability. For example, "I get so tired, I just pray to God for strength." "I ask God to just give me patience and strength."

One vulnerability that several participants mention related to their own mortality. Moberg (1981) recognizes the multidimensional nature of spiritual concerns and defines these as "the human need to deal with sociocultural deprivations, anxieties and fears, death and dying, personality integration, self-image, personal dignity, social alienation, and

philosophy of life" (p. 350). While the issue of death and dying was quit explicit in the narratives, many of the other factors Moberg mentions were implicit, such as anxiety, fear, and social alienation or isolation.

Kaye and Robinson (1994) studied the spirituality among caregivers. They concluded:

> The spiritual behaviors practiced by caregivers may be one method of coping with the perceived lack of support that occurs in caregiving. Spiritual behaviors described by caregivers such as praying, reading spiritual materials, talking to friends or family about spiritual matters as well as sharing problems and joys of living according to one's spiritual beliefs can mediate the stress created by the lack of support persons. . . . Divine interaction reflects a positive reframing of the losses and heightens a sense of order and coherence in the stressful experience in caregiving. Negative feelings may be neutralized and coping improved. p. 220

The caregiver stories in this study demonstrate the neutralization of negative feelings. Although negative situations were frequently described, negative feelings were consistently denied both verbally and non-verbally.

Leaping-in/Leaping-ahead

Benner and Wrubel (1989) explain Heidegger's terms, leaping-in and leaping-ahead very well.

> Because concern is qualitative (i.e., a meaning term) we can talk about how the concern is lived out. For example, Heidegger (1962) talks about two types of concern: (a) the kind of solicitude that leaps in and "takes over for the Other that with which he is to concern himself" and (b) the kind of solicitude that "leaps ahead" of the Other, "not in order to take away his (or her) 'care' but rather to give it back to him (or her) authentically . . . ." In the first kind of concern, the Other is disemburdened completely to take it up again "as something finished and at his disposal" (pp. 158-159). When [people] are extremely ill and dependent, there is no choice but to "leap in" and take over, but the problem is that this kind of "taking over" can extend past the point of necessity either on the part of the one

caring or the one cared for. That is, the one cared for may find it difficult to take up his or her care again. The first kind of solicitude, the kind that "leaps in" for the Other, can easily slip into domination and dependency or even oppression, even if the domination is subtle and not apparent to those involved. The second kind of solicitude is a form of advocacy and facilitation. It empowers the Other to be what he or she wants to be, and this is the ultimate goal in care relationships. pp. 48-49.

Both leaping-in and leaping-ahead are seen in the narratives of this study. Mary, the paradigm case, leaped ahead in the doctor's office when she served as advocate for Auntie and facilitated Auntie's inclusion in the conversation. Much of Mary's "maneuvering" was related to her effort to leap ahead and empower Auntie to do for herself. An example of possibly inappropriate leaping-in is in Pat's story. Her husband was very capable of much of what Pat did for him. A special example is the reconnecting of the oxygen tubing that Pat took on as "her job." It would almost appear that Pat's husband "rebelled" at Pat's insistent leaping-in and instead of her dominating by that action he turned it into servitude to him. This appears in the following parts of Pat's story.

> [He] calls me 50 times a day for nothing. He wants this, he wants that, especially when I'm looking at my story [on television]. But he get on my nerves. When I get interested in something, he goin to want a glass of water. I keep a pitcher of water but he's goin to want something, a sandwich, a piece of cake with ice cream. I have to get up when I'm looking at something that's real interesting to me. I don't know what it is but he come in here and sit on that bed right yonder and he see me just sitting down and lookin like I'm comfortable. I guess he goin to call.

Remembering that this is a man who sits on the front porch most of the day visiting with friends and repairing lawnmowers for money the described behavior appears inappropriate. Pat does not mind. She says, "It's nothing, I mean really, it's routine for me. . . . It grows on you, part of you, everyday."

Leaping-in is necessary for some of the participants. Diane tells of having to intervene when she discovers that Auntie bathes only her legs when left alone at bath time. Several participants tell of the need to provide transportation and prepare meals due to the care recipients' inability to do so for themselves.

Maneuvering

The name of this theme, "maneuvering," is taken from Mary, the paradigm case. The same practice is referred to by all the participants. Some say "going back and forth," "work around," "talk him into it," and "work it so she think it be her idea."

The Webster's College Dictionary (1995) offers these definitions of maneuver: "an act or instance of changing the direction of a moving vehicle, a physical movement or procedure, esp. when skillful, a clever or crafty tactic, to position or manipulate, to steer as required, to scheme; intrigue." The caregiver practice of maneuvering includes all the actions given in this formal definition.

It is interesting how "dancing" closely relates to the definition of maneuver. In the caregiver dance, a unique skill, often clever and crafty, is exercised to move, physically or mentally, the care recipient into a more favorable position. With the caregiver in the lead, this dance is accomplished best when the recipient is "in-step" with the scenario. Many times this maneuver is in an effort to provide safety and preserve dignity. Most of the caregivers in this study (Pat being the possible exception) were very skillful in the practice of maneuvering.

Constitutive Pattern

Constitutive patterns are the highest level of hermeneutical analysis. They represent the relationship of the relational themes and document the patterns that are present in all the narratives. The constitutive pattern that emerged in this study is the "practice of centering."

Centeredness means sensing both self-awareness and an in-balance with self and others. Centering is a means to live life as an art, "a mode of being in which elements of form and content; style and meaning; feeling and rhythm. . . may be imaged and [lived]" (Richards, 1964, p. 40). Being centered requires ongoing nourishment and energy to continue to strengthen self and reach out to others. Lashley et al. (1996) expands on centeredness.

> Centering can be described as a returning home, a sense of place to come back to, finding comfort in renewed self-awareness, and in hearing a call for response to greater human need beyond oneself. Centering means being authentic, more whole, creative, and free. . . Centeredness implies growth. Growth is possible, a movement to and fro, a movement beyond one's grounding, a reaching out to others in response to a call to care. . . . To care for others we need to move outward from a firm foundation, to build on prior learning and move beyond. pp. 203-207

When people join in a relationship with others they become decentered. They are then transformed somewhat in the process of becoming recentered (e.g., Lashley et al. p. 206).

The themes that are identified in this study all relate to maintaining centeredness or becoming recentered while in the act of caregiving. Religion provides that "ongoing nourishment and energy for growth." Tradition supplies the "firm foundation."

Maneuvering and leaping-in/leaping-ahead are how the participants achieve "a movement to and fro, a movement beyond one's grounding, a reaching out to others." Manevuering and leaping-in/leaping-ahead are the actions that produce the interventions needed to bring self into balance while maintaining safety and dignity for the care recipient.

It is intriguing how being centered is like self-actualization in Maslow's hierarchy of needs (e.g., Taylor, Lillis, & LeMone, 1993, pp. 100-103). If lower level needs are not met, such as love and belonging, or safety, a person feels vulnerable and cannot reach the higher, much desired, state of self-actualization. Taking action to meet the lower level needs creates possibilities for self-actualization. It is believed that when a person (in this study, the caregiver) becomes decentered they act (maneuver, leap-in or leap-ahead, pray) to regain a balance and thus work toward a recentered state.

The Research Questions

The true question in phenomenological research is "What is the nature of this lived experience?" "What is it like to be a caregiver?" To develop other questions is a Cartesian pitfall. Van Manen (1990) says,

> If we wish to remain responsive to the commitment of phenomenology, then we should try to resist the temptation to develop positivistic schemata, paradigms, models, or other categorical abstractions of knowledge. Instead, we should refer questions of knowledge back to the lifeworld where knowledge speaks through our lived experiences. . . . From a phenomenological point of view we keep reminding ourselves that the question of knowledge always refers us back to our world, to our lives, to who we are, and to what makes us write, read, and talk together. . . it is what stands iconically behind the words, the speaking and the language. p.46

The research questions of this study can only be answered from the perspective of any new understandings that have been gained from the lived experience of the seven African American female caregiver participants.

Question one: What are the interpersonal concerns, feelings, cultural influences, and background meanings involved in the caregiving experience? Each participant had different lived experiences to share. The commonalties are presented in themes that occur across texts. Several of those themes may answer this question. Caregiving as a tradition may well be part of a cultural influence. But how then do we explain why caregivers' siblings are many times not as involved in caregiving? Background meanings are hard to capture because they are just that, in the background. Since they are in the background they are hidden. Caregiving as a practice is in the background for these participants, it is everydayness to them.

Concerns, in the usual sense (not as used by Heidegger), and feelings are expressed. Several participants express frustration and becoming tired. Some are more assertive and say "he gets on my nerves," "I cry 'I get so tired of my dad'," and "I worry what will happen after I die." Several feelings were ruled out in the process of understanding these participants and their lived experience. They do not feel "burden." They do not feel "obligation." When asked about obligation Mary said, "It is not an obligation, I am filling a need." Paula said, "It is not a pay back, I want to do this."

When asked about loss of freedom or feelings of imprisonment or restriction Mary answered, "I am just putting some things on hold. I do neglect myself at times but I look

at it this way, things are just on hold." TV says, "I am a free spirit. . . I do this of my own free will, for love and from love in my heart. It does limit my choices but any time you choose one thing you give another up." Paula makes the point that if you are doing what you want to do how can that be seen as restrictive? "Mom is my best friend. . .nothing I'd rather be doing."

The term "consigned" was chosen to describe this "on hold" or restricted choice that participants included in their stories. When an item is placed in a store on consignment it is held by the store but ownership does not transfer. The owner's options are restricted in the use of the item but the freedom to take it off hold still exists. The participants were willing to accept this word (consignment) as descriptive of their situation. Several felt this was not exactly right but close and no other single label seemed better.

Questions two and three: Do those concerns, feelings, cultural influences, and background meanings change with community support (specifically that support provided by the Living at Home/Block Nurse Program [LAH/BNP]) and how is the LAH/BNP embedded into the lived experience of caregiver? The only area that may be influenced by the LAH/BNP is that of concern. There was a general sense of comfort or reassurance with nurse visits. The LAH/BNP has thus far missed the target of providing support for the caregiver. It is meeting the goal of keeping older adults in their home but primarily the help is directed toward the person without a caregiver. This utilization is being determined by clientele based on perceived need and the value seen in the services rendered. Societal

pressures to remain independent and free from "charity" is involved in the difficulty of

serving able-bodied caregivers.

Perhaps the group utilizing the LAH/BNP will benefit the most from its services.

Davis, Moritz, Neuhaus, Barclay, and Gee (1997) conducted a study to examine

> whether living arrangements and changes in living arrangements are associated
> with survival among older community-dwelling adults, and whether differences in
> health status account for observed differences in survival. . . . Older adults who
> live alone or who change from living with someone to living alone do not have an
> increased mortality risk. However, living with or changing to living with someone
> other than a spouse may be associated with increased mortality risk. p. 371

In the analysis of the lived experience of African American female caregivers four

themes from across seven stories were identified: (a) tradition, (b) religion,

(c) maneuvering, and (d) leaping-in/leaping-ahead. These four themes come together as

aspects of the practice of centering which is the constitutive pattern in this study. Each

participant did other things to remain centered but they all incorporated these four themes

in their lived experience.

Chapter 6

SUMMARY/DISCUSSION

The purpose of this study was to describe the shared experiences and common meanings of African American women who provide care to an older person with the support of the Living at Home/Block Nurse Program (LAH/BNP). Seven African American women were engaged in audio-taped conversation sessions to explore their lived experiences with caregiving. The research questions were answered by uncovering concerns, feelings, cultural influences, and background meanings involved in the caregiving experience.

Validity was addressed by the conversational relationship developed between participants and the researcher. It was recognized that because the researcher is White, cultural bias cannot be ignored. Validity continued to be addressed during the interpretive phase. Narratives and the resulting interpretations were validated with the participants. A team of three interpretive researchers participated in the interpretive process. This team reviewed the narrative for indications of researcher biases. They also verified the narrative interpretations.

The underlying objective of interpretive research is better understanding of existing knowledge. It does not generate new knowledge and it cannot be generalized in the Cartesian sense. Van Manen (1990) explains the phenomenological finale.

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When you listen to a presentation of a phenomenological nature, you will listen in vain for the punch-line, the latest information, or the big news. As in poetry, it is inappropriate to ask for a conclusion or a summary of a phenomenological study. To summarize a poem in order to present the result would destroy the result because the poem itself is the result. The poem is the thing. So phenomenology, not unlike poetry, is a poetizing project; it tries an incantative, evocative speaking, a primal telling, wherein we aim to involve the voice in an original singing of the world (Merleau-Ponty, 1973). But poetizing is not "merely" a type of poetry, a making of verses. Poetizing is thinking on original experiences and is thus speaking in a more primal sense. . . .

Some argue that phenomenology has no practical value because "you cannot do anything with phenomenological knowledge." From the point of view of instrumental reason it may be quite true to say that we cannot do anything with phenomenological knowledge. But to paraphrase Heidegger, the more important question is not: Can we do something with phenomenology? Rather, we should wonder: Can phenomenology, if we concern ourselves deeply with it, do something with us?" p. 13-45

There are some interesting new understandings to be gained from this study. One example is the use (or non-use) of the LAH/BNP by older adults with caregivers. Implications for such programs are numerous. Program planners need a good understanding of what caregivers need, want, and find positive. Ethnographic studies are indicated to determine if caregivers' support needs differ based on race or ethnicity. There are implications here for all community development programs and their financing. The LAH/BNP is community developed and community driven. Is there a better way to provide support services than neighbors helping neighbors? It appears that when caregivers are coping with their situation help is not help and not wanted from any source or in any format. Programs such as the LAH/BNP might well take McKnight's (1995) advice and concentrate on the assets in the community rather than developing problem lists with suggested interventions. Based on the understandings shared by the participants

in this study one asset is the ease with which caregiving occurs without outside intervention. To help ensure that this asset is shared and appreciated a caregiver from the community might be included on the board of programs that are considering them as clients.

Another new understanding relates to the use of language. All the participants of this study have the words burden and obligation in their vocabulary but the essence of these words did not match that of previous researchers. The participants saw no burden or obligation associated with their caregiving. Even when the words were defined for them with examples they denied experiencing any burden or obligation. Among the possible implications is the need to validate labels that are assigned during research reporting.

There are several models and theories in health care that address the assessment phase of the health care professional's work. For example, in the PRECEDE model by Green and Kreuter (1992), the educational diagnosis is built on factors such as knowledge, attitudes, values, and perceptions (along with others). A health educator must be careful when determining these factors. As this study demonstrates, the best source for this information is the participant. Understanding of these factors comes from time spent with individuals in the target group.

Based on the understanding acquired in this study, programs of education or hands-on services would need to provide mechanisms to help caregivers remain or regain centeredness. This group of caregivers identified religion, family tradition, and

maneuvering in various ways help them maintain centerdness. The most successful actions by healthcare professionals might be to strengthen these already in-place mechanisms.

These participants are at or below poverty levels. Would there be a difference in the themes, attitudes about labels, or basic practices of caring among African American females with a higher income? The care recipients in this study varied greatly in age and ability to function. Would the findings be similar if all the care recipients had an active disease process? And just how might these themes play into the total of these female caregivers' lives? For example, do they use the same strategies for all life situations? If so, are we then looking at the phenomenon of caregiving or something more general such as coping?

An interesting comment by Mary has implications for further study. She said that when they (older people) are at the doctor's office "it is though they are being disrecognized." What are the disrecognizing practices in all areas of health care? Is it more common to see this disrecognition toward African Americans, the older adult, or all people who may pose a communication difficulty? How does disrecognition occur in the health education process? Are caregivers educated when the care recipient is the appropriate student?

Another issue that has surfaced with new understanding is that of the "problem." Who gets to decide what the problem is that health care professionals set about to fix? While a thorough assessment is supposed to lead to a diagnosis that is interpreted as "the

problem," does the participant in the situation concur? Not only do labels need verification by participants, the inferences and diagnosis also need validation.

With the aging population and the increase in the percentage of the total population being African American it would be wise to include this group in more research efforts. Interpretive research belongs as a part of other research efforts to keep findings true to the participants' understandings. Interpretive researchers would be able to add that element of usefulness in the context of the real world with real people who have various backgrounds that influence understanding.

This study calls attention to the shared practices of caregiving and explores the essence of language and its impact on research findings. The hermeneutic analysis of the stories of caregivers reveals the practice of centering. This centering is accomplished by many methods but common to all the participants is religion, tradition, maneuvering, and leaping-in/leaping-ahead. It is hoped that the explication of these common experiences and practices will evoke not only thinking and future research but also conversations between health care providers and the recipients of their services.

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Appendix I

Initial Letter to Prospective Participants

Dear_____,

My name is Penny Moore. I am a registered nurse and am working on a Community Health Education degree at Texas Woman's University. _____ from the Living at Home/Block Nurse Program gave me your name as someone who might be willing to help me with a special project.

I want to find out more about what it is like to be a caregiver. I want to be able to understand and describe that experience from your viewpoint. If you would be willing to participate in this project please complete the following questions and return it in the enclosed envelope. If you have questions you can reach me at _____.

1. How long have you been a caregiver?

2. Please check each of the following care activities you perform: _____bath; _____dressing; _____feeding; _____toileting; _____cooking; _____laundry; _____transportation; _____manage money; _____provide medications

3. List other caregiving activities that you perform:

_____

_____

4. What services do you receive from the Living at Home/Block Nurse Program?

Thank you for considering this request.

Sincerely,

Penny Moore

Appendix II

Human Subjects Consent Form

Penny Moore

TEXAS WOMAN'S UNIVERSITY

Subject Consent to Participate in Research

Title of Study:

The Lived Experience of African American Female Caregiver

in a Community-Based Support Program:

A Heideggerian Hermeneutic Study

Investigator: Penny Moore

Advisor: Dr. Susan Ward

Phone numbers:

817-898-3375 TWU Office of Research and Grants

817-645-3921 ext. 514

817-898-2843 Advisor

You are invited to participate in a research project designed to explore the caregiving experience through the eyes of the caregiver. Participation is completely voluntary.

1. What does the study consist of?

You will be asked to spend about one hour on three occasions talking to me in your home. I will audio-tape our conversations and would like to take your picture.

2. Are there any risks?

You will be donating 2-3 hours of your time to share your caregiving experience. It is possible that through discussion you could experience some painful memories or thoughts. You could feel some embarrassment with discussing these experiences with a stranger or feel that the conversation will be made public. The audio-tapes and typed pages will be kept confidential and only the research team (myself and three associates) will ever have access to the full transcripts. The three associates will review my work to assure that I am representing your story accurately. They are all experienced professional researchers. The audio-tapes will be electronically erased after five (5) years. Any identifying information from the text will be removed. Very short parts of your story may be selected for inclusion in a report but your name will not be used. Should you experience any adverse effects from the sharing of your experiences I will provide a list of professional counselors close to your home who could provide services.

3. Are there any benefits?:

It is possible that you could experience some new insight into the caregiving experience that is comforting.

4. What if you change your mind?

You are free to withdraw from this study or refuse permission for the use of your transcript at any time.

Before you sign this form please ask any questions you may have about the study. I want you to understand everything to your satisfaction.

Authorization: I, _____, have read and decide to participate in the research project described above. My signature indicates that I give my permission for information I provide (including audio-tapes and pictures) to be used for publication of a dissertation or research articles, books, and/or teaching materials, as well as for presentation at scholarly conferences. Additionally, my signature indicates that an offer to answer all of my questions regarding the study has been made and I have received a copy of this dated and signed consent form. A description of the possible attendant discomfort and risks reasonable to expect have been discussed with me. I understand that no medical service or compensation is provided to the subjects by the university as a result of harm from participation in research. I understand I may terminate my participation in the study at any time.

I do hereby consent to the recording of my voice and/or image by Penny Moore acting on this date under the authority of the Texas Woman's University. I understand that

the material recorded today may be made available for research and educational purposes. Only Penny Moore and three research associates will have access to the tape recordings. The recordings will be kept locked in Penny Moore's office. The audio-tapes will be electronically erased and the transcripts shredded in five (5) years. I do hereby consent to such use and release the Texas Woman's University and the undersigned party acting under the authority of Texas Woman's University, from any and all claims arising out of such taping, recording, reproducing, transmitting, or exhibiting as is authorized by the Texas Woman's University.

If I have any questions about the research or about my right as a subject, I should ask the researchers: their phone numbers are at the top of this form. If I have questions later or wish to report a problem I may call the researchers or the Office of Research and Grants Administration at 817-898-3377.

_____   _____

Signature of Participant   Date

The above consent from was read, discussed, and signed in my presence. In my opinion, the person signing said consent form did so freely and with full knowledge and understanding of its contents.

_____   _____

Representative of Texas Woman's University   Date