## CAREGIVING: AN EXPLORATION OF AFRICAN AMERICAN MALE CAREGIVER ROLES IN TEXAS

#### A DISSERTATION

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To the Dean of the Graduate School:

I am submitting herewith a dissertation written by Janice F. Moore entitled "Caregiving: An Exploration of African American Male Caregiver Roles in Texas." I have examined 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 Family Studies.

Joyce Armstrong, Major Professor

We have read this dissertation and recommend its acceptance:

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Accepted:

Dean of the Graduate School

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#### **DEDICATION**

To my dear husband, Donald Payton, who took on many roles and encouraged me to follow my dreams. Special thanks to Dianze Thompson, Doretha Hudspeth, Jamila Dawn Payton, Robin Washington White, Jacquelyn Kyle, Bettye Turner, Bonnie Scott, and my dear friends and family who supported me on my journey. You gave me a sounding board whenever there was a "sea of red." Joyce Bell, Vonda K. Freeman, and Eileen Richardson, I appreciate your constant inquiries about my progress. Your inquiries helped me to stay focused on completing my studies.

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#### ABSTRACT

#### JANICE F. MOORE

CAREGIVING: AN EXPLORATION OF AFRICAN AMERICAN MALE CAREGIVER ROLES IN TEXAS

#### MAY 2010

Over the last three decades of family caregiving research, only a few studies have provided insight into the roles men play (Fromme et al., 2005), and even fewer addressed African American males. Traditionally, caregiver research focused on females as primary caregivers. The National Alliance for Caregiving and AARP (2004), indicated four out of ten caregivers are men. This qualitative study explored the role of African American male caregivers in Texas. Face to face interviews were conducted using an open-ended questionnaire to gather data from African American male caregivers 50+ years of age who provide care for their mother, father, stepmother, sister, aunt, companion, brother, and fictive kin. Study participants self-identified as caregivers who provided formal or informal caregiver assistance to the elderly with activities of daily living and instrumental activities of daily living such as bathing, toileting, transportation, meal preparation and personal care. Four major themes arose in the study. Major themes were (1) personal choice as a caregiver, (2) non-traditional caregiver roles, (3) skill malfit, and (4) range of duties as a caregiver. This study has implications for family and consumer sciences

specialists, gerontologist, educators, and service providers as they plan and coordinate caregiver support for communities at the local, state and national levels.

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#### CHAPTER I

#### INTRODUCTION

Over the last three decades of family caregiving research, only a few studies have provided insight into the roles men play (Fromme et al., 2005). Females generally assume the role of caregiver for their aging parents and relatives. Russell (2007) suggested that males in their roles as caregivers are often called upon to perform a myriad of tasks that have traditionally been interpreted as "women's work." Some of the personal care tasks they perform may be considered awkward for men to do. According to the 1999 National Long-Term Care Survey and Informal Caregiver Survey, approximately two thirds of primary caregivers were female, although male caregivers were increasingly represented across all relationship types over the decade of interest (Wolff & Kasper, 2006). The National Alliance for Caregiving and AARP (2009) estimated there were 54.1 million American caregivers age 18 and older who provide unpaid care to an adult age 18 or older.

Harris (1998) indicated demographic and social trends, such as the growing elderly population, smaller average family sizes (resulting in fewer siblings available for eldercare), greater sibling mobility, and changing gender roles, point to the probability that a growing number of sons will become caregivers to their elderly parents. According to the Metropolitan Life Insurance Company (2003) study, researchers suggested that men have a more difficult time providing care because the caregiving role

is closely tied to gender. Kramer and Thompson (2005) suggested men's caregiving roles are conditioned by the interplay of factors at many levels, ranging from the historical and social structural to the familial to social psychological to individual interactions between person and care situation. Fromme et al. (2005) also suggested another reason to focus on male caregivers is that they are at high risk of adverse health outcomes as a result of their caregiving role.

#### Statement of the Problem

There is very limited information on the role of male caregivers in the United States. According to Levine (2004), caregivers are mainly wives, daughters, or daughters-in-law. However, more men are becoming involved through necessity or choice. This phenomenological research study examined caregiver roles of African American males caring for individuals 55+ years of age. According to the National Alliance for Caregiving and AARP (2004), four out of ten caregivers are men. This difference in caregiver gender and role is very different than what is assumed by society.

The National Alliance for Caregiving and AARP (2009) estimated 24% of the United States population provides unpaid care to friends and family age 18 and older. Barker (2002) discussed caregiving in its most generic form, non-kin caring relationships are naturally occurring and ubiquitous, built out of unremarkable acts of sharing and kindness between people, especially neighbors. Neighbors sometimes performed duties such as watering plants or caring for pets during absences, sharing homemade edible items and handmade goods, dealing with mail and packages, occasionally picking up

groceries, sharing meals or jointly undertaking other leisure activities, and exchanging information about events or acquaintances.

According to Brody (1990), the likelihood of assuming caregiving responsibilities for a family member or friend with a disabling mental or physical health condition during the adult life course increased for men and women. Data suggested that women experience more burden and psychological distress as caregivers (Miller, 1992). It may not be a priority to consistently look at gender based on our culture's perception of the caregiver role. Society generally views females in the role of caregiver. In medical settings, many health care professionals such as nurses and physicians also view females as caregivers. This is primarily based on the health care workers' observations of who accompanies the patient for medical appointments. Current research has not consistently looked into gender differences and gender effects on caregiving. Health care workers and other professionals tend to look at gender differences between male and female caregivers. This view may be based on the health care provider's daily interactions and observations of their patients who are 55+ years of age.

Caregiving is defined as providing emotional support, companionship, and other forms of instrumental assistance that adult children might offer their parents (Pyke & Bengston, 1996). Levine (2004) suggested the spectrum of family caregiving includes tasks that are very modest and relatively unchallenging and also tasks that are identical to nursing home care. Many people do not understand the intricacies of the adult/child dyad when caregiving needs arise. There is a distinct change in roles and role relationships during this time. Similarly, Russell (2004) described caregiving as basically

a solitary activity, carried out in social locations predominantly occupied solely by the care receiver and caregiver dyad. Families often use caregiving to strengthen family ties. In a review of caregiving studies Allen, Blieszner and Roberto (2000) found siblings caring for their aging parents provided another window of understanding into the gendered nature of family relationships.

It is important for others to understand the need for families to provide care based on cultural beliefs. This holds true for African American families. In the African American family, strong kin ties were a result of banding together to share resources to combat economic insecurities (Lee, 1980). Many African American family members may also live in extended families or have strong and committed relationships with friends and fictive kin. For many ethnic minority older adults and immigrants, fictive kinships have both historic and cultural significance (Jordan-Marsh & Harden, 2005). Cultural fictive kin are non-relatives who have a very close and enduring relationship with one another. They are often addressed or introduced to others as a "play mother" or "play daddy." According to Staples (1976), black families rely more heavily on extended kin than white families. The kin network is large. The range of the kin network includes parents, siblings, cousins, aunts, uncles, etc. A unique part of this kin network is the inclusion of non-blood relatives who are referred to and regarded as kinsmen.

Many African American males are caregivers, but are seldom self-identified as caregivers. They generally see their role as taking care of family members out of concern or obligation. Caregivers may have dual family caregiver responsibilities. In African American families, not only does the caregiver come out of immediate or extended

family, they come out of community as well. Pierret (2006) found an increase in the sandwich generation over the last twenty years. He further described the sandwich generation as people squeezed between the demands of caring for their aging parents and dependent children at the same time. Seaward (1999) defined the sandwich generation as those of a demographic age group who are caring for young children and elder parents at the same time. Jordan-Marsh and Harden (2005) viewed fictive kin as an element of the social network of individuals. There is little data on the extent to which informal relationships have a role in maintaining or improving the health of an older adult.

This study focused on the roles of African American male caregivers. Due to the limited research in this area, this is a very fruitful area of study. This research will help to build on limited studies in this area, and encourage additional studies in this area.

#### Purpose of the Study

The purpose of this study was to understand how African American men 50+ years of age view their role as caregivers for those who are 55+ years of age. This qualitative study examined how African American men see their role as caregivers; data were collected via face-to-face interviews with male caregivers. This study was needed to build on and add to the current research about role changes within families throughout the lifespan.

This study is significant to gerontologists and family scientists as they educate and collaborate with businesses to advance the needs of today's family. This study will also help professionals to nurture and investigate peer support systems for African American male caregivers within their respective communities. Families will face many

changes in the years to come. Some of these changes will be due to the aging of the Baby Boomers (those born between 1946 and 1964), changing roles in families, and increased longevity of older adults.

#### Research Question

In order to better understand the issues faced by African American caregivers, the following research question was asked: What are the perceived roles of African American male caregivers in Texas?

#### Definition of Terms

Activities of daily living (ADL) - Activities usually performed for oneself in the course of a normal day including bathing, dressing, grooming, eating, walking, using the telephone, taking medications, and other personal care activities (United States Department of Health & Human Services, 2003).

African American - When referencing African Americans in this research, the term Black will be used interchangeably.

Baby Boomers - Those born between 1946 and 1964 (Singleton & Maher, 2004).

Caregiver - A generic term referring to a person, who helps an older person with the activities of daily living, health care, financial matters, guidance, companionship and social interaction. A caregiver can provide more than one aspect of care. Most often the term refers to a family member or friend who aids the older person (United States Department of Health & Human Services, 2003).

Care receiver - An individual who receives care from a caregiver.

Fictive kin - having quasi-family ties (Mac Rae, 1992).

Formal support - Help provided by professionals, paid helpers, or companies who provide caregiving help (Williams & Dilworth-Anderson, 2002).

Informal support - Care and support from family members, as well as from friends and neighbors (Williams & Dilworth-Anderson, 2002).

Instrumental activities of daily living (IADL) - The six daily tasks (light housework, preparing meals, taking medications, shopping for groceries or clothes, using the telephone, and managing money) that enable the patient to live independently in the community (Bookman, Harrington, Pass, & Reisner, 2007).

Non-kin caregiver - Paid or non-paid caregivers caring for non-family members.

Primary caregiver - Provides assistance in 50% or more of daily personal care activities such as dressing, hygiene, and grooming, and daily assistance in 50% or more of instrumental activities such as transportation, chores in and out of the home, and shopping (Russell, 2007).

Self-identify - Assessing what one does as a caregiver.

Note: Defined (choices researcher makes)

#### Delimitations of the Study

Delimitations to the study included the following:

- 1. The participants in the study only included African American males 50+ years of age caring for someone 55+ years of age.
- 2. The study took place in Texas.
- 3. Study participants were self selected.

- 4. Study included fictive kin.
- 5. Study participants were formal and informal caregivers.

#### The Researcher as a Person

The principal investigator of this study is an African American female, wife, stepmother, grandmother, gerontologist, certified family life educator and doctoral candidate in the family studies program at Texas Woman's University. The principal investigator was involved in her church's Caregiver, AIDS, and Girl Scout ministries.

The researcher was committed to exploring the often silenced role of African American male caregivers. The principal investigator's husband's role as a caregiver evolved as he provided assistance with instrumental activities of daily living (IADL) for his elderly parents. The principal investigator desired to shed light on the need for more research in this area. There were many roles encountered by the principal investigator conducting research. Creswell (2003) indicates the researcher's role is to gain insight into the research site and the ethical issues that stem from entry.

#### Assumptions

This study assumed that African American men are hesitant in self identifying as caregivers for individuals 55+ years of age. It is also assumed that African American male caregivers are limited in number and scope. It is further assumed that African American males believe they possess inadequate caregiver skills. Finally, it is assumed that study participants told their real caregiving experiences.

#### Summary

This chapter describes the purpose of the caregiver study. The purpose of this study was to understand how African American male caregivers in Texas viewed their role as caregivers. There is very limited information on the role of male caregivers in the United States. The principal investigator hoped to gather more data about the role of African American male caregivers age 50+ as they provide care to those 55+ years of age and older. There is very limited data on male caregivers, especially among African American males. More information is needed to better understand the issues and concerns faced by this under represented group. Understanding the issues faced by African American male caregivers provides further insight to social service agencies and policy makers about the daily challenges they face. Subsequently, their issues will impact how social service agencies provide support and access to this underserved group.

This chapter not only describes the purpose and the problems related to male caregivers, it also operationally defines terms, describes the research, and list the assumptions underlying the study.

This study attempted to fill some gaps in the research literature on caregivers, especially among African American males. Harris (1998) believes when the issues and stresses caregiving sons face are addressed and better understood, there will be more services designed to fit their needs. More studies are needed to capture the experiences of males in particular African American male caregivers in our communities.

#### CHAPTER II

#### REVIEW OF THE LITERATURE

This chapter outlines the theoretical framework under which this qualitative study was carried out. This chapter will look at how the study fits into the exchange theoretical framework. Questions were designed based on the exchange theoretical framework. Additionally, the chapter will also look at current caregiving literature, and briefly summarize study findings.

This review of the caregiving literature will be divided into four sections. The first section will focus on caregiving research. The second section will focus on male perspectives of caregiving. The third section will focus on African American caregivers.

The fourth section will focus on African American male caregivers.

#### Theoretical Framework

This study used a qualitative research methodology of open ended personal interviews and demographic information. This study explored and analyzed through the view of the exchange theory. The exchange theory focuses on how relationships develop, how relationships are experienced, the patterns and dynamics that emerge within ongoing relationships, and the factors mediating the stability of relationships (Sabatelli & Sheehan, 1993).

In the exchange theory relationships are viewed on a debits and credits basis (Hayslip & Panek, 1993). Older adults are categorized as having few credits, such as

money, material possessions, and physical attractiveness, and possess large number of debits, such as poor health, they are not viewed as valuable by others. This assumed lack of value contributes to the negative images of aging.

Sabatelli and Shehan (1993) further outlined some basic assumptions about the nature of relationships based on the exchange theory. Social exchanges are viewed as interdependent. The ability to obtain profits in a relationship is contingent on one's ability to provide others with rewards. Experiences within a relationship determine the subsequent exchanges one will receive. Social exchanges are controlled by the norm of reciprocity and fairness. Interaction and stability within a relationship over a period of time results from the paralleling levels of attraction and dependence experienced by the participants in the relationship.

The exchange theory is prevalent in caregiving literature. According to Blau (1964), the exchange theory indicated that the person in a relationship who is most dependent on the services or resources of the other will have less power. McAdoo (1978) indicated the important form of distribution and exchange of the limited resources available to the poor. Trading refers to the offering and acceptance of goods and services. Hirdes and Strain (1995) suggested the ability to provide instrumental support, such as transportation, household maintenance, and personal care, also represents a valued resource that may be particularly salient for older adults. Rook (1987) indicated both kin and peer relationships may be most satisfying in old age if the relationship provides a source of complementary resources. In this study, the exchange theory looked at the scope of care provided by families to care recipients.

#### Literature Review

Caregiver literature consistently identifies females as caregivers. The role of the review of the literature for this study will focus on the role of male caregivers, the types of care they provide and their support network. Due to limited research on male caregivers, the principal investigator hopes to provide an additional source of information to researchers to further study African American male caregivers. This literature review will also serve as a valuable resource for social service providers, civic groups and others interested in this area of study.

This research covers caregiver studies within the last decade. The researcher explored several research studies that addressed male caregiving. Russell (2004) indicated male caregivers have occasionally been mentioned in caregiving literature in the last two decades. Levine (2004) suggested the caregiver literature has treated caregivers as a homogenous group, without systemically examining racial/ethnic differences in the caregiving experience. Examining the differences among caregivers will provide an opportunity to fully understand the caregiving experiences of African American males.

#### Caregiving Research

Some older adults may not have family nearby to provide for their caregiving needs. Some may also form relationships with community members to act as surrogate relatives. The current assumption in caregiving literature is that men prefer to sit on the sidelines rather than deal with caregiving responsibilities. The investigator hoped to provide a different view of male caregivers.

Allen (1994) suggested in the case of male caregiving, role congruence may be the result of skill malfit, that is the lack of necessary household management and nursing skills to perform adequately in the caregiving role, or identify malfit, a discomfort in performing the expressive or hands—on-activities typically thought of as women's work.

Another reason to focus on male caregivers is that they are at high risk of adverse health outcomes (Fromme et al., 2005). In Houde's (2002) review of the literature on male caregivers, many flaws were noted. Some include the lack of male caregivers, and small sample sizes. She further suggested strengthening male caregiver studies by increasing the numbers of sons and husbands in qualitative studies until saturation of data within the particular subgroups occurs. Houde also noted other limitations in the qualitative studies she reviewed. They include issues related to the wide age range of caregivers, sample selection, and cultural issues which could affect research results.

Harris' (1998) qualitative study looked at thirty sons who were actively involved in caring for their parents who had a diagnosis of dementia. The Cleveland Ohio Area Alzheimer's Association chapter provided access to study participants. Study participants had a mean age of 50 years. Seventeen percent of the participants were African American and 83% were White.

Harris identified four common themes and issues. The study results were divided into common themes and common issues. The common themes evolved naturally during the interview process. The common issues were identified through the interview schedule designed by the principal investigator. The common themes identified by caregiving sons (1) included a sense of duty in caring for ill parents, (2) acceptance of the parent's

diagnosis, (3) taking charge of the situation, (4) varying degrees of emotions and flexibility over their work hours. The common issues were (1) loss of role for themselves and care recipient, (2) changes in sibling relationships, (3) role reversal of both sons and care recipient, (4) developing coping strategies and positive outcomes. The principal investigator suggests professionals consider providing more information, care management, support and respite to caregiving sons (Harris, 1998).

Gerstel and Gallagher (2001) examined the gendered role of caregiving. In their study, 188 married male and female couples were interviewed. Study participants included 86% Euro-Americans and 14% African Americans, age 21+, residing in Springfield, Massachusetts. Participants were generated from the local telephone directory. The study consisted of face to face interviews. Areas covered included the type of caregiving provided, employment characteristics, family characteristics and gendered ideology concerning caregiving. For purposes of this review, the gendered ideology in caregiving will be explored. Gerstel and Gallagher measured caregiving ideology by using a Likert type scale related to caregiving. The scale responses included taking care of elderly parents should be as much a son's responsibility as a daughter and taking care of parents should be more a wife's responsibility than a husband.

#### Male Perspectives of Caregiving

This section addresses studies done within the last decade. In Harris' (1998) study on sons as caregivers, four types of son caregivers emerged from the data collected. Each type had common characteristics, but each also had unique characteristics and behaviors that oriented the men to the new caregiving role differently.

Harris (1998) identified four types of caregiver sons in her study as:

- 1. The Dutiful Son felt an overwhelming sense of duty toward their parents, and this feeling was the driving force that motivated them to become involved.
- 2. The Son Who Goes the Extra Mile sons in this group went a step beyond the roles and actions of those of the "dutiful son" group.
- 3. The Strategic Planner orient to their caregiver roles by using the management and planning skills they acquired in their work worlds.
- 4. The Son Who Shares the Care the sons who, as teams with their wives or other siblings, "shared the care" of parents with dementia.

Allen (1994) studied couple responses to expectations for caregiving during cancer treatments. This study examined whether spouses responded similarly when help was needed on a temporary or situational basis or long-term assistance which is often associated with a chronic or debilitating illness. Study participants were comprised of middle-aged and elderly couples. This study also explored male caregivers' readiness to take on or utilize caregiver skills. In this study, it was assumed that males were not prepared for their role as caregiver. Males often assume new roles when serving as caregivers. Patients were recruited at outpatient chemotherapy or radiation treatment centers in Pennsylvania, Rhode Island and New York City. These locales were chosen to include patients living in urban and rural areas. The study sample consisted of 353 patients. There were 188 men and 165 women. All patients had a need for an instrumental activity of daily living (IADL). All interviews were conducted by telephone. The study questions inquired about the patient's ability to perform activities of daily

living (ADL) alone, or whether they needed assistance from someone. Study results concluded husbands were less likely than wives to help their spouses with traditional female household tasks. When the husbands did help, they were more likely to help without assistance from anyone. In some cases, there was a need for formal care. The author suggest that an alternative to formal care is referring men to a caregiver training program which focuses on basic daily skills such as cooking, shopping and caring for the care recipient.

In another study Allen et al. (2000), suggested that typically when investigators included sons, they focused on gender-related task differences in parental caregiving. The researcher in this study focused on a broader range of male caregivers including sons, fathers, son-in-laws, fictive kin, and grandsons. Harris (1998) and Allen et al. specifically focused on sons that were taking care of parents. They did not cover other types of male caregivers in their studies. These studies focused on those sons who were caring for their parents.

#### African American Caregivers

Many caregiver studies view caregiver roles and the level of caregiver involvement with the care recipient. In Levine's (2004) review of the study, African American participants were more likely to use religiosity as a coping mechanism.

Haley, Han, and Henderson (1998), suggested that in nearly all cultures there is a gender specific role expectation of caregiving in which women are expected to be the main burden bearers. Levine (2004) indicated that caregivers are predominately wives and daughters or daughters-in-law, but more and more men are becoming involved

through necessity or choice. Haley et al. further suggested that other caregiving dynamics, such as caregiving responsibilities by grandchildren or other family members outside the usual nuclear family by African American families, have a cultural basis. This sense of responsibility is often viewed differently by those unfamiliar with the dynamics of caregiving within African American families. Williams (2005) speculated that due to the unique historical experience, Black (African American) caregivers may have the needed strengths and resources in dealing with the stresses of caregiving (e.g., use of extended family). Billingsley (1970) indicated Black families were strong and headed by men.

Often times, African American caregivers face their caregiver role in isolation.

This is primarily due to their self-perception of the caregiver role and how others respond to their needs. Williams and Barton (2004), reported findings on the Delaware Valley

Chapter of the Alzheimer's Association study. This study highlighted the feeling of isolation faced by African American caregivers. This Alzheimer's Association chapter covers Southeast Pennsylvania, South New Jersey, and Delaware which have high concentrations of African American residents. Results of the chapter's community needs assessment revealed African Americans often do not participate in traditional family support groups because they assume that they will be the lone minority member and that their understanding of the disease and management style may be expressed and viewed differently compared to what would be expected in a mainstream setting. Feelings of isolation experienced by some African American caregivers can lead to misunderstanding

by outside sources, can create great conflict, and may result in further alienation by African American caregivers from other cultures.

There are many factors which describe the hardiness of African American caregivers. Some of the factors are rooted in African American life and culture.

According to Dilworth-Anderson, Goodwin, and Williams (2004), cultural socialization in the African American community helps create beliefs and attitudes about caring for dependent others in the family that encourage developing coping strategies (resources) to deal with stressors in the caregiving situation. This coping strategy may be viewed as the community's response to crisis or the caregiving situation. While coping with the stressors and demands of caregiving, many African Americans use their faith as a source of solace. According to the National Alliance for Caregiving and AARP Study (2004), more than eight in ten or 84% of African American caregivers say they cope with caregiving stress by praying.

Owen, Goode, and Haley (2001) studied African American caregivers for those with Alzheimer's disease. The purpose of the study was to provide a descriptive account of the caregiver's initial bereavement experiences. Of the 68 participants, 47 were White and 16 were African American. Women were 66.7 % of the participants. The average age for caregivers was 60.8 years old. In the study, they found African American caregivers were more sensitive to the death of a relative. This longitudinal study was part of a larger study which focused on stress and coping of both African American and White caregivers. Study participants completed a structured interview and several questionnaires. The 25 item Caregiver Bereavement questionnaire was used. This

questionnaire measured the caregiver's adaptation to the death of a loved one. One African American male caregiver interviewed expressed his relationship with his wife as having grown closer since the onset of dementia. He indicated it was a 36 hour day, and the caregiver's burden was not reported as stressful.

#### African American Female Caregivers

Traditionally, African American women have been the primary caregivers for their families. Many studies have been conducted to look at the role of African American female caregivers. Jones-Cannon and Davis (2005) study was designed to understand the experiences of African American women who were caregivers for aging parents. This two phase, mixed methodology study used both a focus group and the Basic Interview Schedule surveys. Study participants included 106 African American women who were 30 plus years of age, and caring for an elderly parent 65 plus years of age. Over half of the participants, or 63%, had been caregivers for 3-11 years. The study findings pointed out that African American women who were caregivers expressed using their religion as a coping mechanism when handling the stresses of caregiving.

Many factors and considerations are mulled over when a primary caregiver is selected by a care recipient. Caregiver selection is generally based on the gender, availability, and location of a caregiver. In Pillemer and Suitor's (2006) caregiver selection study of mothers 65-75 years of age, three major themes emerged. They were gender, emotional closeness, and proximity. Many of the women were more comfortable selecting a female as their caregiver if needed. Although this study was conducted in the greater Boston area, it can also be replicated in other urban communities.

Most women, including African American women, experienced multiple caregiving roles and role transitions over their life course as parents, paid workers, and grandparents. The multiple social roles and transitions of women may be a rewarding experience or may develop into a life crisis (Chadiha & Fisher, 2002). Ingersoll-Dayton, Neal, Ha, and Hammer (2003) suggested the distress experienced by siblings who were more involved in caregiving could assume a variety of forms. Jones-Cannon and Davis (2005) studied African American daughters who functioned as caregivers for their aging parents. In the study, past parent daughter relationships that were positive made the caregiving experience easier for most caregivers and improved coping. Caregivers also view themselves differently when taking on the responsibility of caregiving. In Skaff and Pearlin's (1992) role engulfment study, women were more likely than men to report a loss of self as a caregiver. Women tend to give up more of their personal lives and interest as caregivers than men.

Men and women provide care based on their level of comfort, caregiver skills, and their relationship to the care recipient. Fromme et al. (2005) suggested when looking for differences between male and female caregivers that might help explain results, look at qualitative analysis of narrative data. According to Allen (2000), in the 1990s researchers explored several new aspects of the parent-child caregiving relationship that provided greater insight into family caregiving.

#### African American Male Caregivers

Williams (2005) suggested that Black caregivers have the strength and resources in dealing with caregiving due to their unique historical experiences. To date most studies conducted included a very small number of Black males. There is clearly a need for additional research in this understudied population. The role engulfment study focused on male caregiver roles and stress. The study found men, if they were retired, appear to take on caregiving as they would a new job (Skaff & Pearlin, 2001).

#### Summary

Most of the current caregiver research identifies women as caregivers. The exchange theory is prevalent in caregiver research. There are a limited number of studies including males as caregivers. Men and women view their caregiving roles differently. Some experience stress, or strain while others manage their role without difficulty. Men specifically may view their new caregiving role as a new type of work or job. Unique historical experiences may play a role in shaping the way African American men manage their caregiving role. More research is needed in this area.

This study explored caregiving through the use of the exchange theory. The exchange theory focuses on how relationships develop, how relationships are experienced, the patterns and dynamics that emerge within ongoing relationships, and the factors mediating the stability of relationships (Sabatelli & Sheehan, 1993). In this study formal and informal caregivers provided assistance with basic personal hygiene, transportation, grocery shopping, meal preparation, socialization, medical care, and bill paying.

#### CHAPTER III

#### METHODOLOGY

This study examined the qualitative research procedure used to gather data on African American male caregivers. The chapter outlines the methodology the principal investigator used in the study. This qualitative study looked at the role of African American male caregivers in Texas. Data were collected through an open ended interview question. This qualitative research project used the exchange theory framework. This was a phenomenological research study. Cresswell (2003) describes phenomenological research as the researcher identifying the essence of human experiences concerning a particular phenomenon as it is described by study participants. In this study it is the role of African American male caregivers.

#### Sample, Population, and Participants

Study participants for this research project were 20 African American men ages 50+ years of age who were caregivers for elder individuals 55+ years of age. The elder persons receiving care were the caregivers' mother, father, step-mother, sister, brother, companion, church member, aunt, extended family member or fictive kin.

The study sample was generated from research recruitment flyer distribution

(Appendix A) and word of mouth. Some participants were recruited by flyers designed by the principal investigator. Recruitment was conducted through principal investigator

contacts, community caregiver groups, civic groups, local churches, and the snowball method.

Inclusion criteria for study participants was African American male caregivers who were 50+ years of age. There was no limit as to the number of years caregiver indicated he has provided care. Those who have cared for an elderly individual who died within the last 24 months of the study were also included.

Twenty African American males residing in the Texas participated in the study. These participants were self-identified as caregivers who assist with performing activities of daily living and instrumental activities of daily living such as bathing, financial assistance with bill paying, doctor visits, toileting, grocery shopping, feeding, grooming, cooking, socialization, physical therapy, exercising, gait training, walking, telephone reassurance, transportation, meal preparation, and other personal and household duties. Caregiver roles associated with caregiving were clearly spelled out by the principal investigator. Each participant was assigned a code number. It was the principal investigator's desire to explore and add to the current listing of caregiver roles/duties generated by interviewing African American male caregivers.

#### **Human Participant Protection**

Principal investigator followed and complied with Texas Woman's University

Institutional Review Board recommendations (Appendix B). Research caused no harm to
human participants. Great caution was taken to protect each study participant from
unethical research issues. Study participants received and signed a consent form to
participate in the study (Appendix C). The principal investigator read the consent form to

participants prior to conducting the survey. Study participants were also aware of their right to withdraw from the study at any time. Ethical research issues anticipated in this study included participants feeling compelled to complete study, current client participation in study, and misrepresenting focus or outcome of study.

The principal investigator maintained professional integrity throughout the study. This was done by maintaining participant confidentiality. Great care was taken when interacting with study participants. A social service referral list was provided to participants needing professional counseling or assistance after completing the interview (Appendix D). Study data are the sole property of the principal investigator, and will be kept in a locked file box for seven years. After that time, data will be destroyed.

#### Data Collection and Analysis Procedures

According to Babbie (2004), qualitative interviews are simply a conversation in which the interviewer sets a general direction for conversation, and asks specific topics raised by the participant. Twenty African American males 50+ years of age participated in the study. Participants were interviewed and responded to demographic and qualitative questionnaires developed by the principal investigator. The principal investigator administered the demographic and qualitative questionnaires orally. Each face-to-face interview took at least ninety minutes to complete. Participant interviews were taped using an audio tape recorder. Audio equipment was tested prior to interview sessions. The principal investigator also had a back up recorder and extra batteries for use.

The principal investigator listened to tapes, transcribed the data verbatim, read transcripts, coded the transcripts, analyzed data, recoded the transcripts, and read the

transcripts again to look for emerging themes. The principal investigator then put the transcripts aside, and reviewed the transcripts later. According to Patton (2002) triangulation strengthens a study by using different methods of analysis. This includes using different methods or data. To check for study validity, the principal investigator involved three readers as expert members in reviewing transcribed participant responses. The readers read the transcripts and coded the transcripts for common themes. They also coded the transcripts several ways, and a comparison was made between the principal investigator's findings/themes and the readers findings/themes.

#### Timeline

The principal investigator developed study timelines to gather data in a timely manner. The principal investigator anticipated this study would take no longer than twelve months to complete.

The principal investigator designed, implemented and analyzed study results over a twelve month period of time. Study results were presented to participants requesting a study summary upon completion of the study. Great effort was made to place research results in an easily understood format for all participants to understand the study summary. The principal investigator provided the study summary results in graph and chart format to participants. The principal investigator presented the study summary to local churches, agencies, and community groups.

This research used an open ended questionnaire to gather data from African American male caregivers ages 50+ years of age who provide care for their mother, father, sister, aunt, companion, brother, church members, stepmother and non-related

individuals 55+ years of age. Data were collected and analyzed by the principal investigator. The analysis highlighted the roles of both informal and formal African American males who provide care to care receivers 55+ years of age. The principal investigator identified common themes which emerged from the gathered data.

This chapter described results of data collection methods using both the

Demographic Questionnaire Instrument 1 (Appendix E) and Qualitative Instrument 2

(Appendix F). The Demographic Questionnaire Instrument 1 consisted of 19 questions which were asked during a face to face interview conducted by the principal investigator. The first part of the instrument painted a profile of the African American male caregiver. It identified who the African American caregiver is, where he lives, income status, employment status, level of education, caregiver status, hours involved in caregiving and distance traveled to provide care. The second part looked at who received care and the duties caregivers performed. The third part captured the type of training or education caregivers received to perform caregiver duties.

The Qualitative Instrument 2 consisted of 24 questions, in response to which were audiotaped by the principal investigator during the interview session. The first part explored the journey, roles and responsibilities of male caregivers. The second part captured the caregivers perceived role in providing care to their mother, father, sister, aunt, companion, brother, church members, stepmother and non-related individuals 55+ years of age. The third part explored what activities caregivers engaged in to renew themselves as they balanced caregiving and family life. The fourth part explored how caregivers planned on handling changes in their role as caregivers, and offered an

opportunity to express additional comments about the role of African American male caregivers.

Four central themes emerged from the study. The four themes were (1) personal choice, (2) non-traditional caregiver roles, (3) skill malfit and (4) range of duties. The principal investigator conducted a convenience sample of 20 participants who volunteered for the study. Participant confidentiality was protected by assigning each participant a numerical code. Three readers reviewed the transcripts for common themes and to triangulate data. The readers were two doctoral level professionals in Family Sciences and one aging professional.

# Significance of Study

This study will add to the body of literature on caregiving as it relates to African American male caregivers. There are several barriers to African American involvement in research. Some may include unwillingness to participate in research, and not wanting to share personal information with research investigators. The principal investigator must be knowledgeable about the study focus, and the availability of study participants in this area. The principal investigator is a gerontologist with over 27 years of experience in working with older adults and their families.

The principal investigator developed the primary study instrument which consisted of open ended questions. The interviews took approximately ninety minutes to complete during participant interviews. Interviews took place at sites selected by study participants such as participants' homes, care receiver homes, and public places.

In this study, the principal investigator bracketed any assumptions held about African American male caregivers. This was done by asking survey questions in the same manner during each interview, using both verbal and non-verbal forms of communication during interview sessions, and skillfully listening to study participants. The principal investigator made no assumptions about caregiver roles prior to, during, and after interviews. The principal investigator wanted to give a voice to the silenced role of African American male caregivers.

#### Summary

This study examined caregiver roles of 20 African American men ages 50+ years of age who were caregivers for elder individuals 55+ years of age. The elders receiving care were the caregivers' mother, father, step-mother, sister, brother, companion, church member, aunt, extended family member, or fictive kin.

Study participants were recruited from research recruitment flyers, community presentations, and the snowball method. Great caution was taken to protect each study participant from unethical research issues. Each participant signed a consent form prior to starting the research. Participant confidentiality was maintained by assigning a numerical code to each participant. Data were collected through face-to-face interviews. Participants were interviewed, and they responded to demographic and qualitative questions developed by the principal investigator. Interviews were audiotaped and transcribed by the principal investigator. Interview transcripts were coded, analyzed, and recoded to look for emerging themes. The transcripts were placed aside, and reviewed later. To check for study validity, the principal investigator involved three readers as expert

members in reviewing transcribed participant responses. The professor expert members were two doctoral level professionals in Family Sciences and one aging professional.

Four themes emerged from the study. The four themes are (1) personal choice, (2) non-traditional caregiver roles, (3) skill malfit, and (4) range of duties.

#### **CHAPTER IV**

#### RESULTS

This chapter describes results of data collection methods using both the Demographic Ouestionnaire Instrument 1 (Appendix E) and Qualitative Instrument 2 (Appendix F). The Demographic Questionnaire Instrument 1 consisted of 19 questions which were asked during a face to face interview conducted by the principal investigator. The first part of the instrument painted a profile of the African American male caregiver. It identified who the African American caregiver is, where he lives, income status, employment status, level of education, caregiver status, hours involved in caregiving, and distance traveled to provide care. The second part looked at who received care and the duties caregivers performed. The third part captured the type of training or education caregivers received to perform caregiver duties. The Qualitative Instrument 2 consisted of 24 questions, the responses to which were audiotaped by the principal investigator during the interview session. The first part explored the journey, roles, and responsibilities of male caregivers. The second part captured the caregivers' perceived role in providing care to their mother, father, sister, aunt, companion, brother, church members, stepmother, and non-related individuals 55+ years of age. The third part explored what activities caregivers engaged in to renew themselves as they balanced caregiving and family life. The fourth part explored how caregivers planned on handling changes in their

role as caregivers, and offered an opportunity to express additional comments about the role of African American male caregivers.

Four central themes emerged from the study. The four themes were (1) personal choice, (2) non-traditional caregiver roles, (3) skill malfit, and (4) range of duties. The principal investigator conducted a convenience sample of 20 participants who volunteered for the study. Participant confidentiality was protected by assigning each participant a numerical code. Three readers reviewed the transcripts for common themes and to triangulate data.

### **Description of Study Participants**

The principal investigator interviewed 20 African American males who were either formal or informal caregivers for the study. All participants resided in large metropolitan cities in Texas, were 50+ years of age, and caregiving for a mother, father, sister, aunt, companion, brother, church member, stepmother and non- related individuals 55+ years of age. Each participant was assigned a numerical code prior to starting the interview. Numerical codes 1-20 represent each individual who participated in the study. *Age* 

Participants ranged in age from 50 to 81 years. A total of 40 % of participants were 50-54 years of age, 15% who were 55 to 59 years of age, 30% of participants were 60 to 64 years, and 15% who were 65 years or older (Figure 1).

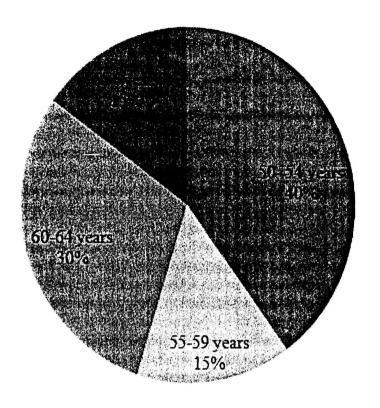


Figure 1. Participants' Age.

## Annual Income

As to annual income, 10% of the sample earned up to \$12,000 annually, only 1% earned between \$12,001 and \$20,000 per year, 15% earned between \$20,001 to \$30,000 per year, 15% earned between \$30,001 and \$50,000 per year, and 15% earned between \$50,001 and \$75,000. The remaining 5% of the sample earned over \$75,000 per year.

One individual declined to provide annual income information (Figure 2).

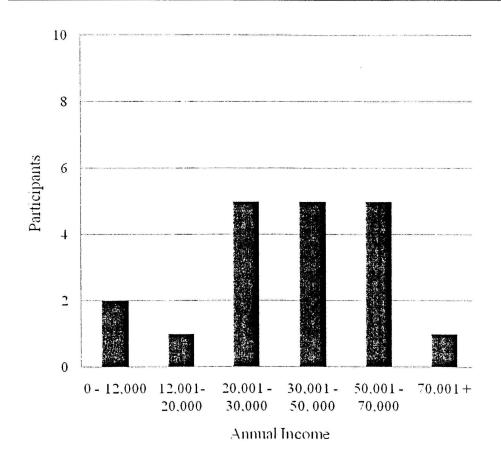


Figure 2. Participants' Annual Income.

# Source of Income

Participants were also asked if they were retired or if they worked full time. A total of 45% of participants stated that they were retired. When participants were asked if they worked full-time, 45% stated that they worked full-time. As shown in Figure 3, those who reported their source of income, a total of eight participants stated that they worked for public transportation agencies and government agencies, three participants

were self employed, three received social security, five participants received retirement money, and two participants received some form of disability payments. Additionally, there was one individual who stated his source of income was from part-time employment and one stated that he had a family-owned business. Frequencies that exceed the 20 participants indicated that participants were able to report more than one source of income. As to types of employment, participants reported working as a petroleum landman, a computer chip maker, a government worker, a physical therapist, a loan officer, public transportation worker, and a music teacher.

#### Education Level

Participants were typically highly educated. The educational levels of participants ranged from grade school to postgraduate degrees. Of those who provided a response as to their education level, 4% stated they received at least a grade school education and 4% stated that they received at least some high school education. As to college education, 21% stated that they received some college education, 17% reported that they had received a degree from a two-year school, 33% reported that they had education from a four-year school. Finally, 8% of participants reported that they have received at least some postgraduate education and 13% of participants reported that they had a postgraduate degree. Frequencies that exceed 20 participants indicated that participants were able to selected more than one option (Figure 4). Some majors or areas of study included Business Administration, Electronics, General Education, Music, Accounting, History, Physical Therapy, Marketing, Management, Political Science, Communications, Psychology, Counseling, Personnel Management and Law.

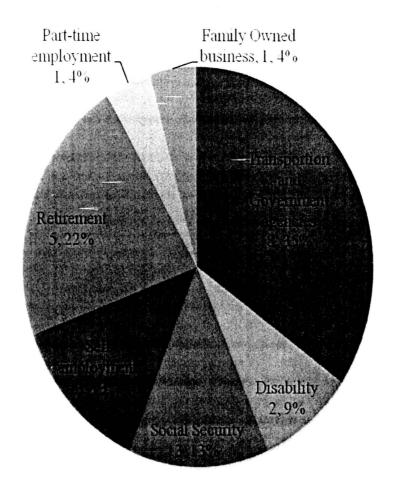


Figure 3. Participants' Source of Income.

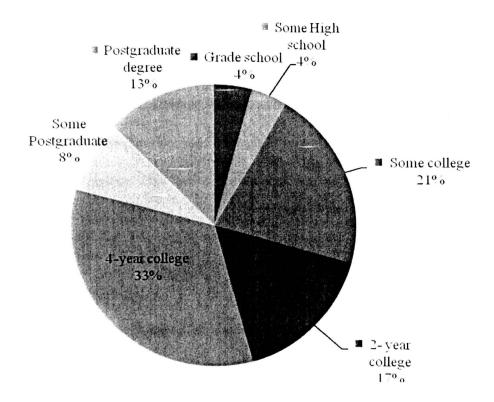


Figure 4. Participants' Education Level.

# Caregivers

Relationships. In this study, African American male caregivers provided care to relatives and non-related individuals. According to participants' responses, care receivers included the mother, father, brother, sister, companion, stepmother, and non-relatives of African American male caregivers. Mothers received 38% of the care provided by African American male caregivers. Fathers received 9% of caregiver assistance; a

stepmother received 3% of care; aunts received 6% of care; brothers received 3% of care; sisters received 3% of care, church members received 13% of care; and non-related individuals received 25% of care (Figure 5). As shown in Figure 6, participants provided care for between 1 and 20 people. A majority of participants (75%) cared for only one individual where as 10% of participants provided care for 2 people. Of the remaining participants, 5% cared for three people, 5% of participants cared for a total of nine people and 5% cared for 20 people. This individual who provided care for 20 people serves as a caregiver for church members at a local church and had no living family members.

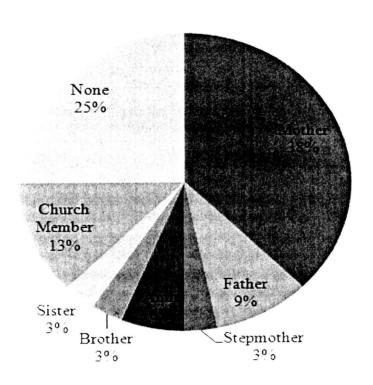


Figure 5. Participants' Relationships with Those They Cared For.

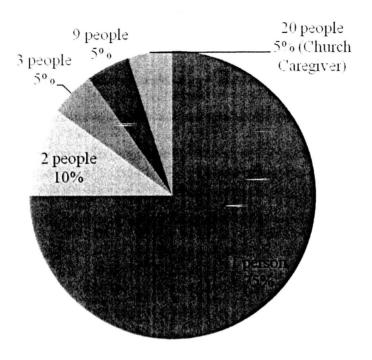


Figure 6. Number of People Cared for by Participants.

Roles. Caregivers indicated they provided an array of caregiver service for family and non-family members and their duties overlapped into other areas of caregiving. Many caregiver duties overlapped into other aspects of caregiving. Not all participants gave response to these questions. As shown in Figure 7, 95% of participants stated that they were informal caregivers and only 10% of participants defined himself as a professional caregiver. Seventy percent of participants indicated caregiving was a second role. Furthermore, 10% received some form of income for caregiving duties. This one

individual is a formal caregiver and received between \$50,001 and \$70,000 per year. Of the 16 participants who responded to the question about type of training, 25% stated that they had received informal training and 31.25% stated that they had received formal caregiving training.

Hours of caregiving. Participants were asked to report the number of hours of caregiving that they provided each week. A total of 19% stated that they provided 4-6 hours of care per week whereas 37% of participant provided 7-10 hours per week. Furthermore, 31% of participants provided 20-29 hours per week; and 13% provided 40-50 hours of care per week (Figure 8).

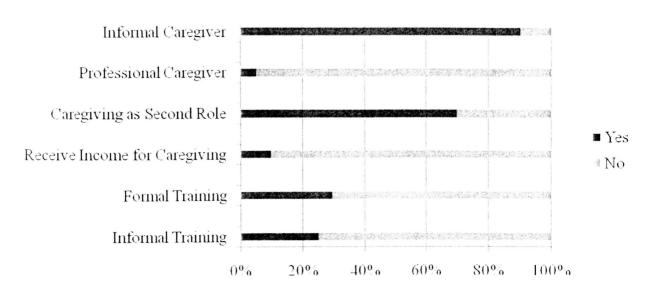


Figure 7. Participants as Caregivers.

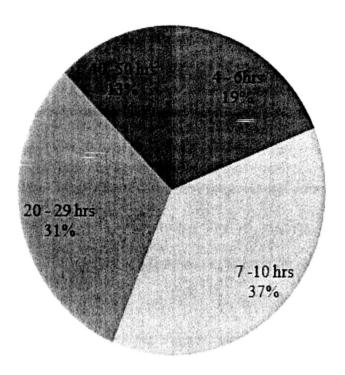


Figure 8. Participants' Number of Caregiving Hours Per Week.

Duties. Participants were asked about the type of duties that they performed for those receiving care. Caregiver duties ranged as they provided a variety of assistance with activities of daily living (ADLs). The duties ranged from personal hygiene duties to transportation duties to even providing socialization, therefore the percentages shown in Figure 9 demonstrate that a caregiver may provide more than one type of duty. A majority of participants stated that they provided some type of socialization for those they

were taking care of whereas 90% reported that they provided transportation. Additionally 75% of caregivers provided some form of medical care and 70% cooked for those they were caring for. A total of 35% assisted in grooming duties, 50% helped with finances, and 95% performed shopping duties. Finally, 30% assisted with feeding, 25% assisted with toileting and 20% assisted with bathing. Other duties included physical therapy training.

total of seven participants received basic caregiver training; 11 participants used lifelong experiences when they provided care; and eight participants used simple trial and error. Furthermore, seven participants read books on caregiving; three participants became involved in support groups; six participants watched films, DVDs, or listened to CDs. Finally, two participants viewed internet modules; three received one-on-one training provided by medical staff and three participants used other modes of training such as in a classroom setting, a local aging agency, formal education, agency temporary service and medical hospitals. When asked about specific types of training, several African American male caregivers expressed having training in working with the elderly. Caregivers had training in many areas which included geriatric psychology, EMT, family counseling, clinical counseling, hospital and nursing home work, certified home health care provider, as well as exercise, gait training, and modalities.

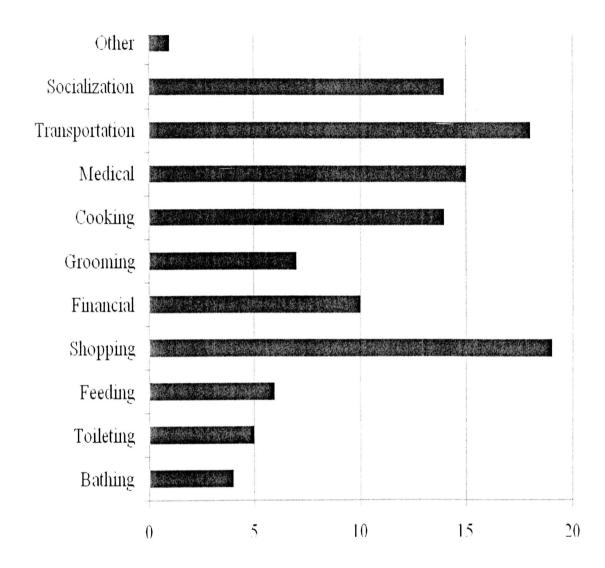


Figure 9. Participants' Type of Caregiving Duties.

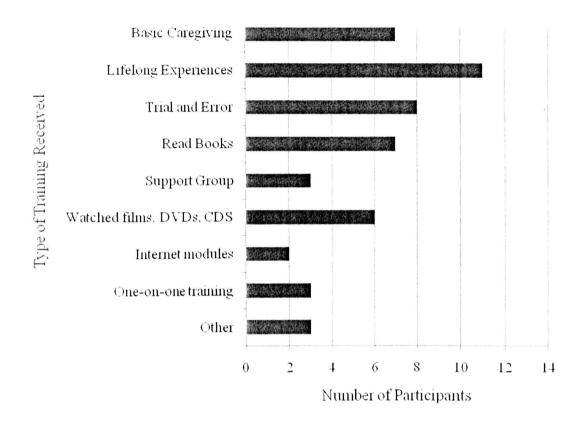


Figure 10: Participants' Type of Training by Number.

*Travel.* Finally, participants were asked how far they had to travel to provide care. A majority of participants lived less than one mile from the care receiver, 25% resided between one mile and 15 miles from the care receiver, 20% lived over 30 miles from their care receiver and 15% lived in another state. No caregiver lived between 16 miles and 30 miles from their care receiver and one individual lived with his care receiver and also traveled one mile to care for his father and step-mother. Three participants were

York to provide care. In additional to traveling over 400 miles to provide care, these caregivers gave daily phone calls to keep abreast of medical and personal needs. These three caregivers traveled over 400 miles away to provide care to their mothers.

Frequencies exceeding the 20 participants indicate that some participants cared for multiple people at various locations (see Figure 11).

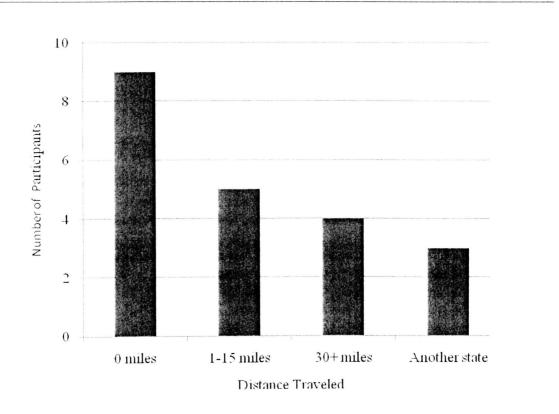


Figure 11: Participants Distance Traveled by Number.

### Study Findings

The purpose of this study was to explore the caregiving roles of African American male caregivers 50+ years of age who were caregivers for individuals 55+ years of age.

The intent of this study was to identify how African American males viewed their role as caregivers. To gather this data, the principal investigator focused on one question:

Research Question 1. What are the perceived roles of African American male caregivers in Texas?

The principal investigator analyzed each participants' responses, and grouped the responses into categories. Themes began to emerge during the analysis. Four themes emerged from the study. They were personal choice as a caregiver, non-traditional caregiver roles, skill malfit, and range of duties.

Theme One: Personal Choice as a Caregiver

Study participants indicated the decision to be a caregiver was a personal choice. Participants took on their caregiving role without any reservations or concerns about their ability to provide care to their mother, father, sister, aunt, companion, brother, church member, stepmother and non- related individuals. Many caregivers did not plan to become caregivers. Caregiving was a role which happened due to circumstances such as not wanting to place a loved one in a nursing home, sudden illness of the care receiver, or simply helping the individual to continue living in their own environment, or age in lace. According to Harris' (1998) caregiver study, many caregivers fit into identified roles. One such role was the dutiful son. In this role sons felt it was their duty to care for their parents. Having an overwhelming sense of responsibility was the motivating factor in

men serving as a caregiver. In this study several of the men addressed caregiving as a personal choice. Many of the men evolved into the role of caregiver. This new role was partly due to illness of a family member or friend, they enjoyed working with older adults, or there was no one else available to provide care.

Because my mom got sick all of a sudden and I just wanted to help her. (P6). Basically my experiences originally started with personal experiences about 6 years ago. My father was diagnosed with lung cancer and for 3 years I became the primary care giver of my dad. The following year my wife was diagnosed with cancer and for those 2 years I became a care giver for my wife. And through those personal experiences it just, I received a passion for caring. It even over flowed into the ministry that God has giving me within my local church and that is the ministry of care giving for my local congregation. (P8)

Well you know, informally, that journey started when I was a child, very small child because there were several elderly people that lived on the block, and I don't know how I was drawn to them, and I don't know if my parents introduced me, or said "Ah you ought to go down and help Ms. C." or "Go down and help Mrs. P," but whatever happened, these older people always wanted to have me help them do something. And that was an informal start to helping elders when they needed help. And it just progressed over the years to a couple of elderly cousins, being around them, staying with them for a few days at a time – and these are just informal things where I'm just helping them out. And I wouldn't consider it care giving, but I guess it is. And as time progressed, you know being with my

grandmother and helping her out, and then of course when my mother got sick ... and she died, and my father got to the point where he shouldn't be alone; it's just the situation where, here you are a child of your parents and you cannot abandon them, you have to help them, this is family. And that's how my journey kind of started. I'm just, you're there at the right time. (P9)

I am the youngest of four sons and the only one that's not married and don't have any kids. (P10)

You know, I don't know. It's just something I wanted to do. You know I feel like that, that's what I like to do. You know, take care of peoples, you know, give them, make them feel good and have them do something good for them, you know, that's the, it's a real good feeling to me, when I'm taking care of somebody and making them happy, when I can make an old person happy, it makes me feel good. That's where I get my pay at, really there. (P11)

Well this is just something that I just more less I guess maybe started taking up on my own. I just kind of do it. (P12)

I've been in the caregiving field for about roughly 15 years. I found it pretty rewarding. Well being in the physical therapy field is pretty rewarding anyway. But working with the elderly has been kind of like a breath of fresh air. You come home and you've seen you've made an accomplishment in someone's life in the course of the day and it's really been working out well for me and hopefully well for them also. (P13)

It's an experience from my mother. She been here from Hurricane Katrina. I started taking care of things that she needed to get done. (P20)

Well, it was sort of natural. And my mom, like I said, my mom does quite a bit for, you know, just about everything, she can do for herself. Not all the time though. So she has her days where she needs help or when she gets sick. Then I do quite a bit, but...that's a difficult point to answer that. (P19)

year gap between my brothers and sister. My brother lived around the corner. He actually passed away in April, and prior to that 18 months he was battling cancer. So I was, you know, pretty much it. And my sister lives in Port Arthur, which is on the other side of Houston. So she is not up in this area to help out but I have plenty of cousins and stuff but I've been a primary care taker. (P17)

Kind of born into it. For the stand point I am the youngest and there was a 13-15

Well you know I'm a person who's there to help out and never really looked at it as care giving, but I guess I am by the fact that I help my mom and her older sister. (P4)

Well you know it just became something that I do to make things better for my mother and things that I did to make things better for my father before he passed.

(P3)

Long distance caregivers. Three African American male caregivers traveled over 3 states from Florida, Mississippi, to New York to provide care to their mothers as needed. The number of hours care provided by the participants ranged from 7 hours to 20 hours per week. The males were basically the sole providers of care to their mothers.

They spent a great deal of time doing administrative duties while caregiving. These participants telephoned their mothers daily to keep abreast of their medical and personal needs. The men were self-selected as primary caregivers of their mothers because of birth order, and proximity to their mothers versus other family members. These long distance African American male caregivers ages ranged from 50 years of age (2) and 56 years of age (1). These men spent as much as 12% of their weekly time involved in long distance caregiving.

Well, my mother is now 78 years old. As an only child, I have the responsibility of seeing to it that she follows her health care plan, that she follows the instructions that the doctor has given her to maintain a healthy body, and I am although I live in another state I am traveling back and forth quite frequently to see to it that my mother gets the attention that she needs, and she lives alone so I have to make it my business to see that she is safe, and that she follows her doctors, and that she manages to maintain a good psychological atmosphere. (P7) I guess I've been doing it all my life, you know what I mean, just when she got into a, at an age that she couldn't function normally you know, I just stepped in, you know, I've been doing it for all my life. (P5)

I am the youngest of four sons and the only one that's not married and don't have any kids. (P10)

Distance or proximity was not a factor for male caregivers. Of the 20 participants, 3 were providing care at a distance. These participants had a strong commitment to providing care at a distance.

Like I said, basically I'll be looking out for my mom you know, and that's my life for right now until one of us can't look after each other, you know, so that's you know, I'm going to do whatever I need to do for her, that's all I can do. (P5)

Like I said you have to be there for them 'cause they won't be here forever. (P10)

Well I have the type of job now which will enable me to travel back and forth to see about my mother, no doubt that if I were not her primary care giver I could have a full time job, which would enable me to have a higher income, and be in a higher income bracket, but since I have the responsibility of having to care for her and to travel I have to be satisfied with just working part time basis. (P7)

Even though many of the caregivers lived near the care receiver, many traveled to provide care as well as handle other household or family responsibilities. Nine participants lived with the care receiver. Five caregivers lived 1-15 miles away from the care receiver, while four travelled 30+ miles to provide care. Those who live the greatest distance away spent the most amount of time caregiving. One caregiver was among 31% of the participants who spends 20-29 hours per week caring for his mother in another state. This person worked at night, and cared for 2 children under the age of 18 on a daily basis. When asked about caring for young children, one participant shared the challenges of caregiving coupled with caring for young children.

Yes, yes, daily basis, I make sure one gets homework done, some days I cook, I take him to school, pick him up, just you know just playing the father role you know, I don't see him all day, but you know I leave and go to work at night so I see him the next evening, sometime. (P5)

I got a 15 year old, it's plenty of obstacles. I got plenty of obstacles you know. Not basically, you know it's just parenting your children you know, just trying to make sure they have the best you know trying to raise them up right. Best I can do. (P5)

One person left home at an early age to explore living in another city.

Although I left my home in New York at kind of a young age to go to college I decided to live in another state. But considering the fact as my mother began to come up in age she was not able to do as much as she was at a younger age. So as her body began to age she's not able to clean the house, as she had been able to. Certain other responsibilities around the house she is not able to physically meet the challenge. So I find that I have to travel back and forth quite frequently to see to it that the house is in good shape, that it's cleaned and maintained, and to also make certain that she's healthy and that she's doing everything that she needs to do to keep her environment safe and productive. (P10)

As with caregivers living nearby, long distance African American male caregivers deal with daily challenges and stressors too. Some worry about their mothers' physical and mental well-being from a distance.

Any stressors in providing care, no. Challenges maybe but no stressors, there's nothing that I can't accomplish. There's no obstacles so far that I've met that I cannot you know meet head on and take care of. (P7)

Worrying you know sometime because I'm not there and 400 miles between us so you know just sitting and you wonder how they really doing you know, you can

talk to a person all the time but you don't really know until you're there to see about them, you know, so that's probably the biggest stress, just you know how she feeling and what's going on with her health you know. (P5)

Yes there are. I mean, you know, when you have a strong willed person that really think that they are still capable of doing what they used to do or want to do it there way even though you know you have to help them, help them out, that is kind of stressful. Either, you know, you tell them this is what they need to do but they go their way and do what they want to do, it is frustrating to deal with. (P10)

To relieve stress, long distance caregivers indicated they have a variety of ways to reduce stress. Stress relief activities include physical exercise, relaxing and resting.

Oh, I do my daily yoga exercises and meditations and then I usually will walk least a mile or 2 everyday for stress. (P7)

I'm pretty easy going so I just take it one day at a time. (P10)

Oh, ok, really I mean, I don't really stress out about a lot of things. I don't guess so. I mean, just when I get home I just get my sleep because I have a 12 hour shift. Basically that's all you can do, go home and get your nap going and stuff like that. And then on my weekends off I get my nap and then I do something with the kids and on the weekends just like I say, run with the fellas and stuff like that. (P5)

The males also engaged in creative ways to renew themselves while meeting the demands of long distance caregiving. Renewal activities included both indoor and outdoor activities.

Renewed? Listen to music. I like riding, just basically that you know. Just trying to put things behind me you know, that you can that'll renew you and refresh you.

Get stuff off your mind. (P5)

I attend church, hang out with friends, whether it's go to a restaurant or to a club or something for a drink or to the movies, and I also have friends that attend local plays that come to town, so that helps a lot. (P10)

To get renewed I'll take short trips, I might go out to the woods for a hike, or spend some time out to the lake to kind of rejuvenate my spirit, that's about it.

(P7)

Theme Two: Non-Traditional Caregiver Roles

Women are often viewed as nurturers, and carers for others. Men are not generally viewed in this role. Historically, the role of men in the family are the economic provider or family leader (Staples, 1985). Bowers (1999) compared caregiving to parenting, both require nurturance and sensitivity, and remain unexplored life situation in terms of its relationship to gender identity. Martin (2000) speculated men more often distance themselves emotionally from caregiving because their male identity is not tied to success in a nurturing role. Caregivers in this study had multiple roles both inside and out of the home. Some worked full-time, part-time, were retired, cared for children under the age of 18, and provided around the clock care to the care receiver. Even though their caregiver roles overlapped at times, between caring for an elderly person and children, caregivers adjusted their roles and responsibilities to fit their lifestyle. Men are not

typically seen in the role of caregiver. Of the twenty participants, 30% were employed full-time and 20% were employed part-time. Fifty percent of the caregivers were retired.

I get my kicks just taking her to the store. Because she's doing all the shopping, so I just sit there and watch. You know? (P20)

I think it has been enjoyable helping someone. There is an old proverb, if you can help someone as you pass this way your living will not have been in vain. So you see it as a chance to give back to society and in helping them, you're' helping yourself. That's about it. (P18)

I have a grandchild that 1 years old now, so we with him every day. (P20)

Caregivers were involved in many activities with care receivers. Some provided financial assistance such as banking, and transportation, assisted with grocery shopping. While many caregivers remained in the workforce, many stayed at home to provide care. Those in the workforce juggled multiple roles simultaneously with caregiving. Tasks were often completed during caregiver off days or after work.

When I first left the \_\_\_ and I was going through the battle with the \_\_\_ then turning my emphasis on my mom and taking care of her. And I kind of threw all that in all that aggression into taking care of her I became aggressive for the health care keeping up with medicine, her bills and just you know all the things like that. So I thought about it and I was thinking that I was trying hit that career ladder with the \_\_\_, and hit my head on the glass ceiling. But then I sat down and thought about it probably taking care of my mom is the best thing that I've ever done. So with that it gives me a lot of satisfaction and I am not out there

competing so to speak because I am competing only as far as just taking care of her. (P17)

Theme Three: Skill Malfit

According to Allen (1994), skill malfit is the lack of necessary household management and nursing skills needed to perform adequately in the caregiving role, or identify malfit, a discomfort in performing the expressive or hands-on-activities typically thought of as women's work.

Many of the participants in this study expressed discomfort with performing some tasks. The areas of most discomfort included caring for personal hygiene of the parent, such as bathing and dressing. This was also reflected in the demographic surveys. Only five participants said they saw themselves as being able to dress the care receiver (while some caregivers performed tasks with more reluctance than others). Many participants indicated they would take care of their mother's or a female's personal hygiene on an emergency basis, or if no one else was available to perform those tasks. Many indicated this was not an appropriate task for male caregivers. All of the caregivers discussed the issue of responsibility for care receiver's personal hygiene and grooming.

This theme is supported by the research on skill malfit. While all of the participants expressed some discomfort in some areas of the tasks they perform, many of them expressed great discomfort in performing personal hygiene tasks such as bathing and grooming.

Well, I feel comfortable with everything except I guess, you know, dressing them and the toiletry stuff, you know what I'm saying? But if it has to be done, then you just got to do what you got to do. (P20)

Well, I actually have combed my mom's hair. My mom is a beautician so when I was a kid she kind of taught me some things, I guess in African-American community scratching hair, you know softening, I know how to do that. And I have combed her hair, I shampooed her hair and stuff. Naturally, the bathing part, that would be like I said before, fortunately she is able get in and out herself. Maybe down the road that may not be possible, we'll have to readdress that issue. There was one time when she got in the tub and was unable to get out and she called me and I basically had to pick her up to get out. But other than that I am pretty much comfortable as far as doing everything else. Like I said I don't cook that's the one thing that we might address but for the most part I do everything and the only thing that she really does is cook. (P20)

The toileting, the bathing, don't feel comfortable doing that, don't do that.

Cooking is fine, socialization is fine. Didn't know my mother talked that much though. She talks a whole lot. I'm not a big-time talker. So that kind of makes it, well, not a problem, but it just---sometimes I just let her talk. I listen. (P19)

You do what's necessary, all of the above, it's not a point of being appropriate or inappropriate, I know that sometimes, perhaps the most difficult if you have a bathing situation, sometimes, that perhaps is more of a challenge, in terms of, that you perhaps, I would perhaps prefer, you know in terms of having female,

because, but if it, so be it, say for instance that if she got into the tub on her on and needed assistance getting out, then you help her get it, so you know it's nothing, you know, I always respect and give ladies ladies-time, in terms of whatever you need to do, what female kind of things need to be done, I kind of, I try to steer clear from that as much as possible, but if it gets to be an emergency need, then you take, you do what needs to be done. And, that's it. (P2) Well I would say the only thing that is challenging, (and the whole being reckless thing and whatever are things I would be doing myself anyway, so that's not a real challenge), so the only thing I would say I find challenging, and something I would find distasteful if I had to do it anyway, is my dad now has gotten to the point where he is incontinent and he loses his bowels in the bed sometimes at night and having to clean up after that is something I really don't like, but someone's got to do it. But I don't really like that. So I find it really quite challenging. Actually it is something I wish I could have somebody else do. But somebody's got to do it, so I do. (P4)

Well I wouldn't I feel comfortable on bathing and ???, but I do feel comfortable in talking to her and the conversations, but I don't, I don't have anything to do with that other part. I just, that's on me, and not what I do. (P12)

Uh the uncomfortable is the toileting. That's about it. (P15)

Theme Four: Range of Duties

Calasanti and Bowen (2006) indicated care work includes personal care and activities that are defined as intimate. As mentioned earlier in this study, some males were comfortable performing caregiving duties while others were not comfortable performing caregiving duties. Duties performed by the caregivers were based on the needs of the care receivers. Physical duties completed by the caregivers were more traditional duties. Traditional male duties include tasks such as transportation, shopping, socialization, home repairs, vehicle maintenance, writing checks and yard work.

Well right now it's just, start out get up in the morning, take care and clothe her and cook her breakfast and everything, first one thing then another, whatever comes whatever comes, just take one minute at a time most of the time, you know, whatever comes up, that's what I do, but taking care of her is just you know, whatever she decides she want to do and I have to base my day on that, whatever I have to do for her, and that's what I have to do about that. (P11) Well one thing I guess with a male, and I've heard this many time and this may be chauvinistic, but women I think a lot of times are glad when there is a male around. Simply because of things that might need to fixed up around the house, basically based on that preference is that they're glad that somebody can fix this, and it may sound a little chauvinistic. However, women are the ones that tell me this. I've heard it from my aunt, I've heard it from a friend of mine her husband died and her house just kinda went down and she said "Now my husband is gone and I can't get these things done." So I've heard this from women in so many

instances. Basically that might be the line of demarcations between men and women. However, as a male, when my mom was sick, it didn't matter who I was. (P9)

The other role with my church, we are a fairly senior church community, and a lot of our members are sick, or shut in, and or unable to attend church. So my involvement with them is to bring the church to them. That's my main involvement is to bring to those members. (P8)

The only thing is that on Sunday I go to church and take my mom to church. We go to two different churches. My church offers eight o'clock service. So I go to eight o'clock service then I come back and pick her up and take her to her eleven o'clock service. (P17)

Some of the caregivers were more comfortable providing care than others.

While traditional caregiver roles for the men consisted of physical care such as lifting, taking care of the house, physically moving items, and food preparation, some of the men felt inadequate performing these and non-traditional tasks. Non-traditional tasks consisted of bathing and providing personal care/hygiene to care receivers. While providing care, one caregiver perceived older women getting a massage from a strange man was different for some care receivers.

In the physical therapy field, men and women train side by side and we are all under the same umbrella to do the tasks whether male or female regardless of gender. It just goes along with your professionalism and most of us don't have a problem with that, but it just goes back to the patient. Can that patient, being a

female, handle a male giving her a massage? Some can and some cannot and vice versa. It just depends on that particular patient and that particular person and how they see you, how they feel about you caring for them. So it's not so much the therapist or the caregiver, its more on the side of the patient, themselves. (P13)

Many of the participants perceived their caregiving duties differently if caring for a male or female. The roles reversed as the caregivers provided care to care receivers. In some cases, the males experienced a level of discomfort providing personal care to their fathers.

Well to restate, the only thing I feel uncomfortable with is when he loses his bowels. And I think that would be distasteful to a lot of people whether they are a woman or man, but they would still do it. And after that, of course I have to bathe him and wash him off because he's got his feces on him, but that's just part of it. I actually have a lady that comes in Monday, Wednesday, and Friday and gives him baths, but I consider that a convenience. But if my dad were a woman, I would probably feel more uncomfortable. If my dad were a female then I would probably feel a little more uncomfortable about giving him a bath, about changing him when he has a bowel movement, about being with her (if it were a her) in the presence of her nakedness, I would probably feel uncomfortable about being with my mom like that. (P4)

Some participants were presented with challenges as they performed caregiving duties. These duties ranged from household maintenance, recordkeeping and bill paying, transportation and driving.

Household maintenance.

And of course living in a house for 35 years, she had accumulated a lot of things in the house and it was kind of difficult to get around. It wasn't too much of a challenge telling her that we needed to clear some pathways because some people are very resistant to that kind of thing. But she was very open to that. So it wasn't difficult at all dealing with her at all because she was in a good frame of mind and so on and so on until those last couple weeks or so. (P9)

Recordkeeping and bill paying.

My caregiving experience consists of taking an older gentleman to the grocery store, his doctor's appointments, and just handling the things that he might need. Like the grocery store and doctor's appointments and paying his bills, utilities, and other errands, shopping for clothing. (P18)

I just recently I've taken over for as paying her bills and I always allowed her do that cause I still want her to still have that independent "I feel like doing that."

Then we had a couple episodes where there were some bills that she had double paid. And so I just wanted to make sure that everything is okay and she kind of agreed aloud to do that. (P17)

Transportation and driving. Eighteen of the participants indicated they provided transportation for the care receiver. Some drove because the care receiver was no longer able to drive. Others drove because care receivers had never driven before.

Basically taking care of his finances and seeing that he has food and taking him to his doctor's appointments. (P1)

Things like driving was not a challenge at all because the first time we went somewhere she drove. She said "I'm going to drive," but after I experienced her driving, I drove. She drove too fast and I could see she can't do this anymore. So after that first initial drive in maybe March or so, she didn't drive not once with me in the car after that, I always drove, but she would drive herself some places. But that was pretty much the challenge, later on of course, it was getting her to eat, but that was in the last couple of weeks of her illness where she just would not eat at all. (P9)

She doesn't drive anymore, she can drive, but she hasn't driven in the last 2 or 3, 3 years for sure. But she is still able to drive. (P2)

Taking her to her doctor's visits. (P3)

I just take him to the barber shop. (P4)

Another time I might have to provide transportation. (P3)

In transporting the person from one place to another becomes a challenge. And transporting that is a major challenge, is getting them from one place to another.

(P9)

Take him somewhere and he'll go wherever you're going. But some place he likes to go for certain and other places ... Sometimes you've got to get him up an hour earlier. (P15)

Transportation I care for her in the car situations get her in the car and all that kind of stuff yeah like that's basically what we have to do. (P16)

Sunday I go to church and take my mom to church. We go to two different churches. My church offers eight o'clock service. So I go to eight o'clock service then I come back and pick her up and take her to her eleven o'clock service. (P

The tasks that I feel comfortable with are taking him to the grocery store, shopping and to the doctor's appointments. (P18)

I take her shopping. (P19)

Mostly like take them to the store. (P 20)

Challenges. Many of the caregivers were faced with challenges in their role as caregivers. Some challenges stemmed from getting the care receiver to assist with daily functions, while some challenges were developing a way to provide care for care receivers. While some caregivers took on their responsibilities without difficulty, some were faced with challenges. Some challenges included getting the care receiver ready for an outing, encouraging them to consume nourishment, being an only child, and getting them dressed. In some instances, this role may or may not have been easy for the caregivers.

She didn't want to drink any water, at all. She hated water with a passion. Getting her to drink a half cup of water, well was quite a bit, but if we're talking about a regular sized glass of water would take an act of congress to get her to drink water, and that was a big challenge because the doctors had repeatedly told her that she had to drink water. You know "Stop drinking the sodas." So that was a really big challenge. There was no problem with her taking medicine, nothing like

that. She had a good appetite. And she was very cooperative, she was very good about her kindness, and not being in a frame of mind that some people get in where they get really hard to be around. So that was primarily the challenge. (P9) Just probably putting up with her until it's time to go because she's ready to go an hour or two before we have to get there. (P19)

Putting on their clothes. (P6)

Well my dad's kind of slow, he's slow, slowing down, uh slowed down pretty much [chuckle] so just uh getting him up and getting him ready to go. (P15)

Some of the African American male caregivers were biological sons, or other related family members. On the other hand some caregivers were not related at all. The non-related caregivers were church members, health care professionals, stepsons, and friends. The males viewed and took on their caregiving responsibilities just as those who were related to the care receivers. None of the caregivers indicated disliking their caregiver role.

Here again, it all feeds back to physical therapy. When I retired from the \_\_\_\_\_, I hadn't planned on going back to physical therapy, I have a Masters in Business, and I wanted to pursue that. But for some reason the business world didn't work out for me, so I found myself back in the physical therapy field. Of course, care giving for the geriatric population out here with all the civilians of probably a multibillion dollar industry, there were more job openings in that particular area of physical therapy that would cater to what I wanted to do on a daily basis. It wouldn't tie me up so much and I'd have some freedom of my own for flexibility,

and it just happened to work out for me. It's not so much that I chose care giving or care giving chose me, it just kind of angled or led in that direction. And this is where I've ended up and I've been really pleased, really happy with it. (P 13)

Now, in the mean time, one other addition is that my roommate's, my partner's great-aunt became ill in California, and she had to have her leg removed. We were trying to get her here before that process happened and it didn't. She ended up losing the leg before we could get her here so, we went there about three times and we finally shipped her stuff back in boxes as much as we could and then we finally were able to bring her here so she is now living with us. She has been with us, I guess, right at a year now, so is now an amputee, and I basically....she has a lady that comes in, but on the weekends what I do, my part is I sometimes cook and do things, but she is very independent. (P1)

I guess through a friendship. We were friends through the years and as he aged he was unable to drive and I offered to assist him in any way that I could help him.

(P18)

Only child. Several of the participants indicated they were an only child in their family. In most cases, this meant they were faced with their own challenges as caregivers.

There's nobody that should be in a position to have to care for a parent who has only one child. And if this one child is able to, then he should take on that responsibility of seeing to it that his mother has everything that she needs to be healthy and to live a prosperous life in her golden years. (P7)

Actually, I'm the only son. Actually, not only am I the only son, I'm an only child as far as my father is concerned. (P4)

Distance. Both long distance and local caregivers were very resourceful in their role as caregiver. Many relied on informal support networks as needed. The informal support networks were neighbors, friends, family and other fictive kin.

I call for help. I call other siblings, other church members, we are a community of care givers, and we have a link and we depend on that link. So I am heavily supported by others. (P8)

Well I have a, she has people around her that can talk to her there. Make sure she gets where she needs to be, and what kind of care she needs or something like that if she can't provide it for herself. (P5)

When I am not there I make arrangements for our tenant, we have a tenant who lives downstairs, and I make arrangements for the tenant to fill in for me in my absence. If my mother has a doctor's appointment that she needs to meet, my tenant would see to it that she is able to make that appointment. The tenant will call a cab and escort my mom to her appointments and she'll also see to it that her medical prescriptions are filled and she does the shopping for my mother, so I have somebody who can substitute for me at times when I'm not there. (P7)

Like I said, I have another sibling that's older that lives there. But like I said if he is employed, is working, so I check with him and I also have a cousin that's like a sister who has a key and when I can't get in contact with her and if I haven't

heard from her, I may call her to make sure that she goes by and check on her. (P10)

Advocate for care receiver. Even though the caregivers had their hands full prior to caregiving, some took on the role as advocate for care receivers. This role encompassed stepping in to act on the care receiver's behalf, and articulate changes in care if needed.

My dad has been married three times. His last wife, was a younger woman. As a matter of fact, his last wife was my age. By her being my age, (they hadn't been married very long, probably only 5 or 7 years). He probably married her because she was younger and stronger and she could help him do certain things that he thought he needed someone to do. However, she was a bad choice. She wasn't the woman who he thought she was and she was with him to take everything she could from him. When I say "take everything from him," I realize marriage is a give and take situation, but the things this woman took were things she would, if she were not his wife, she would be in jail for. In other words, she really took advantage of the situation. So knowing that, I sort of rescued my dad from that situation got him away from that woman so she wouldn't further abuse him financially, abuse him mentally. I got her away from him and started my care giving. (P4)

Billingsley (1970) posits African American families have not been given much study as an institution as it deserves. Staples (1985) indicates other than the church, the Black family has been the only institution to serve as a way for resisting oppression and

facilitating the family's movement toward social and economic equality. Historically,

African American families have relied on extended family members or fictive kin to help
with aging family members. In this study, caregivers relied on friends and family
members to provide care when their schedules changed.

I call somebody that I know or somebody in the family, cousin, or somebody close, a friend, or something, if I'm not there to try see if they can do what I them to do for meuntil I can get there. (P6)

Very good, good question. There are neighbors and friends. You know, next door neighbors, their children, grandchildren. A neighbor up the street has children, grandchildren. And so there is somebody close by, and you know, there is somebody close by. And there are friends who drop in. And there are several people who have a key in terms of being able to, there are other persons within this care giving circle that assist as needed. So, I am fortunate that I am not very far away. Ten minutes away or so, or five. (P2)

When I'm not there, I've got a son and he lives with my Mom, he's there, a wife who's, who sometimes is available, and we've got some family members who are there to provide transportation, to drive at night, to make grocery runs, so we've got a part, got an extended family. (P3)

#### Summary

Participant responses to Demographic Questionnaire Instrument 1 and Qualitative Instrument 2 were analyzed and grouped into categories. From this analysis, four themes

emerged. They were personal choice as a caregiver, non-traditional caregiver roles, skill malfit, and range of duties.

Many factors play an integral part in the perceived role of African American male caregivers. Some of the African American male caregivers faced challenges while providing care for their mother, father, sister, aunt, companion, brother, church member, stepmother, and fictive kin. Some challenges included preparing the care receiver for an outing, being an only child, dressing the care receiver, and encouraging the care receiver to consume nourishment. Several caregivers received caregiver support from others, while others chose to handle the caregiver role alone. Men who identified as being the only child in the family were also challenged with caregiving. These men devised their own plan of care work when faced with challenges. In some instances, they were advocates for the care receiver.

Three men were long distance caregivers, who contacted their mothers daily in Florida, Mississippi, and New York. One of the caregivers was sandwiched as he provided care for children under 18 years of age. These men relied on help and support from extended family members, neighbors, friends, and fictive kin residing near their mothers.

#### CHAPTER V

#### DISCUSSION

This final chapter presents a summary, discussion of the findings, conclusions, implications, and recommendations. This chapter will conclude with the study limitations.

#### Methodology

This study explored the role of African American male caregivers. This study used a two part instrument. Part I of the instrument consisted of demographic questions. Part II of the instrument consisted of qualitative questions. This study used the Demographic Questionnaire Instrument 1 and Qualitative Instrument 2. The Demographic Questionnaire Instrument consisted of 19 questions which were asked by a face-to-face interview conducted by the principal investigator. The second instrument consisted of 24 questions, which were audiotaped by the principal investigator during the interview session. The principal investigator conducted a convenience sample of 20 participants who volunteered for the study. All participants were African American males 50+ years of age and older, living in Texas and caring for their mother, father, sister, aunt, companion, brother, church member, stepmother and non-related individuals 55+ years of age. Participant confidentiality was protected by assigning each participant a numerical code. Three readers reviewed the transcripts for common themes, and to triangulate data. The four major themes which emerged in this study were personal

choice as a caregiver, non-traditional caregiver roles, skill malfit, and range of duties as a caregiver. With personal choice, study participants indicated whether the decision to be a caregiver was a personal choice. Participants took on their caregiving role without any reservations or concerns about their ability to provide care to their mother, father, sister, aunt, companion, brother, church member, stepmother, and non-related individuals. Many caregivers did not plan to become caregivers. Non-traditional caregiver roles looked at what males did to adjust their roles and responsibilities to be caregivers. Men are not typically seen in the role of caregiver. Skill malfit looked at how the caregivers perceived their skill level when providing care to care receivers. Many of the participants in the study expressed discomfort with performing some tasks. The areas of discomfort included taking care of their parent's personal hygiene such as bathing and dressing. Range of duties performed by the caregivers were task caregivers performed. These tasks were based on the needs of the care receivers. Some duties included transportation, personal care, shopping, socialization, home repairs, vehicle maintenance, writing checks, and yard work.

#### Discussion

Harris (1998) indicated there are some men who are involved in providing care to elderly family members, and have gone against traditional roles. This study explored the role of 20 African American male caregivers in Texas. This study has also helped the principal investigator to understand the experiences of African American male caregivers. Male caregivers 50+ years of age shared how they engage in caregiving

activities for those 55+ years of age. Some of the individuals receiving care were relatives and non-relatives of the caregivers. Findings from Demographic Questionnaire Instrument 1 painted a very vivid picture of an under researched population. Study participants were very willing to share their caregiver stories.

These 20 men ranged in age from 50-81 years of age, and served as informal support caregivers to formal support caregivers. Informal support was defined as care and support from family members, as well as from friends and neighbors (Williams & Dilworth-Anderson, 2002). Formal support caregivers were defined as help provided by professionals, paid helpers, or companies who provide caregiving help (Williams & Dilworth-Anderson, 2002). One participant was a formal support caregiver, and 19 were informal support caregivers.

These African American male caregivers cared for older adults, still worked, were economically solid, and had incomes ranging from \$12,000-\$70,001. Only two participants reported an income within \$12,000-\$20,000. These individuals were on a fixed retirement salary and employed full-time. One person was on disability. Eight five percent of the men earned \$20,000-\$70,001+. While the participants were asked about income, they were not asked about their total household income. Some participants had children they were caring for, resided in dual income households, or were sandwiched.

Four major themes arose in this study. Major themes were (1) personal choice as a caregiver, (2) non-traditional caregiver roles, (3) skill malfit and (4) range of duties as a caregiver. Personal choice as a caregiver were those males who selected the caregiver role. Level of satisfaction looked at how the caregivers dealt with their role as caregivers.

Skill malfit viewed the caregiver's level of experience matched with the care receiver's level of care needed. Range of duties captured all of the task and duties caregivers indicated performing for care receivers. While the majority of the African American male caregivers had a choice in their role as a caregiver, some did not. Some had siblings nearby who chose not to participate as a caregiver.

Similarly to Harris' (1998) study, participants were very open during the interview. They were very open about their caregiving experiences, which often triggered an open display of emotions. Some participants were very frank about how they handle their day-to-day caregiver role. The participants were very open during the interview. They provided more information than the principal investigator even asked. They readily gave the principal investigator an overview of how they provided care for the care receiver. Some participants took their caregiver role in stride. This was apparent when participants laughed after responding to interview questions.

As the researcher looked at findings and personal choice these were sons, nephews, non-relatives. In this study, many of the participants were very involved as caregivers. Some of the African American male caregivers lived with the care receivers to accommodate the needs of both. There were both single and married African American male caregivers. Some took on the role as a lone caregiver, and some had help from a wife, partner, family member, friend or significant other. Harris (1998) identified this shared role as sharing the care. Those involved in sharing the care were equal partners in decision making and providing care to care receivers.

In some cases, the caregivers' wives were quasi-gatekeepers during the interview scheduling process. Creswell (2003) stressed it is important to gain access to do research by getting the approval of gatekeepers. There were many interesting observations during the 12 month interview process. Many participants were very willing to participate in the interview without deferring to someone else prior to scheduling. When scheduling interviews some males checked with their wives prior to confirming interview days, and times with principal investigator. One participant met the principal investigator at his mother's home. Two male caregivers were comfortable being interviewed with their mother, the care receiver nearby. Some wives sat in and observed the interview. The wives appeared to be curious about the interview process and questionnaires. Several indicated this was the first time someone asked them to participate in a doctoral research project. Some wives validated their husband's responses by doing a simple head nod. At some point, some of the wives quietly left the room for fear of interfering with or obstructing their husband's response to the interview questions. Several participants gave the principal investigator their personal cell phone number to contact them. This allowed the principal investigator to contact the participant if there were any schedule changes.

#### Conclusions

This research has identified some perceptions, attitudes, and values about caregiving. These men cared for parents who were in close proximity, as well as those that were at a distance. They were very engaged in care work. The men improved the quality of care even though they may have had limited skills in care work.

Several of the participants were sandwiched as they provided care to those who were 55+ years of age as well as children under the age of 18. Further training and research is needed to provide information to families prior to becoming a caregiver. The research should include ways to incorporate caregiving into several aspects of African American life and culture. This includes providing a variety of training methods for family members throughout the life cycle. Training can include viewing videotapes exploring family caregiving needs, and small informal group sessions held at places frequented by all ages of caregivers. Some places include barber shops, fitness and recreation centers, schools, and local libraries.

### **Implications**

Study findings provide many implications for gerontologists, family professionals and others in the aging network and Family Sciences field. This study will help gerontologist as they provide assistance to employers to develop work place policies as it relates to employees who are caregivers. Family scientists can further educate families on caregiver basics and how caregiving impacts family members on all levels. This education would take place in barbershops, recreation centers, places of worship, civic organizations, and men's groups. It would be beneficial to have members of the aging network partner with other community and faith-based agencies, to determine how to best serve this special population.

One major implication of this study is the need for aging and family professionals to develop an understanding of the specific needs of African American male caregivers.

Understanding the needs of African American male caregivers helps to promote trust,

allows opportunities for open dialog about their specific needs, and the availability of community resources. This is important when seeking funding and designing programs to further explore the role of African American male caregivers. Social service agencies may also find it beneficial to explore going to uncommon places to educate African American male caregivers about community services. Some uncommon places are church, men's or civic groups, community diners, drug stores, schools, and libraries. Family scientists can design basic trainings, and build on them as the participants expand their knowledge base. Another method to reach these males is peer-to-peer educational training. This is caregivers training other caregivers on the basics of caregiving. Perhaps this educational component would help to decrease the number of African American male caregivers experiencing a level of skill malfit as indicated in the study.

Designing and disseminating culture specific eldercare or caregiver pamphlets may capture the attention of those needing resource information. In this study, 56% of the participants were employed part-time or full-time. They were self employed and ranged from business owners to government agency workers. Pierce and Steiner (2004) indicated as more husbands and sons take on caregiving responsibilities, it is important to understand how they include caregiving duties into their roles and how service providers should address their needs.

Two participants indicated they were sandwiched or providing care for children under the age of 18, as well as an older adult. As the baby boomers delay child bearing, they will continue to be sandwiched. Families may need to take a service-learning approach to caregiving. This approach includes utilizing the skill set of all family

members. Intergenerational caregiving would provide young children an opportunity to learn about caregiving for family members, and possibly expand to others in the community.

#### Recommendations

Recommendations for Future Studies

Future Research

Although this research explored the roles of African American male caregivers in Texas, this study can be expanded or replicated in other metropolitan or rural areas. Expansion of the study would include exploring the roles of more homogenous groups such as males caring for wives, wives caring for husbands, and sons caring for mothers. Replication of the study will help social service agencies identify the needs of African American male caregivers. Study participants were very open about their caregiver role. All of the participants were eager to share their story with the principal investigator. This can be looked at as a plus for study participants. African American males generally are not willing to share information considered to be personal or private with others. Principal investigator did not experience any level of discomfort during the face-to-face interviews. Study participants often expressed their gratitude for a study of this magnitude.

Caregiver Training

Based on this study, many participants lacked formal caregiving training.

Nineteen of the caregivers did not receive formal caregiving training. One participant was a professional caregiver. The caregivers indicated the training received based on a

predetermined list of training types; 7 received basic caregiver training; 11 used lifelong experiences when providing care; 8 used trial and error; 7 read books; 3 were involved in support groups; 6 watched films, DVDs, CDs; 2 viewed internet modules; 3 received one-on-one training provided by medical staff; 3 used other modes of training such as in a classroom setting, a local aging agency, formal education, agency temporary service and medical hospitals.

## Formal and Informal Systems

Perhaps it would be prudent for both formal systems, such as social service agencies, and informal systems, such as churches to collaborate to provide caregiver training designed specifically for African American males. These trainings would consist of basic caregiving issues including establishing a support network, interfacing with formal and informal support systems, male caregiver support groups and other trainings. These trainings can also provide seminars on personal care and the needs of female care receivers.

Although these men were highly educated, the use of technology regarding caregiver training was limited. Two of the twenty participants indicated they received caregiver training using the internet or on-line modules.

Black churches have always been there for its members, and helped them to gain access to systems which were often closed or off limits to them. Parker et al. (2003) indicated individuals with chronic illness report that attending spiritual and religious beliefs and practices provides them hope, reduces anxiety and promotes a sense of well-

being and purpose in life. Attending religious services or belonging to a church was an important function for caregivers and care receivers in this study.

Study participants eagerly shared ways in which formal and informal systems such as social service agencies, churches and the community can help African American male caregivers. Many of the responses were to add services geared toward African American male caregivers and older adults in the community. Several caregivers suggested having a support group for African American men where the church plays a major role. The church can be an avenue for formal agencies to enter partnerships with informal systems such as the church.

One thing I think of that would be nice, they could do something perhaps on a monthly bi-annual or quarterly thing is that they can have some kind of, some kind of gathering and sort of like a group meeting, sort of like a support group is what I'm trying to think of, its coming, I'm, something like a support group where the African American men can come and share their stories just as I'm doing with you on an individual basis, and not only that, I think when you have that, and when you do that, you tend to grow, you you get some atonement for what you're, the work that you're doing, some satisfaction, some ideas, some suggestions, some people are new at it, they can pick up ideas, they can share their thoughts, they can share what's going on with them, and just to vent situations, and share well you know this happen to me, and this is what I do, yeah, well I'm gonna go try that, yeah man, I'm gonna go try that, those kind of things, just sharing thoughts would be probably the pie in the sky for me you know, and probably for

lots of others that we could come to a place, whenever we'd like on a you know, if it was held monthly, or quarterly, however, even weekly if needed, if it was that great of demand that you know, that you can go to and talk to other people, and share like a support group, so that would be the pie in the sky. (P1) Yeah, one of the churches in the community had is a care giving support group, and they had, I haven't been able to participate as much as I would like but they had appreciations and things and I think that it is very helpful. Again, I hadn't been able to do it, but the fact that they are there to share those experiences, is kind of help broaden your horizons. Mentally, emotionally or whatever and not to feel that you are trapped, you know, and that you are not in this by yourself. Somebody else is and that there are other people who will, that you develop again, a kind of a network and friendships you know so the things, the person who has experienced, say here are the possibilities of the things that may happen, that you can be prepared for. But, yeah, I think churches in particular would do well to engage in or at least care for the aged, having somebody because somebody is going to need that particular kind of help, support and whatever. But you know again, we are fortunate in the church we sit with across the street and the interesting thing of it is, is that she is not a member of that particular church (mumbling) in terms of that particular kind of outreach, if you will. I think is very helpful and appreciated, in terms of that they recognize and know again that socialization and the emotional health issue. That's, one that she is not isolated, she is not, you know, considered to be forgotten, if you will, and I think that their

point of motive is no one to even come by to say hello or that your just there. You know, it does a world of good in terms of minimizing severe depression. (P2)

Like I said, we have the senior program at our church; they have seminars. I think I probably---my wife and I are really thinking about doing the Sunday evening bible study course for caregivers. (P19)

I guess some churches could become active by visiting a elderly person or to have some Sunshine Committee to check up on the sick and shut in. (P18)

I would definitely like to see more information available I would like to see more agencies available for people, for assistance. (P17)

Well I think that if they provide, whatever the situation again calls for, if they provide some level of spirituality, some level of socialization, some kind of group activities, I think everybody has a, everybody and everything has its place. (P3)

Maybe if I was a member of a church I could understand, and solicit, and otherwise just want somebody of my church to have some kind of outreach. Like just coming and sitting and visiting with him, just giving him some outside contact. The reason I say this is because I live in \_\_ and my dad lives in \_\_ and nobody that he knows is here. Most of his friends he grew up with – first of all they're dead – and the ones that are living are back in the town that he came from before he moved here and the place where he was born. If I was a member of a church, I would like for those people he was in church with to come by and give some contact with him, let him know they still think about him. (P4)

Just pray for me. That's really about all they can do to participate in any situation that is not in our hands. (P6)

Emotional support. Just being able to talk and fellowship and be able to have comradery with people of church. (P13)

I'd like to see the churches, and the communities, and other agencies see to it that the people and the elderly are being cared for in a way that their psychological disposition is not down so they can live their golden years in a you know in a peaceful and a pleasant disposition and a good attitude and in joyful moods. (P7) I think that when we get back to our roots and become that village that we need so much to become a part in the lives of those less fortunate even within their own families. If we come together and join in together in caring that will assist me tremendous. (P8)

Cause there is a lot of seniors in that area, in that state period and I think that they do all that they possibly do, you know with state funding. So, I guess that's a big help. (P10)

Sentiments expressed by the African American male caregivers in this study clearly imply there is a need or call for additional research in this area. It is also important to conceptualize what caregiving means to the African American male caregiver who are 50+ years of age.

#### Limitations

The results of this study provided limited generalizability because of the qualitative nature of the study. Even though this was a statewide study, it was limited to 2

urban or suburban areas. It was limited to a general population as well. The study was limited to the times participants were available for interviews, if they were fictive or non-fictive kin, or formal or informal caregivers.

Secondly, females were present during the interview. The women wanted to be a part of the study or see what was going on during the face-to-face interviews. The women may have influenced how openly some of the participants communicated. Due to the fact that interviews were held in family homes, they wanted to hear what was said. While the women did not participate in the study, they were present. The study provided rich data about the roles and duties of African American male caregivers.

Thirdly, studies on African American male caregivers are very limited. This study was designed to explore the role of African American male caregivers as they provided care to their father, mother, sister, companion, stepmother and non-relatives. This study lends itself to further exploration to include studies on care receivers admitted to nursing homes, and the role of married African American male caregivers who are sandwiched between providing elder care and care for children under 18 years of age.

### Summary

This study attempted to fill some gaps in the research literature on caregivers, especially among African American males. Women are generally viewed as caregivers.

Study participants were 20 African American men ages 50+ years of age who were caregivers for elder individuals 55+ years of age. The elder persons receiving care were the caregivers' mother, father, step-mother, sister, brother, companion, church member, aunt, extended family member, or fictive kin.

This study explored caregiving through the use of the exchange theory. The exchange theory focuses on how relationships develop, how relationships are experienced, the patterns and dynamics that emerge within ongoing relationships, and the factors mediating the stability of relationships (Sabatelli & Sheehan, 1993). In this study, formal and informal caregivers provided assistance with basic personal hygiene, transportation, grocery shopping, meal preparation, socialization, medical care, and bill paying.

Study participants were recruited from research recruitment flyers, community presentations, and the snowball sampling method. The sample size was sufficient for this qualitative study. Great caution was taken to protect each study participant from unethical research issues. Each participant signed a consent form prior to starting the research. Participant confidentiality was maintained by assigning a numerical code to each participant. Data were collected through face-to-face interviews. Participants were interviewed and responded to demographic and qualitative questionnaires developed by the principal investigator. Interviews were audiotaped and transcribed by the principal investigator. Interview transcripts were coded, analyzed, and recoded to look for emerging themes. The transcripts were placed aside and reviewed later. To check for study validity, the principal investigator involved three readers as expert members in reviewing transcribed participant responses. The professor expert members were two doctoral level professionals in Family Sciences and one aging professional.

Participants ranged in age from 50 to 81 years. A total of 40 % of participants were 50-54 years of age, 15% who were 55 to 59 years of age, 30% of participants were 60 to 64 years, and 15% who were 65 years or older.

Participants had annual income earnings of \$12,000 -\$70,001+. One participant declined to provide annual income information. They were typically highly educated. The educational levels of participants ranged from grade school to postgraduate degrees.

Mothers received 38% of the care provided by African American male caregivers, and fathers received 9% of caregiver assistance. Ninety participants reported that they provided transportation. Additionally 75% of caregivers provided some form of medical care, and 70% cooked for those they were caring for. A total of 35% assisted in grooming duties, 50% helped with finances, and 95% performed shopping duties. Finally, 30% assisted with feeding, 25% assisted with toileting, and 20% assisted with bathing.

Participants indicated they received little or no type of caregiver training. Seven participants received basic caregiver training, 11 participants used lifelong experiences when they provided care, and eight participants used simple trial and error.

Four major themes which emerged in this study were personal choice as a caregiver, non-traditional caregiver roles, skill malfit, and range of duties as a caregiver. With personal choice, study participants indicated whether the decision to be a caregiver was a personal choice. Participants took on their caregiving role without any reservations or concerns about their ability to provide care to their mother, father, sister, aunt, companion, brother, church member, stepmother, and non- related individuals. Many caregivers did not plan to become caregivers. Non-traditional caregiver roles looked at

what males did to adjust their roles and responsibilities to be caregivers. Men are not typically seen in the role of caregiver. Skill malfit looked at how the caregivers perceived their skill level when providing care to care receivers. Many of the participants in the study expressed discomfort with performing some tasks. The areas of discomfort included taking care of their parent's personal hygiene such as bathing and dressing. Range of duties performed by the caregivers were task caregivers performed. These tasks were based on the needs of the care receivers. Some duties included transportation, personal care, shopping, socialization, home repairs, vehicle maintenance, writing checks, and yard work.

This study indicated that caregiving men took on the role of caregiver for their father, mother, sister, companion, stepmother, and non-relatives. While study participants were asked about their income, they were not asked about their total household income.

Three men were long distance caregivers who contacted their mothers daily in Florida, Mississippi, and New York. These men relied on help and support from extended family members, neighbors, friends, and fictive kin residing near their mothers. One had additional responsibilities as they were sandwiched with taking care of children under 18 years of age.

In this study, these African American males were actually in the role of caregiver.

Roles and expectations changed as males evolved in their caregiver role. This study will definitely add to the body of caregiving research.

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# APPENDIX A PARTICIPANT RECRUITMENT FLYER



# YOU CAN BE A PART OF A STUDY OF AFRICAN AMERICAN MALE CAREGIVERS

# You are a caregiver if you:

- Are male and 50+ years of age
- Care for a 55+ year old elderly parent, neighbor, spouse, partner, friend, play mother/father, brother, sister, step parent or grandparent
- Provide assistance with bathing, toileting, dressing, grooming, meals, house/yard work
- Provide assistance with medication/medical appointments, meal preparation and feeding, financial matters, social outings, transportation, bill paying

Our conversation about your experience as a caregiver will take about 90 minutes to complete at a location convenient for you. Please phone me so I can tell you more.

Janice F. Moore, M.S., CFLE Investigator

Joyce Armstrong, Ph.D., CFLE Advisor

# APPENDIX B IRB RECOMMENDATIONS



#### **Institutional Review Board**

Office of Research and Sponsored Programs P.O. Box 425619, Denton, TX 76204-5619 940-898-3378 Fax 940-898-3416

e-mail: IRB@twu.edu

August 29, 2008

Ms. Janice F. Moore

Dear Ms. Moore:

Re. Caregiving: An Exploration of African American Male Caregiver Roles in Texas

The above referenced study has been reviewed by the TWU Institutional Review Board (IRB) and appears to meet our requirements for the protection of individuals' rights.

If applicable, agency approval letters must be submitted to the IRB upon receipt PRIOR to any data collection at that agency. A copy of the approved consent form with the IRB approval stamp and a copy of the annual/final report are enclosed. Please use the consent form with the most recent approval date stamp when obtaining consent from your participants. The signed consent forms and final report must be filed with the Institutional Review Board at the completion of the study.

This approval is valid one year from August 29, 2008. According to regulations from the Department of Health and Human Services, another review by the IRB is required if your project changes in any way, and the IRB must be notified immediately regarding any adverse events. If you have any questions, feel free to call the TWU Institutional Review Board.

Sincerely,

Dr. David Nichols, Chair

Institutional Review Board - Denton

of J. Michels

enc

cc. Dr. Larry LeFlore, Department of Family Sciences
Dr. Joyce Armstrong, Department of Family Sciences
Graduate School



#### Institutional Review Board

Office of Research and Sponsored Programs P.O. Box 425619, Denton, TX 76204-5619 940-898-3378 Fax 940-898-3416 e-mail: IRB@twu.edu

August 18, 2009

Ms. Janice F. Moore

Dear Ms. Moore:

Re: Caregiving: An Exploration of African American Male Caregiver Roles in Texas

The request for an extension of your IRB approval for the above referenced study has been reviewed by the TWU Institutional Review Board (IRB) and appears to meet our requirements for the protection of individuals' rights.

If applicable, agency approval letters must be submitted to the IRB upon receipt PRIOR to any data collection at that agency. A copy of all signed consent forms and an annual/final report must be filed with the Institutional Review Board at the completion of the study.

This extension is valid one year from August 29, 2009. According to regulations from the Department of Health and Human Services, another review by the IRB is required if your project changes in any way. If you have any questions, feel free to call the TWU Institutional Review Board.

Sincerely,

Dr. David Nichols, Chair

Institutional Review Board - Denton

cc. Dr. Larry LeFlore, Department of Family Sciences Dr. Joyce Armstrong, Department of Family Sciences Graduate School

# APPENDIX C CONSENT FORM

## TEXAS WOMAN'S UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

Title: Caregiving: An Exploration of African American Male Caregiver Roles in Texas

Investigator: Janice F. Moore, B.S.W., M.S... Advisor: Joyce Armstrong, Ph.D......

Explanation and Purpose of the Research

You are being asked to participate in a research study for Janice F. Moore's dissertation at Texas Woman's University. The purpose of this research is to examine the role of African American male caregivers in Texas. In particular this study will examine how African American males enter caregiving relationships, how they view themselves as caregivers and the role they take on as caregivers.

#### Research Procedures

The principal investigator and two assistants will conduct face-to-face interviews with African American male caregivers. The interviews will take place at a private location agreed upon by you and the investigator. Your maximum total time commitment in the study is approximately 90 minutes. There are no direct benefits for participating in this study. You will be audiotaped during the face-to-face interview. The purpose of the audiotaping is to provide a transcript of the information discussed in the interview and to assure the accuracy of the reporting of that information.

A code number, rather than your real name, will be used on the audiotape and transcription. Only the investigator will have access to the tapes. The tapes, hard copies of transcriptions, and the computer diskettes/ flashdrives containing the transcription text files will be stored in a locked filing cabinet at the investigator's home. The tapes, and transcription diskettes/flashdrives will be erased and the hard copies of the transcriptions will be shredded within 7 years. It is anticipated that the results of this study will be published in the investigator's dissertation as well as in other research publications. However, no names or other identifying information will be included in any publication.

Please share information about yourself as you provide services to the elderly. This section will consist of questions pertaining to your providing care to individuals' age 55+. The second section will be a series of qualitative questions pertaining to the person

Participant Initials
Page 1 of 3

receiving care. The researcher will ask you those questions. Your responses will be recorded on a tape recorder.

#### Potential Risks

There are potential risks related to your participation in this study. However, TWU does not provide medical services or financial assistance for injuries or counseling that might happen because you are taking part in this research. Loss of confidentiality is a potential risk. Confidentiality will be protected to the extent that is allowed by the law. Participants' names or other identifying information will not appear on any research publications. The principal investigator will store data in a locked file cabinet. Only the investigator will have access to the stored data. All identifiable data will be shredded in seven years. There is a potential risk of confidentiality in all email, downloading, and internet transactions.

Other potential risks related to your participation in this study include emotional and personal discomfort, fatigue, loss of anonymity and loss of time. Recalling personal and family information may cause some personal discomfort during the interview. If you feel any emotional or personal discomfort and wish to discontinue the study, you may stop at any time. To avoid fatigue, you may take a (break or breaks) during the interview as needed. You may stop answering any of the questions at any time.

The investigator will provide you with a referral list of names and phone numbers that you may use if you feel as though you need to discuss your emotional discomfort with a professional. To reduce loss of anonymity, principal investigator will assign numeric codes to each participant.

To reduce loss of time, principal investigator will start and end the interview session on time. Another potential risk is coercion. All potential participants may choose not to participate in the study. Participants may stop at any time during the study without penalty.

Another potential risk is loss of anonymity and loss of confidentiality during interview scheduling. To reduce the loss of anonymity and loss of confidentiality during scheduling, principal investigator will schedule different meeting rooms at staggered times if more than one participant will be interviewed. Each participant interview will take place in a designated area. Principal investigator will provide specific room location when interviews are scheduled.

Participant	Initials

#### IRB Contact Information

If you have any questions about the research study you should ask the investigator by calling the number at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research and Sponsored Programs at 940-898-3378 or via e-mail at IRB@twu.edu You will be given a copy of this signed and dated consent form to keep. If you would like to have the results of this study mailed or emailed to you, please supply your name, mailing address, or email below following your signature. The area for your mailing or emailing information is identified below.

Signature of Participant	Date
Request to receive a summary of the re	sults of this study
Initials:	
Address:	
City, State, Zip:	
Email:	

# APPENDIX D COUNSELING REFERAL LIST

### Counseling Referrals

Counseling Institute of Texas 705 W. Avenue B, Suite 200 Garland, Texas 75040 http://www.CITexas@aol.com (972) 494-0160

Crisis Counseling & Crisis Line P. O. Box 800742
Dallas, Texas 75380
(972) 233-2233 24-Hour line http://www.contactdallas.org

Legacy Counseling Center 4054 McKinney Ave, Suite 102 Dallas, Texas 75204 (214) 520-6308 http://www.legacycounseling.com

Texas Woman's University
Counseling and Family Development Clinic
http://www.twu.edu/cope/famsci/clinic/index.htm
Denton, Texas
(940) 898-2600

University of North Texas-Dallas Counseling Center 8915 S. Hampton Road, Ste. 215 Dallas, Texas 75232 (972) 780-3646 http://www.coe.unt.edu/CDHE/Centers.htm

Veterans Affairs, Department of North Texas Health Care System

4500 S. Lancaster Dallas, Texas 75216 (214) 742-8387 24-Hour line http://www.north-texas.med.va.gov

# APPENDIX E DEMOGRAPHIC QUESTIONNAIRE INSTRUMENT

# CAREGIVING: AN EXPLORATION OF AFRICAN AMERICAN MALE CAREGIVER ROLES IN TEXAS

# DEMOGRAPHIC QUESTIONNAIRE INSTRUMENT 1 PARTICIPANT ID Number

Please share information about yourself as you provide services to the elderly.

This section will consist of questions pertaining to your providing care to individuals age 55+.

The second section will be a series of qualitative questions pertaining to the person receiving care. The researcher will ask you those questions.

Your responses to the questions will be recorded on a tape recorder.

PART I. CAREGIVER	
1. What is your zip code?	_
2. What is your age?	_
3. What is your annual income?\$0-\$12,000\$12,001-\$20,000	
\$20,001-\$30,000	
\$30,001-\$50,000	
\$50,001-\$70,000	
\$70,001+	
3b. From what source?	
4. Are you retired?Yes No	

106

5. Do you work full-time?YesNo
5b. If no, what part of the time do you work?%
6. What is the highest level of education you have completed?
Grade school
Some high school or less
High school
High school graduate
Some college-no degree
Two year college Major
4 year college degree Major
Some postgraduate work Major
Postgraduate degree  Major
7. Are you an informal caregiver (not receiving pay)?YesNo
8. Are you a professional caregiver (working for pay) for the elderly?YesNo
9. Is caregiving a second role for you?YesNo
9b. If no, what type of work do you do?
10. How many people do you care for?  107

	ny hours /week	of caregiving servi	ce do you provid	e each week?		
		come or salary from	n			
12b. If y			y from caregiving \$/month	g, how much do you receive		
13. How far	do you t	ravel to provide care	e?			
	0 m	iles; they live with	me			
-	_ 1-15 n	niles				
	16-30 miles					
<u></u>	_ 30+ m	iles				
	_ Anothe	er state.				
How	long doe	es it take you to trav	vel there?hrs			
		PART II. ROLES	S AND RESPON	SIBILITIES	]	
14. Who are	you cari	ng for?				
		Gender	Age	Relationship		
Pe	erson	Male/Female	(years)	to you		
1						
2					$\dashv$	

	3					
	What duties do yo	ou perform as a care	egiver?			
_	Bathing		Feeding			
	Shopping	Financial	Grooming		*	
,	Cooking	Medical	Transportation	i		
	Socialization	Other, please	specify			
	PART III. TR	AINING				2 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1
16.	What type(s) of the	raining have you ha	d in working with	n the elderly	?	
17.	Was the training Yes	formal (attended a s No	special class spon	sored by an	agency)?	
18.	Was the training	informal (provided	by a visit?	Yes	No	
19.	Check the trainin Basic caregiv	g you received as ir ving	ndicated below	V.		
	Lifelong exp	eriences/self taught	:			
	Trial and err	or/experimenting				
	Read bo	ooks				
	Caregiver su	pport group				
	The state of the s	eotapes, films, DVI	Ds, listened			

Internet/on-line modules	
One-on-one training provided by medical staff	
Other, please specify	

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# APPENDIX F QUALITATIVE INSTRUMENT 2 ROLES AND RESPONSIBILITIES

# CAREGIVING: AN EXPLORATION OF AFRICAN AMERICAN MALE CAREGIVER ROLES IN TEXAS QUALITATIVE QUESTIONS

## INSTRUMENT 2 PARTICIPANT ID

#### PART I. ROLES & RESPONSIBILITIES

- 1. Tell me about your caregiving experience.
- 2. How did you get selected to be a caregiver?
- 3. How did you start your journey as a caregiver?
- 4. How would you define your role as a male caregiver?
- 5. Has your income changed because of your caregiving role? If so, please explain.
- 6. How does your day start?

## PART II. PERCEIVED CAREGIVER ROLE

- 7. Describe the person you are caring for and the task you perform as a caregiver. Tell me about the daily challenges you face in doing these daily tasks.
  - a. What task do you think male caregivers should do for the person they are taking care of?
  - b. Do you think these tasks are appropriate for male caregivers? Why? Why not?
  - c. What tasks do you think are appropriate for male caregivers?
  - d. What type of personal obstacles have you encountered as being a male caregiver? Do you feel comfortable doing tasks such as bathing, toileting,

combing hair, putting on clothing, meal preparation, socialization, conversation, etc.? Tell me about the tasks you feel comfortable with and what you do not feel comfortable with.

8. What do you perceive as some challenges in getting the person you are caring for ready to go to the doctor's office, hair appointment, visiting family/friends, etc?

### PART III. RENEWAL, BALANCING WORK AND FAMILY LIFE

- 9. Tell me how you handle situations as they arise?
- 10. Do you have responsibilities along with working full-time or part-time outside of the home such as caring for children under 18 years of age on a daily basis? If so, what do you do on a daily basis for the children under the age of 18?
- 11. What kinds of issues do you see in trying to manage both of these roles?
- 12. If you are a professional caregiver, what happens when you are not there? How is care managed?
- 13. If you work part-time or full-time describe how you provide care for the person when you are not there?
- 14. When you are not available to provide care, what do you do?
- 15. What do you do after work?
- 16. What is involved in the activities you do after work?
- 17. Does the person you care for go with you to do these activities?
- 18. Are there any stressors in providing care?
- 19. What does your weekend look like?
- 20. How do you relieve stress and relax on a daily basis?
- 21. What types of things do you do to get renewed?

#### PART IV. AFTERCARE

- 22. If the person you care for has to go to a nursing home, will you continue caring for them?
- 23. What does nursing home placement mean for you as an informal caregiver? What do you see your role as?
- 24. Is there anything you believe your community, social service agencies, places of worship, neighbors, etc. can help or assist you with in your role as an African American male caregiver?
- 25. Do you have any additional information to share at this time about your role as an African American male caregiver?

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# APPENDIX G LETTERS FROM AGENCIES

Date: 30 August 2007

To: Taxas Woman's University Research Team

From: Julia Pathams

Subject: Permission For Conducting Research

## PERMISSION FOR CONDUCTING RESEARCH

Permission has b	een granted t	to Janke F. M	ore, a doctor	ral student at	Texas
Woman's Univers	ity, to collect	data on Africa	in American i	nale caregiver	is for the
purpose of invest	ligating the ro	de of African A	merican mal	e caregivers.	
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Date	· ·			THE STATE OF THE PARTY OF THE P	and the same of the same of

#### PERMISSION FOR CONDUCTING RESEARCH

Permission has been granted to Janke F. Moore, a cochoral stronger at years
Women's University, to conect data on African American Hale earlighest for the
purpose of Wwestigating the total of African American male caregivers.
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sgranue from the Western
File
Organization Librar Foreign Participal Popular
Anthers 1374 Boylow Cambril S. A. F. Carks, 1754
Date

### PERMISSION FOR CONDUCTING RESEARCH

Permission has been granted to Janice F. Moore, a doctoral student at Texas
Woman's University, to use the DaiVis Public Library to collect data on African
American male caregivers for the purpose of investigating their role as
caregivers.
Name (Please pripe) Touta Huskay
Signature Mule Haskey
Title Mendge
Organization Styline February
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Comment of the second