Religion and Spirituality as Resources

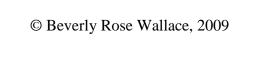for African American Families in End-of-Life Care

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Abstract

Many studies evidence the rewards and challenges involved in providing care for family members at the end-of-life. Some studies have suggested that any differences that may exist in caregiving might be related to how families of diverse backgrounds assess the caregiving experience. Such research indicates that African Americans appear to appraise the caregiving task differently than other caregivers. Such research also suggests that African American caregivers' faith and their religiosity or spirituality attribute to the different appraisal.

One of the criticisms germane to end-of-life research is that some studies do not make clear distinctions or define fully religion and spirituality. Further, few studies have examined the role of religion and spirituality and their influences relevant to African American caregivers' care decisions for family members approaching the end of their lives using caregivers' voices. This study aims to address these research gaps by examining caregivers' narratives disclosing themes relevant to understanding how African American caregivers talk about, understand, and utilize religion or spirituality as resources in end-of-life caregiving.

This current study is part of a larger qualitative study conducted by Dr. William Turner (2004) that sought to understand end-of-life caregivers' decision-making processes in African American families. The research paradigm was primarily interpretive science utilizing a phenomenological methodological approach. Fifty in-depth interviews were held with caregivers to understand the caregivers' role and the processes of decision-making germane to the care of an ill or deceased family member.

The data was collected through the use of an active interview method. A reflective approach was used to allow participants to explore emotional, social, cultural, and systemic factors relevant to their experiences of caregiving and decision-making. For this study, thematic analysis was employed to examine and to identify themes, patterns, and behaviors to describe how African American caregivers experience religion and spirituality as resources in end-of-life care.

The results of this study are categorized into three major themes: (a) how African American caregivers "lived" their religion or spirituality; (b) how African American caregivers utilize religion or spirituality resources; and (c) how African American caregivers use theological understandings as a resource.

The results of the analysis suggest that religion and spirituality can be both positive and negative resources for African Americans caregivers caring for loved ones who are facing the end of their lives. While many caregivers reported attending church, prayer, their spirituality, and reliance on the church community to be helpful, not every caregiver reported the use of these religious resources or reported that their utilization of religious resources, including the use of clergy, to be helpful. This study reports only about the people who were interviewed, and is not necessarily the experience of all African Americans.

In understanding caregiving within the context of the African American family, the power of cultural mandates and religious and spiritual beliefs were found to be important variables to consider. Examining the lived experience of caregivers is essential and assessing caregivers' theological understandings of religion, spirituality, concepts of life and death, and their theological understanding of care is critical.

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CHAPTER ONE

Attending church, praying, and reading the Bible have been among the many religious and spiritual activities engaged in by African Americans as they have negotiated their lived experiences in America. In times of hardships and crisis, it has been their faith that has assisted African Americans in "making a way out of no way." The current era finds many baby boomers caring for their children and for their parents. Growing disparities in positive health outcomes for African Americans make it more likely for African Americans to be sicker, to need care, and to die faster and at a younger age; the question thereby is raised as to the role of religion and spirituality as resources for African American families in caregiving situations.

A mounting interest in end-of-life issues has seen increasing numbers of researchers investigating how families make care decisions (Aranda & Knight, 1997; Byock, Norris, Curtis, & Patrick, 2001; Hudson, Aranda, Krisjanson, 2004; Leichtentritt & Rettig, 2001; Poorman, 1994). Coupled with the growing understanding of health disparities in minority populations, end-of-life concerns in African American families have led some researchers to undertake the task of uncovering how African American families make decisions about how to care for family members (Born, et al., 2004; Connell & Gibson, 1997; Cort, 2004; Crawley, Payne, Bolden, Payne, Washington, & Williams, 2000; Pierce, 2001;Turner, Wallace, Anderson, & Byrd, 2004). A culturally-sensitive understanding of African American care decisions includes consideration of the importance of religion and spirituality in the care decision process. This study is designed to explore this phenomenon.

Purpose of the Study

A few years ago, Turner, et al. (2004) conducted research to examine African American family decision-making at the end-of-life. The study included an exploration of the role of religiosity and spirituality in the decision-making processes. The present study's purpose is to examine the participants' narratives from Turner's study to expose themes relevant to the understanding of how African American family members talk about, understand, and utilize religion or spirituality as a resource in caregiving. It is not the intent to suggest that narratives reported here are normative for all African Americans but it is the intent of this study to share the stories and the experiences of the African American individuals interviewed.

Significance of the Problem

Historically, African American families care for loved ones at the end-of-life rather than use nursing homes or other palliative care facilities for support (Wimberly, 1997). In other words, African American families have traditionally ascribed to the cultural precept "to care for their own" rather than place their family members in alternative care facilities especially at the end-of-life (Wimberly, 1997). However, unlike in the past, African American families today rely on varied combinations of support that include formal services as well as the family to care for family members (Roschelle, 1997). In addition, some African Americans are saying that they would prefer to die in the hospital rather than at home (Neubauer & Hamilton, 1990). These shifting trends in ideologies beg the question of what other traditional norms have changed and what new norms, if any, are relevant to religion and spirituality in African American families providing care.

Ward and Carney (1994) describe "caring" as a transitional process that begins with resistance to the inevitability of the caregiver role and ends with the acquiescence to it. In other words, family members come to know that part of their responsibility and obligation is to care for other family members and so they assume caregiving tasks. Eventually, the task may become second nature and part of the caregiver's daily life.

Yet providing care is not always easy. Studies abound on the phenomenon of caregiving burden (Beach, Schultz, Yee, & Jackson, 2000; Connell & Gibson, 1997; Pruchno & Resch 1989; Schulz & Beach, 1999). Many of these studies evidence the challenges involved in providing care for loved ones. Some of these studies have also suggested that any differences that may exist in caregiving might be related to how families of diverse backgrounds assess the caregiving experience (Cox, 1999a; Picot, Debanne, Namazi, & Wykle, 2002;Wykle & Segal, 1991). Such research indicates that African Americans appear to appraise the caregiving task differently than other caregivers (Cox, 1999a; Picot, et al., 2002). The Cox (1995a) study that examined caregivers' experience with dementia patients found that African American caregivers appraised patient-related problems as less stressful. Reported variations in caregiving burdens as well as rewards were related to caregivers' subjective experiences as well as to the amount and type of social support received (Goldstein, Concato, Fried, Kasl, Johnson-Hurzeler & Bradley, 2004). Caregivers' spirituality was reported as a major factor and means of social support that mitigated the burden of caregiving for some African American caregivers (Born, et al., 2004; Smerglia, Deimling, & Baresi, 1988; Wykle & Segal, 1991).

Religiosity and Spirituality as Resources for African American Families at the End-of-Life

Spirituality and religiosity are already known to be important variables to consider in the study of African American family life. Even with the common belief among social scientists (Billingsley, 1992; Boyd-Franklin, 1999; Brashears & Roberts, 1996; Lincoln & Mamiya, 1990) that religion and spirituality are the means by which African American families cope, to make general statements that African Americans are spiritual or that religion is important to African Americans does not capture the intricacy in understanding the role of religion and spirituality within the African American context.

Religiosity and spirituality are multifaceted constructs. The construct of religiosity is a complex phenomenon that includes behaviors, attitudes, values, beliefs, feelings, and experiences (Taylor, Mattis, & Chatters, 1999). Taylor and Chatters (1991) suggest that there are various dimensions of religiosity that can be expected to operate in unique ways with respect to outcomes such as social support and personal adjustment. "Distinctions between different dimensions of religiosity," says Taylor and Chatters (1991) "provide the specificity in delineating the functional attributes and consequences of various forms of religious involvement" (pp.103-4).

The construct of spirituality is also complex with varied definitions. Clemmons (1991) understands spirituality as the internal ongoing quest for self-knowledge that includes recognition of a higher power's presence. Paris (1995) defines spirituality as "the animating and integrative power that constitutes the principal frame of meaning for individuals and their collective experiences" (p. 22). Mattis (1997) defines spirituality

as an individual's belief in the sacred and transcendent nature of life manifested in a sense of connectedness with others - humans, the spirit, and God.

Often the construct of spirituality is defined in relationship to religiosity. In developing a further understanding of the concept of spirituality, Mattis (2001) suggests that spirituality and religiosity are not the same but rather distinct and overlapping experiences. Elkins and colleague (1988) also suggest "although religion provides a framework for the expression of spirituality, spirituality is more basic than, prior to, and different from traditional expressions of religiosity" (p. 7).

One of the criticisms germane to research studies on end-of-life has been that some researchers have not clearly made the distinctions nor fully defined the constructs of religion and spirituality in their studies (Flannelly, Weaver, & Costa, 2004). Further, few studies have examined the role of religion and spirituality and their influences relevant to African American caregivers who are making decisions about family members approaching the end of their lives. This study will address these gaps in the literature.

<div align="center">Research Question & Paradigm</div>

The primary research question addressed in this study is:

What are the roles and functions of religion and spirituality in the lives of African Americans who are caring for family members at the end-of-life? Specifically, this study will focus on the articulated religiosity expressed by the participants of this study and will uncover cues in understanding their spirituality. This study will also examine how these reported functions of religiosity and spirituality might be understood in terms of the distinctive areas of religiosity and spirituality to the extent these come up in the

interviews. The research paradigm for the present study is primarily interpretive science utilizing a phenomenological methodological approach.

Interpretive Science - Phenomenological Methodology

A phenomenological method was employed in interviewing the participants of this study. According to Kvale (1996), a phenomenological perspective includes a focus on the life world, openness to the experiences of the subjects, a primacy of precise description, and a search for essential meanings in the description. The goal is the description of the experiences and an understanding of the meaning of the experience.

This phenomenological approach attempts to understand people's perceptions, perspectives and understanding of a particular situation (Leedy & Ormrod, 2001). Life experiences are examined in an effort to give the experiences meaning and understanding (Lipscomb, 2003). By looking at multiple perspectives of the same life situation, the researcher can collect data and make generalizations about what the experience is like for those who have experienced the same situation (Lipscomb, 2003). A phenomenological study attempts to answer the question: "What is it like to experience the particular phenomenon?" (Leedy & Ormrod, 2001, p. 153).

The phenomenological researcher collects data almost exclusively by interviewing a selected sample of people who have experienced the same occurrence. Questions are developed to probe the feelings, thoughts, concerns, or worries related to the life event. Lengthy interviews are then conducted with extensive notes taken. In this study, an interview guide was developed by the principal investigator, Professor William Turner and the interviewer, Beverly Wallace (see appendix A).

In phenomenological studies, the interviews often resemble conversations with the research subject doing most of the talking and the interviewer probing for more information (Lipscomb, 2003). The researcher is careful to keep the focus on the research issues, avoiding influence on the participant in any way. The interviewer is also free to follow the lead of the interviewee to probe their lived experiences.

The researcher in this study is African American. She is also an ordained Lutheran pastor with several years of experience as a hospital chaplain. Her past experiences of being with and assisting families with life decisions put her in the position of being culturally aware of some of the dynamics and nuances that are particular to the population under study. Such knowledge and expertise is potentially beneficial in articulating and suggesting interpretations of the findings.

The task of analysis follows the data collection process. Analysis begins when one separates relevant information from that which is irrelevant so as to get a sense of what is being said. Common themes and issues are identified and categorized into "meaning units" (Lipscomb, 2003). The researcher examines the meaning units carefully in an attempt to identify convergent and divergent perspectives. General theories are developed from the common themes and issues. Conclusions are drawn based on the key themes identified that give a general description of the phenomenon as represented from the research participants' perspectives (Lipscomb, 2003).

There are several advantages to utilizing a phenomenological research approach. First, a phenomenological approach identifies deep issues and expresses the feelings of participants. With such an approach, one can determine key themes or issues experienced or perceived by a group in a given situation. Second, a phenomenological

approach can expose taken-for-granted assumptions or can challenge the status quo and bring valuable insights into the life issues being researched by emphasizing the participants' personal perspectives. Finally, a phenomenological research approach can question old assumptions about life experiences from the perspective of those who have experienced it firsthand.

This phenomenological approach was chosen because it allowed for an examination of how African American family members experience the phenomena of caregiving and the process of deciding how to care for ill family members. This analysis of religion and spirituality taps only a fraction of the phenomenology of the people interviewed. This analysis, however, allows for the exploration of this phenomenon as participants explain their lived experience of caring for an ill family member.

CHAPTER TWO

Review of the Literature

This chapter begins with a review of literature relevant to religion and

spirituality as used in the study of African American family life. A comprehensive

literature search of various databases (PsycoInfo 1998-2007, the Family Studies

Database 1970-2007, and BioMed) resulted in a vast amount of literature on religion

and spirituality. As such, only a brief review of current trends and what is known about

religion and spirituality as it relates to African American families will be presented

here. A literature review relevant to end-of-life caregiving in the African American

community will follow. Literature germane to caregivers' experiences in general and

then literature specifically applicable to ethnic communities and those books, book

chapters, and articles related to African American caregivers' experiences will then be

reviewed. How studies of end-of-life in the African American community have been

conducted, specifically the methodologies employed will also be examined. This

chapter will conclude with a review of available literature that has examined the role

and function of religion and spirituality for African American who are caring for family

members at the end-of-life.

Current Trends Relevant to Religion and Spirituality and the African American Family

Religion and spirituality have always been important concepts to consider in

understanding African American family life (Billingsley, 1992; Boyd-Franklin, 1999;

Brashears & Roberts, 1996; Lincoln & Mamiya, 1990). Consideration of these

concepts help to explain how African American families have historically used their

faith and belief in God to assist them in dealing with the many adversities they have faced in being Black in America (Billingsley, 1992; Lincoln & Mamiya, 1990).

This section reviews research that examines African American religion and spirituality. The following aspects of religion and spirituality will be explored: a) how the terms religion and spirituality are defined in the literature, b) who's religious, and c) the characteristics of religiosity and spirituality relevant to the African American family context.

How Religion Has Been Defined

A review of the literature reveals that the concept of religion has been utilized and understood in a variety of ways. Lincoln and Mamiya (1990) define religion as essentially a subjective experience. From their perspective, the experience is personal and viewed from the standpoint of the individual. Carlson, Kilpatrick, Becker, and Killer (2002) define religion as "the formal institutional context for spiritual beliefs and practices" (p.157). Here the understanding is that religion is the place where spiritual beliefs and practices can take shape. Lunn (2003) defines one's religiosity as being related to or manifesting faithful devotion to owns acknowledged ultimate reality or deity. Mattis, Taylor, and Chatters (2000) define religiosity in terms of individual constructs: organizational, non-organizational, and subjective religiosity.

Organizational religiosity refers to behaviors that occur within a church context, mosque, or other religious setting. Such behaviors include church attendance, membership, or participation in church groups. Non-organizational religiosity utilizes religious practices that are tied more to a person's traditional understanding of the importance of their faith (Taylor, Mattis, & Chatters, 1999). Such behaviors occur

outside of a formal religious setting (Taylor, et al., 1999). Non-organizational religiosity is less social in nature and instead emphasizes individual faith practices including private devotional practices, reading religious materials, watching or listening to religious programs, praying, and requesting prayer (Taylor & Chatters, 1991). Subjective religiosity is defined as an attitudinal measure of religious involvement and is measured by such questions as perceived importance of religion, the role of religious beliefs in the individual's daily life, and the individual's perceptions of being religious (Chatters, Levin, & Taylor, 1992; Levin, 1997). McAdoo (1995) further defines subjective religiosity as a person's religious orientation.

Who's Religious?

Researchers have uncovered several predictors of who's religious and the amount of their religious participation within the African American context. Gender is the strongest and most consistent demographic predictor of religious participation (Levin & Taylor, 1993; Levin, Taylor & Chatters, 1995; Mattis, 2001; McAdoo, 1995; Taylor & Chatters, 1991). African American women are more religious and participate in religious activities more often then African American men (Levin &Taylor, 1993; Levin, et al, 1994; Mattis, 2001; McAdoo, 1995; Taylor & Chatters, 1991). Older African American women are also reported to have higher levels of religious involvement (Levin, Taylor & Chatters, 2004; Mattis, 2001; McAdoo, 1995).

Age, marital status, socio-economic status and regional differences are other additional considerations (Chatters, Levin, & Taylor, 1992; Levin, Taylor & Chatters, 2004; Mattis, 2001; McAdoo, 1995; Taylor, 1988b, 1986; Taylor & Chatters, 1991). Married individuals, for example, report higher levels of church attendance and

membership (Taylor, 1988b, 1986), and African American individuals with higher

socio-economic status are found to have higher levels of religious participation than

their poorer and unmarried counterparts (Taylor & Chatters, 1991). Persons with higher

levels of education and income are also more likely to be religiously affiliated. Regional

differences show African Americans who live in the southern part of the country report

higher religiosity than individuals living in the northeast (Chatters, et al., 1992). These

demographic findings indicate that African Americans are diverse in their levels of

religious involvement.

Characteristics of Religiosity and Spirituality

Characteristics of religiosity and spirituality consider how religious or spiritual

individuals are, how often people attend religious services, what religious or spiritual

activities individuals engage in, and how often they pray. Characteristics of religiosity

and spirituality also consider the function that religion and spirituality perform. This

section reviews literature relevant to these characteristics. Aspects of religiosity will be

organized around the concepts of organizational, non-organizational, and subjective

religiosity.

Organizational Religiosity. Current research indicates that a large proportion of

the African American community attend worship services on a regular basis (Taylor,

Chatters, & Levin, 2004). Based on the National Survey of Black Americans and other

national probability samples, about two-thirds of the African Americans report that they

are church members. More than 40% report that they attend church at least once a week

and 70% of African Americans indicate that they attend religious service a few times a

month (Taylor et al., 2004). Elderly African Americans report higher levels of church attendance and participation than younger African Americans (Taylor, et al., 2004).

Non-Organizational Religiosity. Non-organizational religiosity refers to behaviors that may involve private devotional practices, reading religious materials, watching or listening to religious programs, praying, and requesting prayer (Taylor, et al., 1999). Prayer was found to be the primary activity in which African Americans engage (Johnson, Elbert-Avila, & Tulsky, 2005; Taylor & Chatters, 1991). Taylor and Chatters (1991) found that nine out of ten individuals indicated they prayed nearly everyday. About 48% of those who never attended religious services also indicated that they prayed everyday (Taylor & Chatters, 1991). Older African Americans were found to pray on a more frequent basis than their younger counterparts, women prayed more than men, and widowed persons prayed less often than married respondents (Taylor & Chatters, 1991; Taylor, et al., 2004).

African Americans read religious material and listen to and view religious programs. Taylor and colleagues (2004) noted that 44% of African Americans reported reading religious books on a daily basis. In one study, older persons with poor health were more likely to view and listen to religious programs than their healthier counterparts (Taylor & Chatters, 1991). African Americans with higher educational levels were less likely to engage in this activity (Taylor & Chatters, 1991). However, the relationship between educational levels and reading religious materials varied regionally. Chatters, Levin and Taylor (1992) found a positive association with southerners' levels of education and the reading of religious material. No relationship was found among respondents who resided in other regions. It was also found that non-

organizational behaviors were important outlets for religious expression for individuals in poor health (Taylor & Chatters 1991).

Subjective Religiosity. Subjective religiosity is defined as the attitudinal measure of religious involvement (Levin, 1997). In the Taylor and Chatters study (1991), a majority of African Americans still considered themselves religious whether or not they attended church. Taylor (1988) found that more than 40% of respondents who had no religious affiliation and over half of those who never attended religious services indicated that they were either very religious or fairly religious. Married respondents were found to demonstrate higher levels of subjective religiosity, as did women and older African Americans (Taylor, 1988b). African Americans also indicated that they would often seek spiritual comfort and support when confronted with problems regardless of whether they attended worship services (Taylor, Chatters, & Levin, 1995). This was especially the case for individuals with lower income levels and for African Americans living in rural areas (Rosen, 1982). Yet a more recent study (Mattis, Mitchell, Grayman, Zapata, & Taylor, 2007) found that this was not necessarily the case with requests for support from clergy, such requests depended on the nature of the support needed.

Spirituality in the African American Community. Spirituality has also been understood in a variety of ways. According to Powell and colleagues (Powell, Shahabi, & Thoresen, 2003), spirituality overlaps religion but is also distinctive from religion. Clemmons (1991) understands spirituality as the internal ongoing quest for self-knowledge that includes recognition of a higher power's presence. According to Kaut (2002), spirituality may be viewed as a gestalt – the summation of diverse aspects of life

that collectively give meaning to one's existence. Spirituality enables healthy and active investment in life and provides the resources through which one can respond to infirmity, physical decline, and approaching death. Bowen-Reid and Harrell (2002) suggest that spirituality represents "the divine expression and belief of a higher power that governs one's existence" (p. 21), while Mattis (2000), understands spirituality as an "individual's belief in the sacred and transcendent nature of life manifested in a sense of connectedness with others, humans, spirit, and God" (p. 118).

From a theological perspective, Bridges (2001) defines spirituality as the foundation of African American culture, their religion, and their struggle for freedom. She suggests that spirituality informs African American worldview - why African Americans do what they do. However, Paris (1995), another African American theologian, believes just the opposite. He believes that it is African Americans' worldview or cosmology that informs African Americans' spirituality. As suggested by Powell and colleagues, studies with clear distinctions in the constructs are needed (Powell, et al, 2003, p. 50).

Research has shown that spirituality is important for the role that it plays in allowing people to experience connectedness (Pierce, 2001). Healthy spirituality results in a sense of belonging, acceptance, respect, well-being, and inner peace (Pierce, 2001). Research has also shown that African Americans' spirituality serves as a buffer between racism and stress-related health outcomes (Bowen-Reid & Harrell, 2002). Mattis (2001) found that African American women's spirituality, more specifically, "spiritual surrender" - that of turning things over to a higher power - assisted with African American women's meaning-making and coping with life situations. This spiritual

surrender required women to confront and relinquish their limitations. This spiritual surrender however enabled women to "gain the insight, protection and guidance needed to envision and achieve outcomes that they would not have been able to see or achieve on their own" (p. 11).

Religiosity and Spirituality as Sources for Informal Social Support

The above review illustrates that regardless of whether individuals consider themselves religious or spiritual, both constructs perform functions for individuals living their lives. Religious behaviors such as attending church, for example, provide a means for informal social support. Powell and colleagues (2003) found that regular church attendance encouraged meaningful social roles that provided a sense of self-worth and purpose through the act of helping. Taylor and Chatters (1988) found that non-involvement excluded individuals from the traditional spiritual, social, and supportive functions of the church. Religiosity therefore appears to improve people's opportunity to receive support especially when they either attend church frequently or are official members of a congregation (Taylor & Chatters, 1988).

Pierce (2001) understands that spirituality plays an important role in connecting people. As a component of well-being based on values of commitment, love, and affection, spirituality is also believed to reduce the perceived stressful situations of caring and is an important reason given as to why, particularly with African American families, members assume the caring role. Archbold (1995) suggests that spirituality is composed of formal Christian beliefs and the secular value of care for one's own and suggests that one's spirituality is an important reason for African American family members' provision of care. This study explores these assumptions.

Review of the Literature on End-of-Life Studies

This section includes a review of the literature on end-of-life studies. The section begins with a general overview of studies and follows with a review of studies relevant to end-of-life in ethnic communities, end-of-life studies specific to the African American community, and a review of the research methodologies used in studies on end-of-life germane to the African American context.

Studies about End-of-Life - General

The literature in the area of end-of-life issues has been growing steadily. The term itself has been conceptualized in a number of ways and there appears to be no one definition of this construct. Studies often consider the plight of aging and elderly members of families and communities (Cicirelli, 2000; Connell, & Gibson, 1997; Dilworth-Anderson, Williams, & Cooper, 1999; Lawton, Rajagopal, Brody, & Kleban, 1992; Miller, Randolph, Kauffman, Dargan, & Banks, 2000; Tan, Lui, Eng, Jha, & Covinsky, 2003; Wimberly, 1997). Additional research has also explored the young whose life expectancies might be shortened due to illness (Rainer & McMurry, 2002; Williams, 2004). End-of-life studies have also been examined in terms of family members with chronic or terminal illnesses (Turner-Musa, Leider, Simmens, Reiss, Kimmel, & Holder, 1999). The National Cancer Policy Board (2003) has defined end of life as "the period of time during which an individual copes with declining health from an ultimately terminal illness, from a serious though perhaps chronic illness, or from the frailties associated with advanced age even if death is not clearly imminent" (p. 23).

The impact of illnesses and the nature of care, as they impact individuals and families, have been examined in several research studies (Carten & Fennoy, 1997;

Goode, & Haley, 2001; Rainer & McMurry, 2002). These investigations include

examining barriers to optimum care for individuals and families (Krakauer, Crenner, &

Fox, 2002; Winston, Leshner, Kramer, & Allen, 2005). Studies have also examined

caregivers' psychological, social, and health problems (Owen, Goode, & Haley, 2001;

Redinbaugh, et al., 2003). Changes in the interactions between the care recipient and the

caregiver have also been researched in the study of end-of life issues (Rainer &

McMurry, 2002).

Additional research has also included uncovering the values and decisions of

how care is provided for loved ones who are elderly or ill (Leichtentritt & Rettig, 2001;

Turner, et al., 2004). Studies of decisions about how to sustain life and decisions about

life-sustaining treatments (Baker, 2000; Poorman, 1994) have also provided information

on end-of-life care. More recently, studies are being generated to look at how to develop

competency in the provision of end-of-life care (Christ, 2005; Conner, Egan, Kwilosz,

Larson, & Reese, 2002; Mitchell, Bennett, & Manfrin-Ledet, 2006; Stein & Sherman,

2005).

Studies about End-of-life in Ethnic Communities

A growing number of studies examine various aspects relevant to race and

ethnicity issues in the context of end-of-life care. A variety of areas relevant to ethnic

communities and end-of-life have been researched. Researchers have studied attitudes

toward life-sustaining technologies (Born et al., 2004), attitudes toward patient

autonomy (Martin–Combs & Bayne – Smith, 2000), physician-patient communication,

(Hudson, Aranda & Kristjanson, 2004), alternative decision making alternatives

(Carten, & Fennoy, 1997; Waters, 2001), dying on one's own terms (Becker, 2002), and

barriers to optimum care for minority patients (Krakauer, Crenner, & Fox, 2002). Connell and Gibson (1997), for example, in their decade review of studies examined the impact of race, culture and ethnicity on the dementia caregiving experience and found that non-White caregivers were less likely to be a spouse, reported lower levels of caregiver stress, burden and depression, and were more likely to use coping strategies that included faith or such religious practices as prayer. Kwak and Haley's (2005) literature review where race or ethnicity was examined to uncover what is known about diversity in research on end of life decision-making found that differences between groups existed. They suggest that variations within groups were related to cultural values, demographic characteristics, level of acculturation, and knowledge of end-of-life treatment options. All of these studies indicate that there are differences in the way that ethnic communities understand and experience end-of-life issues.

Werth and his colleagues' (2002) examination of cultural diversity influence on end-of-life care and care decisions offers guidelines for culturally-sensitive end-of-life care that include considering sociopolitical and historical factors that influence beliefs about illness, health care, and death; determining the locus of decision making; assessing patients and families' religious beliefs, and focusing on meanings, including the idea of hope and how hope is maintained. Kwak and Haley (2005) suggest that that there is still limited evidence to guide the development of culturally sensitive approaches. There is therefore a need, as noted by several researchers (Crawley, Marshall, Lo, & Loenig, 2002; Kagawa-Singer & Blackhall, 2001; Kwak & Haley 2005; Werth, et al., 2002), for further attention to be paid to cultural issues in order to provide strategies for effective end-of-life care.

Studies about End-of-Life in the African American Community

African American families are one ethnic community that has been examined regarding end-of-life issues. Such studies have examined how aging family members are cared for (Barrett, 2001), how African Americans are living with terminal illnesses (Carten & Fennoy, 1997; Williams, 2004), and how coping strategies are employed in end-of-life planning and care decisions (Owen, Goode & Haley, 2001; Turner, et al., 2004; Waters, 2001; Winston, et al., 2005).

Owen, Goode, and Haley (2001) for example, found that African American caregivers of family members with Alzheimer's disease were less likely than European-American caregivers to make decisions to withhold treatment when the family member was approaching the end of life, were less likely to have their family member die in a nursing care facility, were less accepting of their relative's death, and also perceived the loss as great.

Several studies have focused on African Americans' mistrust of hospice and in the use of hospice (Cort, 2004; Reese, Abern, Nair, O'Faire & Warren, 1999; Winston, et al., 2005). Additional studies on cultural differences in the end of life experience, for example, noted barriers to African Americans' consideration of hospice care for terminally ill patients (Connell & Gibson, 1997; Crawley, et al., 2000). Decision-making differences between family-based versus individually-based caregiving decisions was noted. The barriers also included differences in how African Americans embrace death where embracing hospice would mean acceptance of death. African Americans would therefore choose not to use hospice.

Born and her colleagues' (2004) study of African American and Latino families'

knowledge, attitudes and beliefs about end-of-life care also noted that African American

families' low use of hospice care was due primarily to limited awareness of hospice,

lack of trust in the health care system, and also due to health care costs that limited their

use.

Two recent articles examine attitudes toward palliative care. Crawley and her

colleagues (2000), in their article "The Initiative to Improve Palliative and End-of-Life

Care in the African American Community", summarize various to barriers to good end-

of-life care. Historical memories of the unfair treatment of African Americans in

medical institutions, unequal access to hospice and palliative care facilities,

socioeconomic factors, and varied views about death and dying including incompatible

goals of palliative care where African Americans may view death and suffering as not

to be avoided but to be endured as part of their spiritual commitment are barriers to

palliative care. Winston and colleagues (2005) also highlighted these competing values

and understandings. Their research indicated that while African American families

preferred to provide care for their loved ones, the families also desired a means for

reducing caregiving burden and would have been receptive to palliative care if it

included relief caregivers, emphasis on family consensus, and an appreciation of

families' spirituality. These contrasting views warrant further investigation.

Quantitative and Qualitative End of Life Studies

Research on end-of-life issues included both quantitative and qualitative

methodologies. Andershed (2006) conducted a systematic literature review on relatives

or caregivers in end-of-life care. Of the 94 studies she examined, 59 were qualitative

studies and the remaining 39 were quantitative studies. Only twenty-four of the studies were published in the United States (11 qualitative and 13 quantitative).

In line with the distribution of U.S. published studies, Andershed's review found that the majority of studies that have examined end-of-life in the African American community have also used primarily quantitative methods, with a growing number employing qualitative methodologies (Pierce, 2001; Waters, 2001; Williams, 2004). The qualitative-methods studies used focus groups, individual interviews, and observations as means of collecting data. Waters (2001) conducted focus groups to understand end-of-life care planning and decision-making. She found focus groups to be helpful for obtaining information relevant to African American beliefs that dictate decisions on end-of-life care and planning. Reese and colleagues (1999) used a mixed-method approach in their study of African Americans' access to hospice. Participatory action research project engaged community members in their research activities with the hopes of using the knowledge for change in service approaches. The study's qualitative portion of the study consisted of interviews with six African American pastors to obtain information about African Americans families' beliefs about and utilization of hospice care. They found both approaches useful in framing the research questions and for gathering additional information about the community's limited hospice use.

Williams (2004) conducted in-depth interviews with 33 low-income, terminally ill cancer patients, 23 of whom were African American. She explored how terminally ill individuals interpreted and made meaning of dying poor at an early age. Williams' grounded theory approach enabled individuals to interpret their own life events, to

construct meaning from everyday experience, and to obtain information about patients'
own end-of-life experiences. These studies illustrate that qualitative methodologies are
an effective means of obtaining rich sources of information relevant to the study of end-
of-life care in the African American family and community. Yet, as noted by Sinclair
and her colleagues (2006), in their review of the literature on palliative care, many of
these qualitative studies suffer from methodological issues and poor designs. There is a
need, they suggest, for more rigorous studies of the phenomena.

Studies on Caregivers

A number of studies examined caregivers' roles relevant to end-of-life issues.
Studies focused on caregivers' general well-being and coping, and caregivers' stress
and care burden (Aranda & Knight, 1997; Stull, Kosloski, & Keacher, 1994; Roscoe,
Osman & Haley, 2006; Wetle, Shield, Teno, Miller & Welsch, 2005). Andershed (2006)
in her review of the literature, places caregivers' studies into two primary categories –
the caregivers' "situation" and the caregivers' "needs". Most of the research has
highlighted the caregivers' "situation".

The caregivers "situation" can be defined in terms of how caregivers function
with the caregiving role. This includes role mastery and role burden. Lazarus and
Folkman's (1984) transactional stress and coping model acknowledges that family
dynamics and family members' unique responses to caregiving affects family members'
psychological response to the caregiving situation. Much of the research in this area has
informed our knowledge regarding the experience of caregiving.

Several researchers have examined caregivers' role mastery (Cox, 1995a;
Lawton, et al., 1992) and the quality of the caregiver-care receiver's relationship

(Cicirelli, 2000). Braithwaithe (2000), for example, found that those caregivers high on psychiatric symptoms were likely to have a more dysfunctional and less loving relationship with the care receiver. Researchers have also examined the rewards of caregiving (Kinney & Stephens, 1989; Lazarus & Folkman, 1984; Picot, et al., 1997). Kinney and Stephens (1989) proposed that there are "uplifts" in the caring experience that may prevent caregiving stress from dominating the caregivers' life.

Other researchers have examined factors associated with caregiver burden. Goldstein and colleagues (2004) found that the caregiver's feelings and perceptions of burdens, caregivers' social support system, and caregivers' restricted activities were important considerations. They found, for example, that young caregivers, because they were not prepared for the responsibility, expressed increased feelings of burden. Highly emotional caregivers, caregivers in poor health or with low mastery and low self-esteem appear to struggle in their caregiving tasks and were unable to utilize social support. Caregivers' restricted personal and social activities also led to increased caregiving burden. Caregivers with high task demands felt less positive about life but, interestingly enough, were not necessarily likely to complain of burden or were likely to manifest psychiatric symptoms (Goldstein, et al, 2004).

Increased severity of the patient's illness, poor caregivers' health, more limited social networks, and the gender of the caregiver - specifically being female - were found to be associated with increased caregiving burden (Braithwaite, 2000; Pruchno, 1989; Sulik, 2007; Zariet, 1980). Braithwaite's study (2000) suggested that caregivers' resiliency was associated with less burden. She found that caregivers with low

resilience did not have the personal resources necessary for adapting to their stressful

caregiving situation.

Caregivers' "situations" can also be defined in terms of nature of the caregiving

situation. Researchers have studied caregivers caring for a chronically ill member

(Haley, Allen, Reynolds, Chen, Chen, & Gallagher-Thompson, 2002; Hudson, et al,

2004; Lawton, et al., 1992; Miltiades & Pruchno, 2002; Owen, et al, 2001; Peterson,

Sterling & Weeks, 1997; Pierce, 2001). Hudson and his colleagues (2004) found that

caregivers' circumstances and feelings of burdens also impacted care. Wetle and her

colleagues (2005) examined family perspectives of end-of-life care experiences in

nursing homes. They found that family members had to be vigilant because of the lack

of attention dying family members were receiving in nursing homes during the end-of-

life period. This lack of attention added additional stress on caregivers. Several other

studies also looked at caregivers for terminally ill family members (Goldstein, et al.,

2004; Hudson, et al., 2004). These studies reported similar findings. Caregivers'

interpretation of situational events is critical for providing stress reduction.

The second category of caregivers study focuses on caregivers' "needs". Rosco

and her colleagues (2006) examined cargivers' needs in the Terri Schiavo's case.

Families provide the majority of care for chronically ill individuals, thus end-of-life

caregiving and decision making are among the most stressful events in family life, they

suggest (p. 151). Families' provide care because of their sense of attachment, cultural

expectations, and a preference for avoiding institutional care. Hospice caregivers, they,

report show high rates of depression, low life satisfaction, and poor health. (p. 151).

Families need emotional and practical support when making life and death decisions for

their loved ones. Caregivers' needs are often overlooked. However, a few studies have examined caregivers' needs.

Andershed's (2006) review of end-of-life literature found that caregivers' needs included the assurance that their family member received high-quality care and that the patient's wishes were respected (Andershed, 2006). Hudson's study (2004) echoed Andershed's and found that caregivers do not want to put their needs before the patient's. This finding might suggest some unarticulated caregiving needs.

Research on caregivers' needs has also highlighted the significance of social networks, and caregiver's physical and psychological health. Waldrop and her colleagues (2005) examining caregivers' transition to end of life caregiving, suggest that resources such as religion, and faith practices as well as social support were extremely important. Waldrop (2006) in a separate study found that friends' social support were often derived from faith communities suggesting again that social support is a core element of end-of-life care.

Studies on Caregivers in the African American Context

Increasing number of studies have examined caregiving within the African American family context. Some studies have suggested that there are differences in who African American caregivers are and how African American caregivers experience their caregiving roles (Connell & Gibson, 1997; Braithwaite, 2000; White, Townsend, & Stephens, 2000; Sarkisian & Gerstel, 2004). Studies have found that African American caregivers are more likely to be an adult child, another family member, or a friend, and are less likely to be a spouse (Connell & Gibson, 1997). Caregivers are also more likely to be cared for by a member of their extended family (Peek, 2000). African American

caregivers appear to appraise their situation as more rewarding, with less stress, and fewer depressive symptoms (Braithwaite, 2000; Connell & Gibson, 1997; White, et al., 2000), and higher levels of overall coping mastery than white caregivers (Haley, et al., 2002). The study by White and colleagues (2000), for example, found that African American women reported less stress and reported more role rewards when caring for a mother or mother-in-law.

However, a number of other studies found no differences in the amount of stress experienced by African American caregivers in comparison to European American caregivers (Cox, 1993; Young & Kahana, 1995; Wood & Parham, 1990). Young and Kahana (1995), for example, suggest that factors such as caregivers' age, hours spent providing care, and the care recipient's physical condition eliminate any racial or ethnic differences. Sarkisian and Gerstel (2005) suggest that family structure and not ethnic differences that account for differential responses to stress. Several other researchers suggest it is the caregiver's values and religiosity that mediates the differences in how African American caregivers handle their caregiving roles (Aranda & Knight, 1997; Dilworth-Anderson & Anderson, 1994; Picot et al., 1997; Segall & Wykle, 1988). Many of the studies appear to be comparative in nature. Additional studies are needed to look specifically at the caregiving roles, situations, and needs.

Studies Relevant to Religion and Spirituality and End-of-Life Care in the African

American Community

With much of the research highlighting the importance of religion and spirituality, the nature of these constructs as it relates to African American caregivers' situations, needs further examination. This section will note studies relevant to religion

and spirituality and end-of-life care and then studies specifically within the African American community.

In a decade review of literature published in three palliative care journals, one hundred and fifty-five articles addressed religion or spirituality to some extent (Flannelly, et al., 2004). About 30 of the articles (20.2%) were research articles, with 12 studies including religion or spirituality as the primary focus of the investigation. Many of the studies published examined religion and spirituality as resources for coping with the care of ill or terminally ill individuals (see review by Powell, et al., 2003).

Lunn (2003) describes the role of spiritual resources in end-of-life care. Although spiritual care can be done in the context of religious faith and ritual, it is not synonymous with religious faith, doctrine, or beliefs, she suggests. She argues that spiritual resources provide one with the principles and tools needed to deal with conditions and challenges of everyday life. Spiritual resources for Christians, she says, may include prayer, regular bible reading, receiving Holy Communion, and participation in a faith community.

Other studies have examined the roles of religion and spirituality as they inform coping strategies (Kaut, 2002; Miltiades & Pruchno, 2002; Moritz, et al., 2006; Picot, et al., 1997; Pierce, 2001; Sinclair, Perieira, & Raffin, 2006; Sprung, et al., 2007; Thune-Boyle, 2006). Sinclair and his colleagues (2006) conducted a review of the literature related to spirituality within the palliative care field. They found 58 articles that fit their inclusion criteria. Six themes emerged from the literature review including the effects of religion in palliative care. Of the 58 articles, three studies focused on this particular theme and found that strong religious convictions and belief in an afterlife were

associated with less anxiety and acceptance of death. The studies also found that religious belief had a substantial positive correlation to life satisfaction, while religious activity was correlated significantly to life satisfaction and happiness. The review also focused on spirituality as it impacted the patient and not necessarily the caregiver.

Thune-Boyle and colleagues (2006) examined whether religious and spiritual coping strategies affected illness adjustment in cancer patients. They found that religious/spiritual coping might serve multiple functions in long-term adjustment to cancer. Seven studies of the seventeen they examined found some evidence for the beneficial effect of religious coping. One study, however, found religious coping to be detrimental in a sub-sample of their population. Three studies found religious coping to be harmful and seven found non-significant results. Thune-Boyle and colleagues also noted that many of the studies suffered from serious methodological problems, especially in the manner in which religious coping was conceptualized and measured. Sprung and colleagues (2007) examined physician's religiosity on end-of-life decisions in a European setting and noted that there were significant differences associated with religion, religious affiliation, and culture.

Several studies explored the role of religion and spirituality in regards to African American families' end-of-life issues (Branch, Torke, & Brown-Haithco, 2007; Johnson, Elbert-Avila, Tulsky, 2005; McClain, Rosenfeld, & Breitbart, 2002; Martin-Combs & Payne-Smith, 2002; Owen, Goode, & Haley, 2001; Reese, et al., 1999; Waters, 2001). Johnson, Elbert-Avila, and Tulsky (2005) conducted a review of the literature on the influence of African Americans' spiritual beliefs and practices preferences. They reviewed thirteen articles addressing spiritual beliefs specific to end-

of-life decisions. Common themes included the belief that only God has the power to decide life and death and a belief in divine intervention or miracles. Additional themes included prohibitions against physician-assisted death, including advance directives, and the importance of spiritual beliefs as a source of comfort, guidance and support. They suggested that spiritual beliefs strongly guide many African Americans as they cope with illness. Moreover, these studies document the importance of spirituality for some African Americans in making decisions about end-of-life care.

Branch and his colleagues (2007) also reported the importance of spirituality in African Americans' end-of life experiences. While Branch and colleagues did not define specifically define what they meant by spirituality, they did find that prayer, faith in God's plan, and a sense of an ultimate connection to God helped patients tolerate their situation.

Wallace (2004) reviewed several studies for their conceptualization and measurement of religion and spirituality as it related to end-of-life research on African American family life. The review revealed that religion and spirituality can be categorized in terms of its essential nature as cultural resilience and their effects can shape African American values and cultural expression, and as it relates to end-of-life care can impact decision-making.

McClain, Rosenfeld, and Breitbart (2002), for example, examined terminally ill cancer patients' end-of-life despair. They found that spiritual well-being meant finding meaning in one's life and that spiritual well-being protected against despair and hopelessness for those patients where death was imminent. Owen, Goode, and Haley (2001) explored care for family members with Alzheimer's disease and reactions to

death. They did not directly define the terms of religion or spirituality but measured instead the concepts in terms of participants' utilization of clergy persons. They reported that African Americans were less likely than whites to seek clergy assistance.

Martin-Combs and Bayne-Smith (2000) conceptualized religion in terms of non-organizational religiosity. They investigated which non-institutional practices and beliefs contributed to quality of life satisfaction, and they found that prayer and watching religious programs aided in positive quality-of-life for dying family members. Reese and colleagues (1999) researched African American families' access to and use of hospice. They defined religion in terms of the historical importance of religion in African American family life. Their study found that participants prayed for a miracle rather than accepted terminality. Acceptance of terminality was seen as a lack of faith. Reese and colleagues also reported that African Americans' spirituality and involvement with a trusted family member, friend, or pastor helped mitigate their decisions to end life in cases of terminal illnesses.

McClain, Rosenfeld, and Breitbart (2003) found that spiritual well-being was a strong correlate of end-of-life despair. A positive view of the ultimate meaning and purpose for one's life was found to buffer the effect of depression and the desire for hastening death for those patients who were terminally ill. McClain and her colleagues also found that although many patients turned to organized religion, others reported obtaining support through their spiritual beliefs outside of the context of organized religion.

Waters (2001) looked at end-of-life planning, care choices, and decision-making. Using the terms religion and spirituality interchangeably, she found that

religion and end-of life care planning were paradoxically related. She found that while

the participants of the study believed in fatalism and divine intervention and had little

faith in health institutions, they also chose and desired aggressive medical treatment.

Studies Relevant to Religion and Spirituality and African American Caregivers

Only a few studies have examined the role of religion and spirituality relevant to

African American caregivers (Miltiades & Pruchno, 2002; Picot, et al., 1997; Pierce,

2001). These few studies found that religiosity serves as a positive coping resource for

African American caregivers.

Miltiades and Pruchno (2002) examined the effects of religious coping for

maternal caregivers of adults with developmental disabilities. Miltiades and Pruchno

conceptualized religion in terms of "religious coping", as an "uplift," an inner resource

that helped caregivers frame caregiving in a positive light. However, there was no

consideration of religion as a burden or additional obligatory responsibility. The

study's results showed that mothers expressed higher levels of religious coping, but

there was also a positive relationship between African American mothers' religious

coping and care giving burden. African American mothers reportedly had poorer health

and experienced higher levels of burden. In addition, the study found that religious

coping did not reduce African American mothers' caregiving burdens.

Picot and colleagues (1997) also examined the role of religion and its effects on

caregivers' appraisal of their situation. Comfort received from prayer, they found,

mediated the relationship between perceived rewards and race. Like Miltiades and

Pruchno (2002), Picot and colleagues found that African American caregivers perceived

that they received more rewards from their caregiving roles than their European

American counterparts. But they also found that caregiver's educational level made the difference. African Americans with more education, for example, appraised their caregiving role as less rewarding. A limitation of the study was that all religious indicators did not function as mediators in the same way. Picot and her colleagues suggested that separate analysis of religiosity indicators should have been conducted. In addition, while the study used a mixed-method approach, the study did not report qualitative findings.

Pierce's study (2001) qualitatively examined the construct of spirituality by exploring the lived experiences of African American caring for family members with strokes. Uncovering eight caring expressions of spirituality, Pierce noted that spirituality represented a "complex process in constant motion between caregivers and their environment within the caring situation" (Pierce, p. 344). Spirituality was the impetus for some caregivers' caring actions. In that study, caregivers' spirituality was reflected in how they lived, whereby caregivers accepted life as it was while they simultaneously hoped for whatever would happen in the future.

These few studies reflect the significance of and the importance of religion and spirituality in the lives of African American caregivers. These studies uncovered positive aspects of religion and spirituality for caregivers and looked for reasons why religion and spirituality were important and would be a stress deterrent or a stress buffer (Picot, et al., 1997). Yet the studies did not explore the full spectrum of emotions and lived experiences of caregivers' experiences, both positive and negative in terms of religion or spirituality. This proposed study will be unique because it will examine how African American caregivers - in the position of making care decisions at the end-of-life

- utilize religion and spirituality in their lives. The present study hopes to garner new and perhaps complementary theories using a qualitative research methodology regarding religion and spirituality of African American caregivers caring for family members at the end-of-life.

CHAPTER 3

Method

This study used a qualitative phenomenological research methodology. According to Kvale (1996), a phenomenological perspective includes a focus on the life world, an openness to the experiences of the subjects, a primacy of precise description, and a search for the essential meanings in the description. The goals of this research methodology include the description of lived experiences and a meaningful understanding of human experiences.

This study is part of a larger qualitative study that sought to understand end-of-life caregivers' decision-making processes in African American families. The larger study conducted by Dr. William Turner sought to understand end-of-life caregivers' decision-making processes in African American families. Three sources of grant money to Dr. Turner supported the project: (1) The University of Minnesota Agricultural Experiment Station, (2) The University of Minnesota Graduate School Grant-in-Aid, and (3) The University of Minnesota President's Multicultural Research Grant.

The author of this dissertation, who also worked as principal investigator's research assistant, administered all measures and conducted all but one of the interviews. Two other research assistants, Jared Anderson and Carolyn Byrd, also worked on this project.

Fifty in-depth interviews were held with caregivers regarding their role and the processes of decision-making germane to the care of an ill or deceased family member. Descriptive information about the caregivers can be found in Appendix B. Audio-taped and transcribed interview data were analyzed. A doctoral student transcribed the

majority of the interviews. The graduate student had extensive experience in the task of transcribing recorded data. Three undergraduate students also assisted in transcribing several tapes. The graduate student checked undergraduate students' transcriptions for accuracy. The interviewer reviewed all transcriptions to ensure that the interviews details and nuances were captured accurately. The transcriptions were coded and examined for themes that emerged from the interviews. Themes relevant to religiosity and spirituality are the focus of this dissertation.

Research Procedures

Research procedures include the recruitment procedures, criteria for inclusion in the study, and the interview procedures followed.

Recruitment

Participants for the study were recruited from three regions of the United States: the Northeast Region (New York City); the Southeast Region (Atlanta, Georgia, and two cities in North Carolina); and the Midwest Region (Minneapolis - St. Paul, Minnesota, and Chicago, Illinois). These areas were chosen in order to obtain a diverse sample in the African American community. The western part of the United States was not included due to funding limitations. Regional differences will not be examined in this current study.

Participants were recruited through contacts in various churches or community organizations located in the target cities. Names of potential participants were given to the interviewer. Participants were contacted by phone to schedule times and places for the interviews. Potential participants were given a brief explanation of the study at the initial contact; a more detailed explanation was provided at the interview. At the

interview, the interviewees were informed about the nature of the study and were given a written consent form to sign (Appendix C). Participants were then asked to sign a form indicating their awareness that they would be mailed $25.00 for their participation in the study.

Confidentiality

Participants were assured of confidentiality when asked to read and sign consent forms. The principal investigator, his research assistant, and a graduate student who assisted with the transcription were the only individuals with access to the interview tapes. All names were either altered during the transcription process or deleted. Only pseudonyms are used in this dissertation, with no disclosure of the participants' identity. After transcription, all tapes were placed in a locked file in the principal investigator's office and will be destroyed after five years.

Criteria for Inclusion in the Study

Participants that were included in the study self-identified themselves as African Americans who had cared or who were currently caring for a terminally ill family member. Participants were not of any particular religious background but indicated their faith tradition and denomination at the time of the interview.

The Participants

All participants that completed the interviews and the surveys were considered the sample of this current study. The total sample size was 50. Nine participants were male and forty-one were female. More detail information about the sample can be found in the results section in Table 1.

Qualitative Design

Interviews

Most interviews were held in the participants' homes. Several interviews were held in the classroom spaces of the church participants attended, the business offices where the participants worked, or at a location that was most convenient and comfortable for them. All of the interviews, with the exception of an elderly woman who needed assistance with reading the consent form, were done without the presence of others. The participants were then asked for permission to proceed with the interview, and all gave it. Most interviews took at least ninety minutes.

Interview Procedures

The data was collected through the use of an active interview method (Holstein & Gubruim, 1995).

The Approach. A reflective approach was used in the interview process to allow participants to explore emotional, social, cultural, and systemic factors relevant to their experiences of caregiving and decision-making.

The interview procedures followed the order of rapport-building, briefing, asking questions, and debriefing. This process was followed with all participants. Answers to questions on the interview schedule, although not necessarily obtained in the schedule's order were still all captured.

A relationship between the interviewer and the participant was first established in order to help set the participant at ease. The interviewer recognized the need to create a warm and comfortable environment that encouraged participants to share the full range of their emotions as they told their stories. This rapport-building was essential to

establish trust with the interviewer and the research process, and was accomplished by asking questions such as "how are you doing today?" or connecting statements such as "I really like your home." It was deemed important that the interviewer be of the same ethnic background as the participant to assist in the creation of this atmosphere. This philosophy is extremely important when working with African American participants as it is important to help the participant feel comfortable with the researcher. Having the researcher be of the same ethnic background can help with this.

The interviewer, an African American doctoral candidate in Family Social Science, is an ordained pastor and the author of this dissertation. As a hospital chaplain, she has had considerable experience in interviewing and talking with African Americans about grief and end-of-life issues.

Interview Content and Questions

A copy of the interview schedule is included in the appendix (Appendix A). Demographic information was obtained in the interview process. The participants were asked personal information about themselves including age, educational level, and the number of years living in the city in which they resided. They were asked about other household members and others who they considered close family members.

The interviewer then prompted the participants to tell the story of the family member who was the focus of the interview - the person for whom they had or were currently providing care. Because of the topic's sensitive nature, participants were reminded throughout the interview that they need not answer any questions or that they could stop at any time if the interview became too uncomfortable.

The nature of the illness was part of the story. Details of the decision-making processes were obtained. Content areas included the cause of illness or death, daily care activities, family involvement in the care, family-of-origin questions relevant to learning to care, negotiation of the health care system, negotiation with the insurance industry, questions of perceptions of racism and discrimination, projection of future care for self, and perceptions of the major issue of care-giving decision-making in the African American family and community. Information regarding participants' religious practices and issues related to participants' spirituality were also obtained in the interview. Questions asked to garner this information included: "How did your religion or spiritual practice assist you in your decision making process?" and "You mentioned that you attend church. Tell me how the church supported you and your family in all of this?"

Quantitative Design

A survey packet was given to the participants for completion at the end of the interview. The packet consisted of a demographic coversheet, the 10-item Justification for Care Survey; and Bonner and Ferran's 25-item Black Caregivers Trust in Physicians Scale. The Justification for Care Survey and the Black Caregivers Trust in Physicians Scale will not be discussed in this dissertation.

Data Analysis

Thematic Analysis

Thematic analysis was the primary technique employed to examine the research question. Thematic analysis focuses on identifying themes and patterns of living and /or behaviors (Aronson, 1994). Data is sorted into thematic categories. It is "a way of

seeing, as well as a process for coding qualitative information", according to Byrne (2001). This process of thematic analysis was used to describe how African American caregivers experience religion and spirituality as resources in end-of-life care.

Thematic analysis of data involves compiling answers to each interview question from all respondents and identifying categories for the responses given. The transcribed text is approached with a formal categorical system in mind: how respondents are reporting on issues of religiosity or spirituality as they cared for a family member at the end-of-life. Themes are uncovered as the narratives are read and re-read.

The first stage in this analysis aims to gain a sense of the whole story (Kvale, 1996, p. 194). Understanding participants' stories is necessary. All of the interview transcripts were read in order to get a full sense of participants' narratives.

Identifying meaning units is the second stage of this process. The "natural meaning" units as expressed by the participants are determined by the researcher (Kvale, 1996, p. 194). Notes were taken and significant aspects of the interview were highlighted so that important elements of the story could be realized.

Significant thematic units are uncovered during the data analysis. As quoted by Fereday and Muir-Cochran (2006), "themes are a pattern in the information that at a minimum describes and organizes the possible observations and at a maximum interprets aspects of the phenomenon" (p. 4). The responses are then thematized as understood by the researcher (Kvale, 1996) with minor themes clustered under categories of major themes.

Finally, the meaning units are synthesized. Themes are organized to reflect the experiences' meanings and essences and to create a narrative description of the experience. In this study, the narrative is of the caregivers lived experiences and the role and function of religion and spirituality in caring for a family member at the end of life.

Validity and Reliability

Throughout the entire process, the research is validated and reliability established. Reliability pertains to the consistency of the research (Kvale, 1996) and is used to counteract haphazard subjectivity (Kvale, 1996), though, as Kvale suggests, it might also counteract creative innovations and variability. Reliability is supported in this study by consultation with qualitative research experts who provided an independent assessment of the data presented.

Validation is the degree to which a method investigates what it is intended to investigate and the extent to which observations reflect the phenomena of interest (Sullivan, 2001). Validation is a process for developing sounder interpretations of observations. Miles and Huberman (1994) emphasize that there are no rules for establishing the validity of qualitative research, but validity is built into the research process with continual checks on the credibility, plausibility, and trustworthiness of the findings. To validate, therefore, is to check. The researcher adopts a critical outlook on the analysis, states explicitly his or her perspective on the subject matter studied, and identifies the controls applied to counter selective perceptions and biased interpretations (Kvale, 1996). In qualitative research, validity is related to the quality of the knowledge produced in the research study and to how one obtains the information from which suppositions are made (Kvale, 1996). In this study, care was taken in how the questions

were posed to the participants, in how the interviews were transcribed, and in the

interpretation of the findings. In addition, references will be made back to the literature

in order to make inferences about the validity of the narratives allowing the story to

"stand with merit" as is part of the process of thematic analysis (Aronson, 1994).

Quantitative Analysis

Quantitative analysis was also conducted. The quantitative analysis includes

basic descriptive statistics including the respondents' gender, age, educational

attainment, mean and modal income, relationship to the care recipient, length of

caregiving responsibility, denominations and faith traditions represented, as well as the

caregiving recipients' gender, age, and type and duration of illness.

CHAPTER FOUR

Results

Participants' Demographic Characteristics

The participants' demographic characteristics can be found in Table 1. Of the fifty participants, forty-three were women and seven were men. Subjects ranged in age between twenty and eighty, with a mean age of fifty-six. One individual did not indicate her age. Sixteen of the participants were single, and sixteen were married. Eighteen of the respondents were divorced, widowed or were widowers.

Two caregivers had less than a high school education and eight had either high school diploma or one year of college education. Ten respondents had at least two years of college and another fourteen had either a bachelor's degree or some graduate education. Two caregivers held a master's degree and one caregiver had post-master's education. Another five caregivers had Ph.Ds and another five of the respondents reportedly held a technical degree. Information on the educational level of three of the respondents is missing. All of the names of the participants have been changed for reporting their comments.

Twenty-one of the respondents were caring for their mothers and eight were caring for their fathers. Of the remaining twenty-nine caregivers, two respondents cared for a daughter and two respondents cared for a son. Six other participants cared for a sister with one caregiver responsible for her brother's care. Four respondents reported that they cared for a husband and one reported caring for his wife. One other respondent cared for an aunt and another for her cousin. Two caregivers reported caring for their

mother-in-law and grandmother respectively, while another respondent indicated that she cared for both her mother and her father.

Forty–one caregivers in this study indicated that they attended church. Almost all caregivers said that they were Christians with one participant not indicating the faith tradition to which they adhered. Participants were primarily Baptist (8), Lutheran (12) or non-denominational (10). Other denominational affiliations reported included Church of God in Christ/Church of God (3), African Methodist Episcopal/African Methodist Episcopal Zion or Christian Methodist Episcopal, (2), Presbyterian (2) and United Methodist (1). Nine participants reported no denominational affiliation.

Respondents also noted the faith traditions they practiced during their formative years. Several caregivers talked about how they explored other faith traditions as well as the importance of attending church. Brief examples of caregivers' faith traditions are noting here using pseudonyms of the respondents. Maurice, who talked about his caretaking experience with his mother, said that he and his family were raised Jehovah's Witness. Doris, who cared for her father, reported that though she grew up Baptist, she explored the Buddhist tradition. Sheila, who had cared for her sick and aging mother, attended an Episcopal church in her formative years. Grace, who also cared for her mother, said that she grew up with a strong Baptist background and joined a non-denominational congregation while in college. She indicated that attending church was an essential part of her life.

I grew up with a strong Baptist influence. During my college years I became a

part of the Church of Christ, that's a non-denominational New Testament based

Christianity. I was converted probably around the age of eighteen. I'm actually

attending that church, the first Church of Christ that I ever attended back in 1978. Still an active member there, and my husband also attend with me and it's a very central part of our life.

Will, who made care arrangements for his father with the assistance of his siblings, also talked about his family members exploring other faith traditions:

When I was a kid I was going to everyone's church and going to temple and my late uncle, the one that was always in trouble, when he was in jail one of the times he you know, became a Muslim and so I got to learn about that. And at one point I was looking at the Ba'hai faith and so I kind of was eclectic (laughs). I. Ecumenical? R. Yeah.

Yvonne, who helped her mother make care decisions for her grandmother, did not attend church on a regular basis. Yet for her, attending a "black church" was important:

I think we (attended) one other church, Ray's friend from college... They're black, they're African American… The church that they got married in it's not a black church, but they're blacks that go there, but it's not a black church, no. … All this new, new age, that just, that just, didn't do it for me.

Table 1

<u>Demographic Characteristics of Participants</u>

	N
Gender	
Male	7
Female	43
Marital Status	
Single	16
Married	16
Divorced	7
Widow/Widower	11
Age Distribution	
20's	2
30's	5
40's	13
50's	13
60's	8
70's	5
80's	3
Missing Data	1
Education	
Less than High School	2
High School	7
Some College	11
Technical School	3
Bachelor's Degree	12
Some Graduate School	2
Master's Degree	1
Graduate or Profess. Degree	4
Ph. D	5
Missing information	3
Person Cared For	
Mother	21
Father	8
Sister	6
Husband	4
Son	2
Daughter	2

Brother	1	
Grandmother	1	
Mother-in-law	1	
Mother & Father	1	
Wife	1	
Aunt	1	
Cousin	1	

Gender of Person Cared For
Male	16
Female	34

Attend Church
Yes	41
No	9

Faith
Christian	49
Missing Information	1

Denomination
AME/AME Zion/CME	2
Baptist	8
Church of God/	
God in Christ	3
Jehovah Witness	2
Lutheran	12
Presbyterian	2
United Methodist	1
Non-denominational	10
Not Applicable	9
Missing Data	1

The Care Arrangements

Information obtained from interviews revealed various care arrangements. Table 2 shows the distribution. Family members primarily provided care in a home setting. Sixty-four percent of the caregivers (n = 32) cared for their relative at the infirmed individuals' residence or at the home of the caregiver. This finding was not surprising, as there is the expectation that African Americans care for their own (Wimberly, 1997).

Thirty–six percent (n = 18) of family members were cared for in nursing homes or other

care facilities. Three caregivers who cared initially for their family member at home

eventually had to place their loved one in an alternative care facility.

Table 2

Distribution of Care Arrangements

Care at Home	32
Care in Care Facility	18
Change in Care Arrangements	3

The Care Decision

Participants expressed a variety of feelings expressed about the care decision.

However, many respondents did not report on the role strain or stress typically noted in

caregiving research. Many caregivers reported that they were all right with the

caregiving role. Ms. Conners, who cared for her bedridden husband, found it a pleasure

to attend to her husband's needs at home:

I think it's a joy for you to be able to (provide care). It's a joy if you're able to

do it because you can pray with them, sing with them and enjoy the time...

Having God in your heart will make things possible and one would not need to

place a loved one in a nursing home.

There were however, a number of caregivers who had difficulties in the caring process.

Fourteen of the caregivers reportedly struggled with care decisions and arrangements.

One caregiver, Cynthia, who cared for her husband at home before his death, made the

following observations about care arrangements:

You do what you need to do...you, just do. I know that it had its impact on

me…I know the feeling of being overwhelmed; the physical; you recognize a

sense of depression setting in. And perhaps this is the way I dealt with things all

my life is that you just keep on going. You don't have time to sit around and

analyze it and well "how am I feeling today." (laughter) You just keep on going,

but in the process you're losing something. It's the strain or whatever. It's

impacting you.

Another caregiver, Alice said this:

During the course of the time I was caring for my mother, I went through a lot of

emotional upheaval. For one, because I'm an only child; two, because my

mother and I didn't get along very well. We always had a very strained kind of

relationship. When I had to move over here (to stay with her mother) it didn't sit

well with me. I actually started to drink (laughs).

An issue for some of the caregivers was whether or not to place their loved one

in a care facility. Rose, for example, whose mother asked her to place her in a nursing

home, still struggled with the decision.

She kept asking me to put her in a home. And I didn't want to. I really had that

feeling that that's just shoving your family away and not taking responsibility in

caring for your elders by putting them in the nursing home. And so, I really

refused to do it. She spoke to the Pastor that we had at the time who began

saying, "Your mother really wants to go and she really should go. And you have

to let go."

For some caregivers, nursing home care was not an option. Will, a caregiver for his

father, replied to the question of the choice to place his father in a care facility in this

manner:

No that was never an option. It really never was even a possi(bility)- … I mean

maybe some families would have done that see, but it just never was an option

because one, we felt we had the capacity to maintain him at home. Two, he

wanted to be at home. He wanted to be on his own and at home. Three, the

doctors didn't feel that that was really needed. They said if anything, you might

want to think about hospice. And some of us felt strongly that yeah we should

do that but some of us didn't even feel that was something they wanted to do.

These diverse responses indicate that while most caregivers adhered to the idea that

African American caregivers care for their own, not everyone had that choice or made

that decision. The care decision for most caregivers - whether to give care at home or to

place the loved one in an out-of-home care facility - was not an easy one. Whether there

were struggles in the care decision or joy in caring for family members, religious and

spiritual resources, did, however impact how caregivers were sustained during the

caregiving process.

<center>*The Roles and Functions of Religion and Spirituality*</center>

Themes from the interviews relevant to the roles and functions of religion and

spirituality for African Americans caring for family members at the end-of-life were

coded primarily into three categories: (a) how African American caregivers "lived"

their religion or spirituality; (b) how caregivers utilized religion or spirituality as a

resource; and (c) how caregivers' theological understandings was a resource. Specific

sub-themes emerged in each of the categories.

The Lived Experiences

Caregivers' lived experiences included the religious experiences and the messages they received in their family of origin about religion and spirituality. The use of religious and theological language and the employment of Christian traditions in their everyday life were additional elements in this grouping. One could infer such influences in some cases, but in many of the cases, the impact of the experiences was spoken.

Family of Origin Religious Experiences

A majority of participants were influenced by Christian values in their formative years. Thirty-five caregivers indicated that they grew up attending church. Thus most respondents had some religious background that may have served as a resource for family care decisions and for providing care.

Patrice, for example, who cared for her dying mother, recounted how important going to church was for her mother's life as well as her own life during her early years:

My mom was always there. There was no outlet for her. Except she would go to

church on Sunday and sometimes she wouldn't go, but she would always send us.

And so I felt that - really feel like she made a great deposit in our lives… We really

didn't realize how much that had an impact in our life when we grew up.

Another caregiver, Paul, who said he attended church as a child, also expressed how significant it was for him:

The spiritual activity in our home was very important. (Mom) was a real stickler

for the community, for the family, and God and the local church.

Despite not adhering to any particular faith tradition, Yvonne said that her mother and grandmother's spirituality was also a part of her formative years:

> She was a … I wouldn't say a devout Catholic, but kind of the, kind of Catholic
> where she believed very strongly (and yet) she would be out all night the night
> before. That was just part of life, part of her outlook on life. Just had fun and
> drank and cursed (laughter). Then you went to church (laughing). You went to
> mass. …

One caregiver, Martha, who cared for her mother, said that it was in attending church
that she learned to care and gained the stamina to do whatever she had to do:

> … I have worked in church all my life and (so) I know that you can do all
> things through Christ who strengthens you. You can do the impossible. You can
> do whatever your mind tells you that can do. So…if you dedicate yourself,
> somehow or another He will give you the means to do it.

Paul, who cared for his mother, also talked about learning to care in the church and its
impact in the decision making process. When asked how the caregiving arrangements
for his mother were arrived at, Paul replied,

> It came about by early training. Our father taught us how to handle things,
> watching him, his example and then our spiritual background.

Even for those who did not now attend church, the values and influences from their
early years were still present. Sheila, who was caring for her mother and whose father
was ill too, said this about her parents' influence:

> …all the values and that my mother and father had instilled in us as far as to
> how to live right, take care of yourself, what's right, what's wrong (influenced
> her).

Alice, who reported not attending church during her early years, appeared to struggle

the most. Alice talked candidly about the difficulties of caregiving; these difficulties

were not typically voiced by other caregivers. She described the task in terms of its

"ugliness" and its "Hell".

> So I moved in and from that point on my aunties proceeded to make my life hell
>
> because nothing I did was right. … And that was just the first of a multitude of,
>
> uh, ugliness that I had to deal with during the caretaking of my mother. I mean it
>
> was, it was…..it was a great deal of hell for me for the most part in dealing with
>
> taking care of my (parents) because you know what they were saying to me was,
>
> "Well you know your father is, is, is just laying there in the bed, he doesn't need
>
> much help. Your mother's rolling around here with her eyes open.

Alice felt she served no real purpose. But she did believe that the caregiving role was

her responsibility. In her words, it was her destiny and a legacy that she was to uphold.

It could therefore be said that religion and spirituality were there for caregivers to use

and learn from, even for those individuals who fell away from the church.

Christian Traditions and Institution

Christian traditions were also part of some respondents' lived experiences.

Sixteen individuals talked about some sort of Christian ritual or practice in recounting

their caregiving experiences. Christian traditions included celebration of religious

holidays, religious rituals such as house blessings, and the use of Christian facilities

including Christian counseling resources. Godparents appeared to be an important part

of some caregivers' belief and support system. One caregiver, Pamela, for example,

talked about her dying cousin having godparents to help take care of her cousin's

surviving four year old daughter. Sharon, who continues to care for her mother with Alzheimer's disease, spoke of having her pastor bless her house. She also talked about using Christian counseling and looking for a Christian care facility for her mother. At least ten caregivers made reference to a religious holiday in telling their story. The mention of religious holidays as a point of reference might suggest that these Christian traditions were important.

Use of Religious and Theological Language

The majority of the respondents in this study used spiritual, religious, or theological language in recounting their care stories. A list of religious and theological terms used can be found on Table 3. Forty-five of the fifty caregivers used some sort of religious terminology during the interview. Such terms included: "God is Good," "Oh, my God," "Higher power," "Peace," "The Lord….," "My Lord," "Thank you Jesus," "My prayer," "God has blessed," "Predestined", and "Holy Spirit", and "Thank you Jesus".   Participants also employed language about God's faithfulness, the power of God, and God's awareness of their situation. Participants also used religious and theological idioms to support care and caring, with the language of thanksgiving expressed often. The use of the terms "spirit" and "Holy Spirit" were also used frequently. One might surmise from the ease by which religious and theological speech was used that this language was part of respondents' everyday lives.

Table 3

Religious and Theological Terms Used

All things work together for good
Amen
Asked the Lord for help

By the grace of God
Can't beat God giving*

Faith
Felt the Spirit of God

God has a way of working things out
God has blessed…
God is able
God is good all the time
God knows
God rest her soul
God spoke to her heart
God will make a way
My God

I can do all things through Christ…

Lord
Oh Lord
Oh my God

Open up to God's spirit

Thank God
Thank you Jesus

The Holy Spirit
The Lord put her there
The Lord worked it out
The Spirit of the Lord …

What ever you sow, you're going to reap**
With the help of the Lord
With the help of God

Utilization of Religion or Spirituality as Resources

The second thematic category is the utilization of religion or spirituality as a resource. According to resource theory, a resource is "any commodity, material or symbolic, that is transmitted through interpersonal behavior and is available as a means for positive or negative needs-satisfaction" (Foa & Foa, 1974, p. 34). Here I define resources as that which is available to provide needs satisfaction. Caregivers in this study described religion and spirituality as resources. The satisfaction of needs, both positive and negative, was examined.

Three major themes with several sub-themes emerged during this analysis of religion and spirituality. The Church as a resource was the first theme assessed in this category. The second major theme was that of the utilization of the church community as a resource. The use of religious or spiritual practices as resources was the third theme uncovered.

The Church as a Resource

The Church as a resource included attendance at a place of worship and any changes in church attendance.

Attendance at a Place of Worship. As noted above, the majority of caregivers grew up attending church. Church-going appeared also to be an activity of caregivers even during the period of caregiving. Of the fifty caregivers, only three reported not attending church on a regular basis. Five caregivers reported going to church more than once a week. Nancy, for example, who cared for her dying grandmother, talked about the relief she found when she attended church multiple times during the week:

On Wednesday night, there was a church around the corner from my house that I

had been to a couple of times, but they had a service on Wednesday. So I would

go there every Wednesday. … And even on Monday night they had an hour

prayer service and I would go there ... And then my church, we have a Thursday

night (service), I would go out to church but it really helped (be)cause normally

I may go to church like twice a week, once a week. But I found (laughter) I had

to go to church. And that's what people don't realize. You have to have that

outlet. You have to go to church. You have to take the time to be in God's

presence, you know, just so your spirit is being filled so you're not getting

depressed or, anything like that.

Renita, who cared for her sick and aging mother, also reported her own need to attend

and be active in her church. Renita said that her nerves were bad, but her attendance and

active participation in the life of her church helped her.

But not all caregivers who went to church attended there for support. At least

one respondent said she went for a variety of other reasons other than personal support.

Eve said the following:

I don't come to the church for support. I come to the church for fellowship,

praise, worship, (and) a word from God. That's what I come for.

Yet the majority of caregivers utilized the church as a supportive resource.

Change in Church Attendance. It would be expected that with the responsibility

of the caregiving task, there might be some change in the amount of time caregivers

would have available to attend church. This was not necessarily the case. Most of the

respondents did not report a change in their church participation.

Several of the caregivers could attend church because they had other family members available to assist them with caretaking task. Martha, who cared for her mother, said that she was able to attend church on Sundays and talked about the ability to engage in other activities because she received her extended family members' help. When asked if she wished her siblings would assist her more she responded:

> No, I had two brothers and then, and a sister, two and I had to work and she (her sister) couldn't hardly work. They all help, you know. She (her mother) really didn't tie me down, because I did my bowling (laughter). My brother wasn't working so Tuesday morning he would come down and keep her and I'd go bowling and on Thursday he'd come down and keep her and I'd go bowling … and on Sunday we went to church.

For eight caregivers, however, there was some change during the caregiving period. Tasha, a 21-year old who took care of her father while she attended college full-time, seemed to be too overloaded to attend church as often as she desired.

> I don't really go because Sunday's my day .…I would usually get back.…I don't know like maybe 3 or 4 (o'clock), and after that would go work out and do like just my catch up time, because usually I don't do my homework. (when she's caring for her father in his home).

At least three caregivers noted that they had difficulty attending church on certain days. Carrie, in talking about her husband's care and death, recollected her response to her mother's death and the changes in her church attendance after that death:

> I did not go to church that Mother's day, the next Mother's day, or the next Mother's day. For three years I did not go to church because it was really heavy

at that time. 'Cause Mother's day always were bad, but I didn't feel that,

because I still had a mother. But after she left, it just too much, I can't do them

(holidays).

Still others talked about not attending because of their anger or because it was a

powerful reminder of the loss. Pamela, for example, who lost her cousin, said she didn't

attend church as frequently as she had in the past because she was angry with God.

I know during the care giving I wasn't going to church as often. There was a

time I was very mad at God for allowing this person to be sick when she's never

done anything wrong to anyone.

Lynette, who lost her mother, reported that while she attended church periodically, she

did not go regularly. She reported that she did not like going back to her family's home

church because it was such a powerful reminder of her loss:

Lynette: I go, but I don't go on a regular basis like I should or like I could. I

don't know, since I lost my dad, I kind of just can't take it.

Interviewer: You can't take church?

Lynette: Not going to "our" church". ….As far as my church, the church where

my mom and dad and both of us all used to go, it's kind of, it is kind of hard

when you go and don't see them. I don't go.

Not all caregivers whose attendance changed decreased the amount of time that

they attended church. One respondent's caregiving experience had just the opposite

effect. Mary reported how the death of her father and the illness of her mother charged

her to attend even more often:

When my dad passed, I didn't really go to church very much. I really didn't go because I wasn't moved by the services. I didn't have a regular church that I went to but I would go to church every now and again. But I realized at that point, when my dad died because it was so sudden that life is not promised and really the next second…. I had been to a funeral before but it really hit me how things can change in an instant. But when my mom had her stroke and was able to come home, I started going to church regularly. (I. Because?) Because I just feel like I needed some other type of strength or source of strength and that I needed to get my life right (laughing) because things do happen so quick. I've always believed in a higher being, in a higher power, but that I really needed to get myself together. And I'm still probably not together but I'm hoping that I'm more on the right path of being together from a spiritual point.

The Church Community as a Resource

Another theme identified in this analysis was the idea of the church community as a resource. Pastoral support, both positive and negative, the availability of the church family for support, and the use of other spiritual advisors with both positive and negative experiences, were some of the ideas expressed.

Pastoral Support. Pastoral support describes the availability of and the perceived helpfulness or ambivalence of support offered to the caregivers by pastors. Pastors' roles during times of caregiving are described here along with the utilization of other religious leaders during the caregiving period.

It appears that pastors were not readily available as a resource for caregivers. Twenty-two respondents, less than half of those interviewed, reported that they received

religious or spiritual support in caring for their family member by their pastors.

However, when pastors were available, caregivers mentioned the usefulness of the

pastoral presence. Seventeen individuals indicated that this was the case. Two

caregivers reported that their pastor was somewhat helpful. A little more than ten

percent - six of the fifty respondents - said that they did not receive any pastoral support

or that their pastor was not helpful.

Sharon talked about how her pastor, who himself had cancer, was there for her,

during the time she cared for her parents and even earlier in the pastoral relationship.

She reported that her pastor had prepared her for coping with the death of her father and

the care of her mother:

Just a wonderful guy, a wonderful guy. ….The good thing about my pastor who

passed away is that unbeknownst to me, he prepared me for a lot of stuff in our

talks. ... In our conversations, he would say stuff to me that just made such a

difference to me. Even when, when he (the pastor) was diagnosed with cancer,

he and I used to e-mail each other. … So he knew everything that was going on

in my life. When my dad was diagnosed with cancer, he was on the phone with

me, praying with me. Just, you know, just there. (I) always told him that he was

my cornerstone. He was the one that kinda held me up, together. …

Some caregivers held ambivalent feelings about the availability of pastoral

support or feared that the clergyperson would not be supportive. At least four caregivers

expressed these concerns about clergy support. Renita felt that the pastor was present

simply because it was obligatory. She reported how her mother's pastor knew to come

because she (Renita) would have been angry if he had not:

(My mother's pastor) moved to a different church during my mother's illness. But he had come, you know. Before he left I was getting – well, I was ready to call him because he hadn't gotten here. But I guess he must have felt me coming. So then he came.

At least three caregivers believed that their ministers would not be responsive to their need for support. The fear may have come less from their own experience than from others' situational accounts. Channelle, for example, who cared for her mother before her death, discussed the experience of a friend whose pastor was not present during the time of the friend's mother dying:

So this person (the pastor) ... I know you got kids and you got wife, but how can you just not come by, you know it's like you gotta make time.

While many of the respondents reported positive or even ambivalent experiences with clergypersons, at least three caregivers reported negative pastoral support. Barbara, whose mother was placed in a care facility, talked about an incident with her pastor during the time of her mother's stay in a nursing home. She felt the pastor was not as supportive as he could have been:

Pastor M. was (supportive) when he found out. … because he had his father and he knew how it was to care. He's an only child, so because of that we were kind of close there for a while and he could relate to that. (But) when Pastor first came, he got caught up in this "my daughter just won't do a thing for me." Now at one time, I think there was another person in the church that told him that my mother just needed me to love her. I think that was (name of church member) because she's got a lot to say about a lot of things. I think she told him that my

friend Mary feels that if her daughter loved her, she would be (cared for) … and
he (the Pastor) looked at me and (said) people need love and so and so needs
love and maybe there's someone here who needs love *{Pastor appears to be
preaching to the respondent while mother is in attendance at church}* and I just
looked around and looked at my mother wondering, and she was sitting up there
like she didn't hear. I think about this (and) that his (the pastor's) father has
died, you know. I said, "Has he forgotten?"

While the reports are the perspective of the respondent, the sense of non-support
might add to the burden of care, leaving some caregivers feeling as if they are alone.
Another caregiver, Bernice, who was responsible for her mother's care also talked
about her Pastor not being considerate:

Pastor was not really supportive. It was like he was shocked. He's the one that
asked me. And I said "yes, she's, she's, she passed away two weeks ago". And
(he) didn't even realize that she was gone.

Yet even when a clergyperson was not always helpful, there was still a respect for the
office of the pastor. Channelle told a story about how her mother made plans to have
her pastor preside over her funeral, even when he was not very helpful or positive in
another family emergency:

There was a pastor of this church… he's not there anymore. But he did
something that she (her mother) didn't approve of the way he treated one of her
grandson. And I mean my mom is not one to just (say), nobody in my family
don't do any wrong. But what he said was kind of inappropriate. Regardless of
that she (her mother) still listed him. She wrote out her program for the service,

what she wanted and gave him that due respect. So I'm saying, like see, all right,

no he ain't doing my service cause we have a, we have a pastor in our family he

does all of our weddings and funerals. So we knew he was going to do the

eulogy and she could've had him (the pastor) not do it all.

The Role of the Pastors during times of Caregiving. Pastors performed several

roles for families during the caregiving process. When clergypersons were present, they

were providing pastoral support visits to participants' loved ones and to the family, and

when the death occurred, pastors also presided over funerals and helped family

members make the funeral arrangements. Pastors enacted these roles even when the

caregiver or family member was not active in church. One caregiver, Yvonne, talked

about how her grandmother used the service of the pastor although she considered

herself spiritual, but not very religious. Like Channelle's mother, Yvonne's

grandmother made plans to have a clergyperson preside over her funeral:

(Grandmother) wanted the priest to give the eulogy and all that to perform the

service you know, so that was taken care of.

Other Religious or Spiritual Leaders. Congregational pastors were only one

source of support during end-of-life care moments. Other religious and spiritual leaders

were utilized as resources for care as well. Seven respondents mentioned that they

received support from a pastor or clergyperson other than their own. Eleven of the fifty

caregivers reported that they talked to some other church leader about their caregiving

decision.

Chaplains were one source of support especially when non-home care was

provided. Chaplains provided support for the sick family member and for the caregiver.

Channelle talked about using the hospital chaplain when she was coping with the sickness and death of her mother:

> I remember going to the chaplain in the hospital just not being able to accept this reality.

A hospice chaplain went to see Nancy and her family in their home:

> We had a chaplain that came out on Mondays during the day that would minister to her (grandmother). Most of the times when he came (grandmother) was kind of sleeping. He probably ministered to me more than he ministered to her (laughs) which is fine.

Caregivers used other individuals - including spiritual advisors, family members, or friends - who could provide spiritual support during caregiving. Channelle talked about her use of a spiritual advisor to guide her decisions:

> There's a letter where I had to write some questions to God and then Joe (a pastor) was kind of a spiritual advisor for me at that time and so he talked to me about fasting and gave some scripture and so forth.

For at least one caregiver, a family member provided spiritual support in lieu of a religious figure. Sharon talked about using her husband, who was of another faith tradition, to assist her in her time of uncertainty:

> He has a very calming spirit about him. My husband is a Muslim. He's not a practicing Muslim, but he was raised Muslim.

The Church Family

Members of the church, often called the "church family," also played a role in supporting caregivers and care recipients. While the majority of caregivers did not

comment on congregational support, fourteen of the fifty caregivers mentioned that

their church family was helpful. When asked if her mother's church was there for her

mom and her, Renita responded:

"Yeah, well, … I guess to the extent that they were there for communion, once a

month. There were a few in the church they came once a month for the

communion.

Barbara also reported that when it came to caring for her father, her father's church

family was very supportive despite the negative experience that she had with her own

pastor:

(My father) had a good church. People loved my father and he was fortunate to

have people come see him from the church. They would come over and dress

him, the deacon board, and take him to church and bring him back.

Performance of these roles, whether individuals were connected to a faith community or

not, did help give support to caregivers during this critical time.

Yet one caregiver who was a pastor himself, and who was not a recipient of any

pastoral support, believed that it was not the role of the pastor alone to provide care for

the family at the end of life. John believed that the pastor's role and the church's

responsibility were to connect families and also believed that the pastor and the church

sometimes assumed too much of the family's responsibility:

There's always a first cousin or a third cousin or a distant cousin, and I think

churches can do a better job of putting people in touch with their relatives. And I

don't think that it should be, just because somebody can benefit economically

from the demise of a relative, but I think that if they, if you, can connect people,

they might even find that they like the person or they can learn a lot about themselves from this kind old person. Since I've been at this church, I've had three people who've asked me to be the executor of their estates and I have in each case found a distant relative, one was even in Germany, to connect the person with… And those three people actually fulfilled what I thought should be their responsibility. And they actually befriended one another as kind of a mutuality.

Supportive Church Members. Caregivers did report that church members were supportive and used as a resource. Select members from within the church family appeared to be helpful to some respondents. When asked if the church helped out, Lynette replied,

"Oh yeah, the church, the pastor, and everyone. They would come here on Sundays. … Yeah they would come here on Sundays to see her and everything. She always had company. Everyone loved her, so she always had company… The pastor and his children, everybody just loved her.

Greta said:

Like I said, her church friends would come over. They would visit and we would let them have prayer, and then they would come out and talk to me separate(ly).

Non-supportive Church Members. While several respondents reported having positive experiences with church members, this was not necessarily the case for a number of caregivers. Barbara remarked on how members of her church were not

supportive at all. She recounted the story of how her mother convinced church members of her mistreatment:

> If people would come (they would say) "oh you are going to hell the way you treat your mother." And I got to where I didn't even come to church. And she (her mother) even gave pastor the impression that I was neglecting her, (that) I didn't want to be bothered and I didn't care about her in her old age, and I didn't want to do anything for her.

Barbara also talked about how church members and friends criticized her for the choice of placement:

> She and her doctor got together and she wanted to go to (a particular nursing home). And so I didn't have anything to do with that (but) a lot of people, and there were a lot of people calling me talking about "Well I see you finally put her in the home", and I did not put her anywhere.

Renita also recalled that the members of her mother's church were not as supportive as they could have been in caring for her mother.

> A couple of them kept in contact with her. And also picked up little things that they thought she needed like lotion and stuff like that.   I don't know if it was as much as they could have, but at least there were some that were there.

While her mother's church members were not as attentive as she thought they should have been, Renita mentioned that the members of her own church were helpful. Support therefore appeared to be offered by the care recipients' church members and by the caregivers' church family.

Religious or Spiritual Practices as Resources

Several religious behaviors and practices were used as resources to assist caregiver: praying, reading religious material, listening to religious music, fasting, and testifying and anointing sick family members and places where sick family members rested.

Prayer. A majority of respondents, forty-two out of fifty, used prayer as a coping mechanism. Only one respondent mentioned that she had difficulty praying. Table 4 indicates to whom and with whom caregivers prayed, who prayed, and prayer themes.

Caregivers prayed to God, prayed with God as well as with friends, and prayed for family members. Caregivers reported that family, friends, pastors, and church members prayed for them. Prayer themes included prayers for and about care recipients' situations, decisions to terminate care, and prayers for mindset to assist with the caregiving role. One caregiver prayed for their own end-of-life situation, that of having a long life and a short death.

Table 4.

Prayer Themes

To and with Whom Prayer Took Place	*Themes of Prayer*
Prayed to God	Prayed about the family member's Situation
Prayed with God	Prayed about the decision to terminate life
Prayed for Family Member	Prayed that nothing on her mind would be unpleasant
Other Family Members Prayed	Prayed for a long life and a short death
Prayers of Friends	Prayed her way through
Prayed with Friends	Prayed for faith
Prayers of Church Members	
Pastors Prayed	
Support of Those Who Prayed	

Sharon, whose father died of cancer while she also cared for her mother, said:

> I did a lot of praying while I was dealing with my dad's health.

Barbara, who struggled with placing her mother in a nursing home said:

> If it weren't for prayer, I guess I don't know what I'd do.

Patrice, who cared for her father said:

> I would take off that time to pray with my dad, to encourage my father and my
>
> mother as well. And I would pray for my father, cast those spirits off and tell
>
> him there are certain things you got to maintain in prayer and through your
>
> relationship with God and having communion (and) conversation with God.

Many respondents mentioned praying with families or friends. Paul, whose mother died of cancer said this:

> We prayed together and talked. Two weeks later she (his sister) died.
>
> We (the family) prayed for the release of mom's spirit…

Patrice prayed with friends:

> I had friends come over and we would have prayer every morning in the house, driving out the spirit of death.

For some families, the sick or the dying person would also instruct the family in how to pray from their hospital room. Channelle told this story:

> I remember being in there once and I said to my brothers and sisters… I said you know it says where two or more are gathered… We need to agree but we need to be silent. Now I thought, we were kind of like outside the door, I thought she (her sick mother) was happily sleeping or whatever. She was awake and she was like, "what you need to pray is for God's will".

Paul, who had to make a decision to terminate care for his mother, also reported how his mother instructed him and his siblings from her bedside to pray. The family was not in agreement on the decision to cease using mechanical life support.

> We called a family meeting on that Sunday after the communion and after talking to mom, mom said that she was ready to go. We were praying for a miracle and a healing and she told us, stop closing the door… let the door be open. You all keep closing the door. I want to go through the door. And we understood, as long as we prayed, the door would close.

It was rare that a caregiver reported not engaging in prayer. Yet one respondent did not pray. Yvonne, who cared for her grandmother from afar, said that she did not engage in prayer although other family members did pray.

My mother was very religious and I think that she did, she prayed and I gave her all of my support… She really thought about it (the care decision) and prayed and all of that and then the next time she called me after that she told me, she said, "I, I let her go." So …., they just took the machines off so it was really after all it was very, very calm and very peaceful.

In conclusion, prayer was an important and powerful resource utilized by caregivers. As one caregiver, Sharon said, it is the power of prayer that helps get caregivers through:

My prayer is that when I don't understand, give me faith. Just help me to realize that you (God) are in control of this; that I don't have to be worried about anything.

Fasting, Testifying, and Anointing. Three other religious practices used by at least two participants were that of fasting, testifying, and anointing. These practices and rituals, while not mentioned by the majority of the caregivers, still served a function for these few.

Channelle talked about how she fasted, stopped eating, and only consumed liquids in order that she could concentrate on God and have God's will be done in the case of her dying mother:

I'm like, ok I have been fasting, I have been fasting up until this time and I don't

know how many, it might have been twenty days, thirty days, whatever, on

liquids thinking that that would…. that was my way of dealing with it

Greta, who also talked about caring for her dying mother, and who was herself also

living with cancer - talked about testifying, giving a public statement in a religious

service setting - about her illness:

I have testified about my illness and how I feel God has healed me. Because in

my church we speak on healing and I feel that I'm healed; that God healed

me….

Nancy mentioned performing the ritual of anointing, using oil that had been prayed over

and was considered holy, as part of her spiritual tradition of healing:

… I used to go in her room every night and I would anoint the room and I would

pray over her.

These religious practices and rituals seem to give these few caregivers some comfort

and some support.

Use of Religious Material

Religious material was not a resource utilized by the majority of caregivers.

Twenty-one respondents (less than fifty percent of the respondents) mentioned the use

of religious material to assist them during caregiving. This was an unexpected finding.

It was assumed that more caregivers would rely on religious material such as the Bible

as other literature has suggested. Further exploration of this phenomenon is warranted.

When caregivers used religious material, they most often reported using the

Bible as a resource. Caregivers also utilized teachings from the Bible, biblical language,

and recitation of scripture even when the Bible itself was not mentioned. Additional

material included other religious writing, such as meditation books and scholarly

theology books.

Bible, Biblical Teachings, and Scripture as Resources. Religious material was

an important resource for close to fifty percent of the caregivers. Twenty respondents

said that they used the Bible as well as other media for support. Lynette, for example,

said she read the Bible and watched religious television programs:

> I read the Bible. I look at a lot of church programs that come on TV. I like to
>
> look at those. I pray every day and night.

Several of these respondents used lessons from the Bible that were taught to them and

recalled during the crisis period. Several respondents did not necessarily read the Bible

but instead used scriptural references. Paul's mother's biblical teaching sustaining him.

> It was my mother. …at the death of my father when he died, I just felt like God
>
> was punishing me by taking my father. So mom sat down and told me, she said,
>
> "son, we do things backward. We are supposed to cry when a newborn child is
>
> born..." I didn't know anything about the word in the Bible at that time. She
>
> said, we are supposed to cry when a newborn baby is born but when one dies in
>
> the Lord, we are supposed to rejoice. And I remember those words and I
>
> remember saying that over and over at different funerals and all that. That's
>
> what sustained me.

Pamela used a biblical character to describe the aunt who cared for her cousin:

> She (aunt) had the patience of Job because there were times when I wanted to
>
> strangle Taylor (her cousin for whom she was caring).

The majority of these caregivers also reported that the use of religious material was helpful, though a few caregivers indicated that use of scripture, especially by others, was not helpful at all. This was the case for at least one caregiver. The use of scripture by others made Barbara feel guilty about her decision to have her mother placed in a care facility:

> People always want to bring up, Honor thy father and thy mother. I've had that thrown in my face so many times. Honor thy father and thy mother. But there is also a place in the Bible says "chickens don't lay up the hens, hens lay up the chicken and it had something to do with provisions being made. …" For God's sake, don't bring the Bible into it. You know, you feel bad enough no matter how much you do for your people. It's never enough. You are going to always feel guilty. You can be perfect and you will always feel guilty.

Use of Other Written Religious Resources. A least three caregivers used other written religious resources, such as meditation books or theological writings, to help them cope. Mary, who cared for her mother who suffered a stroke, mentioned reading *"Healing Remedies from the Bible."* Mary also said she used a book of meditation that her mom had introduced to her. She was able to quote references from one of the books:

> My mom used to meditate in the morning and she had read this book… *Mind Power* …. I purchased this book myself to start reading and meditation and it was an evening meditation and a morning meditation that she would read every morning. And so when I would go to the hospital, I took my book… It starts "Every morning is a fresh beginning, everyday is a world made new. Today is a new day. Today is my world made new. I've lived all my life up to this moment

to come to this day. This moment, this day is as good as moment in eternity. I

shall make of this day, every moment of this day a heaven on earth. This is my

day of opportunity." I would continue to read this to her because I just felt like

that was important to do.

John, a pastor, who cared for his dying father, did not limit his reading to the Bible but

read all sorts of books and materials:

I'm a voracious reader and I think that just moving words and concepts through

my head a lot helps me process stuff. I have to read theology every week for

sermons... and that involves just a wide realm of stuff, books, magazines. … I

listen to sermons. Actually I buy sermon collections and listen to them.

Religious Recorded Media as Resources. The use of religious recordings and

music was noted by five of the caregivers. Channelle said that she purchased religious

tapes and music. Barbara said that she played church hymns on the piano for her

husband (and for herself). Patrice said that music and watching gospel programs on

television helped her and her infirmed father as well:

He (Dad) did the best that he could from the standpoint of him being at home,

listening to gospel on the TV and buying gospel tapes. You know the Bible

tapes and all that. And God did make a big turn around in my father.

For Ms. Conners, who cared for her husband, watching religious programs on television

was especially helpful because she was unable to get out and attend church.

My son gave me this DirecTV and they have church. They have a religious

station and you can get all those people all day on Sunday. And I go from one

(program) to the other.

Music was an important resource helping Nancy through her difficult time in the pending death of her grandmother:

> I just got in the car and I drove to the mall parking lot and I just sat there. I put on some praise music. I just cried and I kept saying you know, but thank you God. Thank you God because the joy of the Lord is my strength.

Nancy also talked about a special ritual where she would get away in her home and listen to music and also mentioned engaging in something called a praise party:

> I do something, it's called Tub Time. I have tub time when I get in the bathtub with my praise music (laughs) and I just let God minister to me and I cry. And just kind of like, "Okay kids. Mommy has to go take a bath now, so you all can't come in here…"

She continued:

> (We had) a praise party and we started singing praises to God, I'm like, just gotta praise you Lord. So we just sang praises to God….

While it appears that religious material was a resource for some of the caregivers, use of the Bible, biblical teachings, religious media and music was not the norm for the majority of the caregivers.

Theological Understandings as Resources

A final category not often explored in the field of social sciences is the examination of how theological understandings influence and support individuals. This study explored African American caregivers' use of theological understanding. Theological understanding is the way in which participants expressed their concept of who God is and how God functions. The caregivers' relationship with the divine is also

considered as part of this theological understanding. Five themes were uncovered in this analysis. The themes include (1) faith and trust, (2) the importance of God, (3) "Soul Theology," an African American cultural understanding of how God functions inclusive of other cultural and folk beliefs (4) philosophies and theologies of sickness, of death and dying and of caring and (5) theodicy questions.

Faith and Trust

The ideas of faith and trust in God were prominent themes expressed by thirty-five participants. Faith is defined as the belief in a higher power or the belief in the power of that that higher being possesses. Trust is the belief that a higher power (God) will take care of matters and that one could depend on God to do so.

Sarah who cared for her sister and other family members, stated that faith helped her enact her caregiving role:

> Yeah. My faith, and … I have so many nice friends and telephone calls and you know in my church … But the most of it is my life with the Lord. And so He's carried me through all this, and blessed me and so if I had to do it all over again I'd do it again, I sure would.

Ruth's faith was the only thing that kept her going while she cared for her sister:

> That's the only thing I have going for me. My faith. I do believe that…I just asked the Lord to guide me and to let me know when I'm doing the right thing. …It seems like the good Lord says, "You do what you know you're supposed to do… and I'll bless you." See, that's how I live.

Faith and the belief that situations would turn out the way they were suppose to sustained more than a few of the respondents. "I just trust that everything will be all

right…", said Greta, who talked about caring for her mother who eventually died in a

nursing home. Charolette, who cared for both her son and her husband, said it this way:

> I am because He is and I don't even know how to explain (laughs), I just know
>
> that if I didn't have faith, I would not exist or I would be in a mental institution,
>
> if I did make it.

Faith also assisted some caregivers during the caregiving process and when

death was occurring. Bernice's faith, for example, prepared her and her sister for her

mother's death:

> We have always been a church going people. And it helped me to know that as I
>
> tried to read to her and to talk to her that this is not the end and we have to
>
> prepare ourselves for the final end. So my faith came in there very strong
>
> because I could be blaming the nurses, (saying) "Oh you give her pain med, it
>
> didn't help, give her something more".

Some caregivers emphasized trust in God's use of other people. This was the

case for one caregiver, Patrice, who trusted the social worker who assisted her family.

> There was a social worker from the hospital that really invested time into my
>
> mom and looking at her assets, showing her the best route to go that (dad's) care
>
> would be paid for and that (mom) could live where she wouldn't be struggling.
>
> So that is what she did because he gets a monthly check for social security. And
>
> so the social worker worked with her and I prayed with her and told her, I said,
>
> "You know, God sometimes intervenes in ways that we can't see.

Expressing "God"

Many caregivers spoke of "God." Eighteen respondents mentioned God as they narrated their caregiving experiences. Caregivers talked about who God was in their life; the importance of God; how God functioned for them; and how God assisted them, sustained them, and was present with them in the caring for a loved one. Caregivers also talked about how God was with them when their loved one was dying. Many caregivers also noted the importance of simply knowing God. As Eve, who cared for her mother with breast cancer, said, God was everything to her.

Several caregivers spoke of God in terms of their relationship with God. Bernice, a nurse, whose mother was diagnosed also with cancer and who died four months after the diagnosis, said this about who God was to her:

> I think about a song that says "He'll be your mother, He'll be your father". You know. He is my family…"He's the doctor in the sick room, He's the lawyer in the courtroom".

Caregivers talked about how importance of God enabled them to handle difficult situations. Rita, for example, who cared for several siblings including the sister who was the subject of the interview, mentioned God's importance in her family's life:

> When facing any challenges they (the family) could not control, then it was always God.

Many caregivers spoke of God in terms of what God did and what God would do for them in the caregiving process. Nancy, whose mother died only a month before the interview, talked about being sustained by God:

> When we first started this interview, we were talking about my parents and all the other people that had died in my family over the past three years. So just the

fact that I'm not insane now is to the glory of God (laughter). Because it just

helped me through everything that I've been through and with my

grandmother's death was probably a little easier for me because I've been

through so many other things … God had to get me through that, I don't have

that type of strength where I could go through that on my own, and not go

insane. God had to get me through that.

Ms. Conners, an eighty-year old woman who cared alone for her bedridden husband

explained how God provided her with the strength to give care:

If you have it in your heart, God will make it possible. We don't have to stick

our loved ones in the nursing home and let them stay there and die and forget

that they've done anything for us.

Joelle struggled with the caregiving task. She cared for her son that had suffered suicide

attempt related brain injury while he was in jail. Yet she spoke about the importance of

having God in her life:

I have so many struggles. Andre (the son for whom she cares), my work, myself

working with the kind of family system I came from…I think….that…we better

know God, we better have some God (laughter). We better have some God in

our life. We better have something to hold onto and believe in, in order to be

able to get up and make it on a daily basis.

Sharon, expressed a similar sentiment:

God forbid anybody gets into a position where they have siblings or extended

family and they (siblings or family) don't support them. That's more reason to

draw closer to God because that' the only way that you're going to see it though

cause you can actually go crazy.

At least one caregiver bespoke God's power in the decision making process: Valjean,

whose mother received hospice care, suggested that the care decision was God's work:

So they (family members) would be in the room talking about things that

shouldn't be talked about like, where they're going to get the money from and

this, this, and this; the insurance and (whether) can they do this and can they do

that. I was trying to educate them on what kind of accounts and this, this, and

the other cause I didn't want to make them think, we dropped the ball. No we

didn't drop the ball. This is God's work.

Embracing God changed at least one respondent view about her own desire for

care placement. Patrice said:

I wouldn't put that burden on my children… I would go into a nursing home.

My views have changed because of God.. …My life belonged to God and that

I'm in His care.

Ms. Gertrude, an elderly woman paid for her sister's care at her sister's

residence. She eventually had to move her sister into a personal care facility after family

members began to steal from her sister. Ms. Gertrude advised knowing and using God

when one has problems:

My advice might not be right. I can give you my opinion, but I don't tell you to

go on that. Better go take it to--too big for me, hon. Take it up there (laugher).

They'll tell you in a minute. …girls aren't acting right, I say, honey, give it to the

man upstairs. He'll straighten it out for you. If you're sincere to Him, He'll be

sincere to you.

Soul Theology and Other Cultural Beliefs

African American caregivers in this study also used their own cultural

theological understanding, Soul Theology, as they recalled their caregiving experiences.

Soul theology is a set of spiritual core beliefs held by African Americans that uplift,

heal, and empower during life challenges (Cooper-Lewter & Mitchell, 1991).

Caregivers used these core beliefs and other embedded cultural religious languages to

support them in making sense of and working through the tasks of caring for a family

member dying or at the end of life.

Sharon's use of soul theology, for example, helped her maintain a positive

attitude even during challenging times. She holds the belief that nothing could go wrong

because God would provide an alternate way out of any situation:

I know you hear these clichés, "When a door closes, a window opens." I said

what I say is that nothing in my life has ever gone wrong. Nothing… when I

look back at the outcomes of everything that has happened, I'm who I am today.

So nothing ever goes wrong.

Joyce also struggled with her family over decision-making matters. Several sayings

helped her understand how God would help her face adversities: "God don't like

ugly," meaning that God would handle situations when individuals were treated poorly,

and "Nothing never goes over the devil's back that don't come back and buckle,"

meaning that bad and evil will not prevail. Greta and Maurice used the term "standing

in the gap" to explain how God would assist them fulfilling unmet needs during the

caregiving task. Bernice mentioned how she hoped to handle her own care at the end of her life:

> I hope that when my time comes, I can keep my eyes above and my hands on His hands.

Thus Bernice used a typical black theological statement of her trust in God.

Folk beliefs also manifest in cultural and soul theologies and mythologies. Yvonne, who assisted in the decision making for the care of her grandmother talked about how her mother used folk beliefs to help make sense of the loss of Yvonne's grandmother:

> We have this really weird picture of the girls. It's just one of the flukes of a camera, a shadow in the camera or so I believe, so I think, but my mother and sister, they were both here. I think it must have been just my sister holding the babies and then they're looking off like that both of them are, they're distracted. They're looking, and then there's this wisp of something like the light is shining through and making a shadow or something ....and so they're both looking over that way and so my mother (says), "See, see! (laughter) That's your grandmother."

Soul theology, grounded in African Americans' lived experiences included biblical teachings that were sometimes reframed to illustrate caregivers' own unique understanding of how God functioned. "Everything you do in secret, God will bless you openly," was voiced by Bernice, who apparently meant that God would appreciate and perhaps even reward noble acts especially when one would not act to obtain attention. "He's binding her to soul care," and "prayer makes a way out of no way," was

said by Patrice, seemingly meaning that prayer works and God will take care of things. The rewording of and reworking of these cultural theological understandings provided comfort and understanding.

Embedded Theology as Cultural Mandates for Care

Embedded theology is often deep-rooted in the psyche and suggests ways of handling difficult questions. These embedded (and often unconscious) theological beliefs are assumed to be normative values held by all and are often taken as cultural mandates – expected ways of thinking frequently supported by interpretation of scripture and often reinforced by the community. Half of the respondents in this study (twenty-five) expressed this theological understanding to uphold their way of thinking about their situation.

Myrna, a seventy-year old woman, provided at-home care for her husband for three years until his death. Like so many other African Americans, Myrna used the following saying about responses to birth and death:

The Bible says you ought to cry and weep at the coming in; rejoice at the going out.

At least three caregivers expressed the cultural belief that one never questions God. Many African Americans adhere to belief. Pamela embraced this belief to face the death of her family member. When asked why her cousin had to die, Pamela's response was,

"It's not your place to ask why. Everything happens for a reason."

Another caregiver, Chanelle, also expressed this belief that God should never be challenged: "I never questioned (or) say, God why are you doing this kind of thing". Embedded theology and cultural mandates can also explain why caregivers care.

Some caregivers believed that they were expected to provide care. Bonnie cared for her sister at her sister's end-of-life. Bonnie and her sister's seven children bore primary decision-making power. Growing up, Bonnie attended church and was taught that someone had to be responsible and had to do the right thing. She said that she cared because she didn't want to disgrace her parents. These religious beliefs, couched in cultural mandates, undergird some caregivers' sense of their caregiving obligation. These beliefs might make it easy for some individuals and families, granting credence to the caregiving role. Yet the belief may also make it difficult for others to veer away from this cultural mandate to assume the caregiving role.

Philosophies and Theologies of Sickness and Death and Dying

Caregivers - whether their understandings of God derived from traditional Christian religious influences, from African American Soul Theology, from embedded cultural mandates, or from a combination of these - expressed both philosophically and theologically their thoughts about sickness, death, the theodicy question, and their theology of care. These philosophies and/or theologies also appeared to be grasped and used as resources to sustain caregivers as they cared for their loved ones at the end-of-life. A specific question about their philosophy of sickness and death and dying was asked of each of the caregivers.

Philosophies of Sickness. Caregivers had their own understandings or theologies of sickness. Renee believed that sickness was normative and part of life. Sheila, whose

mother and father both were recovering at home, believed that sickness was

unavoidable:

> I don't know, I mean I know a lot of people who eat healthy, take care of
>
> themselves, get sick. I know people who live, don't give a doggone about
>
> nothing, eat all the fried foods, eat all the stuff you're not supposed to do and
>
> nothing ever happens to (them). I kind of just think if it's going to happen to
>
> you, it's going to happen to you …

Doris, who at one time was a Buddhist and who was caring for her father had another

view of illness:

> I think sickness is frustration of life. When you are frustrated and you're not
>
> being
>
> free, then the sickness come.

Will cared for his father with his siblings assistance of siblings. Will had this

understanding of illnesses:

> I think it was, that came out of my training that says you know, if somebody has
>
> an illness, a chronic illness, the first thing you need to do is make a place for the
>
> illness. The illness has to be real. It can't be a hot potato that every body passes
>
> to the next person and you can't just ignore it. You have to make a place for the
>
> illness. And this illness (speaking of his father's illness) was very real.

Theodore suggested that some illnesses might be related to issues of race and ethnicity:

> Well in terms of diabetes, like I say maybe a racial climate, not in all cases ok,
>
> not in all cases, but just a pattern that I'm starting to notice, cause of illness, it
>
> goes back to diet.

As noted earlier, some caregivers believed that everything happened for a reason; this sentiment revealed beliefs about illness as well. Yet a few individuals rejected such beliefs. Myrna was one. She rejected the idea that sin was the cause of sickness, and instead ascribed to a different philosophy of sickness:

> We think if you're sick you sinned. That concept is at least more than 2,000 year old. Sickness may be the universe renewing itself.

Patrice also rejected the sin-based concept of illness:

> Christ created me to live abundant life. And in speaking that, that word became living in my heart and God changed my heart because all those ailments that my dad had: arthritis, bursitis, back ache, head ache, all that, I had that too, before I became a born again Christian. And then when I learned my rights as a Christian, as a child of God, I said, I have to reject that type of thinking.

These understandings appeared to help caregivers make sense of why their loved ones were ill and of the need for their caregiving roles.

Philosophies and Theologies of Death and Dying. Several caregivers responded to the question about their understanding of death and dying. As they recounted their caregiving experiences, caregivers had various perspectives on the topic. Bernice, for example, said this about death:

> I understand death as an event, an inevitable end. We're not here forever. Unfortunately some of us are taken away at a very young age before we accomplish what we want to. That is unfortunate, but death, I feel that's something that my view towards will not change when it comes, I'll be ready. I go to sleep or I don't wake up or, I hope I don't suffer.

Renee, whose mother was actively dying of breast cancer at the time of the interview, said this about death:

> Death is something that I know we all have to pass through. It's hard when you lose a loved one. It's hard when you lose a friend, much less someone who's so close to you. But that's something that's inevitable. We all have to go there. And we will grieve with crying. We will have our sad moments, but there is a lot of good times that we can reflect on and say well you know we did this together and this was like that, and that sorta helps.

Doris, the former Buddhist, believed that humans are on earth for a reason:

> I feel you're here on a mission and when your mission is complete and when you've done everything you've came to do, you move to the next level, the next door or the next. I don't think it's a continuation,… life and death, it's one.

Channelle's discussion of death focused on who was in charge of death. For her, the timing of sickness and death was not humanity's decision; it was God's.

> I wasn't about to accept how they, Hospice, could tell you what time it was.

Nancy shared a similar sentiment:

> I know my God and I'm like, only you know the time or the hour. It's not up for us to determine when somebody's going to die.

Bonnie also shared how she embraced death and prepared for her sister's end-of-life:

> I don't grieve about them leaving me because I know that they're in a better place. So I don't really sit and worry that they're no longer with me. When He (God) gets ready He's going to send for us. No matter which way it goes, some of us are going to go just suddenly, some of us are going to suffer and some of

us…so, I always prepare my mind to deal with these kinds of things, I never

know which way, whether its me, (or) one of mine.

The Theodicy Question

Even with their faith and trust, soul theology and their theology of sickness and

death, some caregivers still wrestled with the theodicy question: why does God allow

suffering? Caregivers' questioned death and dying issues; they also questioned how

God functioned in the care of family members. At least two caregivers were ambivalent

about whether to maintain the cultural belief that one does not question God. Chanelle

said she adhered to the belief that God knew what time it was. But she also confessed

that she had questions about her mother's illness and death and how God dealt with

people's suffering. She said that she had to write down some of her thoughts so that she

could ask the questions:

> I didn't know how to deal with this. It's like I couldn't figure it out and I wrote
>
> down some questions. … Part of "the word" where you gotta suffer, and I guess
>
> I wasn't finding consolation or buying that. It's like I know you gotta suffer, but
>
> how do you bear this. So I accepted it - to a certain point….

Wrestling with the question and obtaining permission to ask the question (whether or

not the inquiry was resolved) appeared to support at least one caregiver. Bonnie felt she

could raise the theodicy question because her pastor helped her:

> I have a little nephew that is (mentally) slow. I don't know what is wrong with
>
> him, the mental capacity. But he said to pastor, "Why…why did my
>
> grandmother die." "If God loved her, why did he take her?" And everybody got
>
> quiet. Everybody got quiet because this child is only eight or nine, but he asked

the question. So pastor said, "Don't get upset. He has the right to ask the

question. So pastor tried to explain to him and said, "Oh, what make you sure

that she's going to heaven?" So pastor started to explain to him, because

everybody got upset with the way he was asking the pastor, he said, "No, let it

be, let it be. He has a right to know." Pastor tried to explain to him as much as

he could so that this child could understand where his grandmother was going.

Bonnie, who had been in conflict with her sister a few years before her sister's death,

simultaneously held this divergent sentiment:

Sometimes we have to accept things even though we don't like it, we don't

agree with it. I just feel like, I tell people this, "don't keep talking about 'Oh

she's gone. Why did God pick this person away from me?'" You got to think

about the good times you had with this person. Think about the good things that

happened. Not that the person has left you physically. They're no longer with

you. That's one thing, because spiritually they're always here.

Philosophies and Theologies of Care

Finally, several caregivers expressed their spiritual understanding of care and

the caregiving role. Some caregivers found caring to be a positive experience. At least

one caregiver believed that there were some present or future benefits if they cared for

their ill family member. Donnella, whose mother received home care, expressed this

sentiment: "I knew that God was going to give me something else."

Two other caregivers described their task of caring as either a "blessing" or a "calling."

Bernice said that she was born to care:

It's like an ingrown thing, or inborn thing in me to care for people. And I look

around my family and I try to see who needs whatever. By helping others the

Lord has helped me too.

Pamela recounted how she explained her caregiving role to her boyfriend:

This woman (her cousin) would do the same for me. I've known her all my life,

so, if I can make her time on this earth easier, I will do it. And there's nothing

you or anyone else can do about it. If it were you, I would do the same thing. If

it was your mother, I would do the same thing."

She went on to say:

"There is no such thing as caring too much. You do what you can. And I don't

think there is anything wrong with that."

Myrna, who assisted in the care and care decision of her father, said that she was taught

that it was her duty to care:

One of the things that my dad felt was part of his Christian duty was if a man

asked for help regardless of who he was, to help him.

Mrs. Conners, the 80-year old woman who cared diligently for her husband even as she

appeared too frail to do so, described her theology of care in terms of loving one

another:

I don't believe Jesus put us here to just love us, but if we love one another like

He said, you will, even when the times get bad, … You have to make sure that

you know Jesus. Because if you love one another you will, love covers a

multitude of sins. If you feel in your heart that you love this person and you

want the best care for him then you got to want to. …Having God in your heart

will make things possible and one would not need to place a loved one in a nursing home.

When Doris was asked about her theology of care and who would take care of her, she replied (even using some soul theology):

> Who's gonna take care of me? God knows and that's it! I don't know and I don't worry about it. But I know what goes around comes around and I don't think I'll have a problem.

These philosophical and theological understandings appear to support caregivers. While the caregivers were intentionally asked to articulate their understandings of sickness, death, and dying, expressions of soul theology and understanding of care were forthcoming without probing. Philosophical and theological understandings, and retreat from the religious and cultural mandate to not question God, helped to give meaning to and for the caregiving experience.

CHAPTER FIVE

Discussion

This discussion interprets the study's results. The results will be used to

formulate an understanding of religion and spirituality's role in end-of-life caregiving in

African American families. Implications for practice will be offered. Methodological

limitations and suggestions for future research will follow.

Summary of Findings

This study examined African American caregivers' narratives to uncover

thematic understandings of how African American family members talk about,

understand, and utilize religion or spirituality as resources to care for a family member

at the end-of-life.

The results of the analysis suggest that religion and spirituality can be both

positive and negative resources for African Americans caregivers caring for loved ones

who are facing the end of their lives. The results of the analysis further suggest that in

researching the experiences of African American caregivers, the power of cultural

mandates and religious and spiritual beliefs are important variables to consider. In

addition, providing support for African American caregivers, assessing caregivers'

theological understandings is critical.

The fifty participants in this study resided in different parts of the country

although regional differences were not examined. The majority of the participants were

women as it is typical for women to provide family caregiving. These caregivers were

also primarily single. An equal number of caregivers possessed a high school diploma,

some college education, or post-master's degrees. It appears that this sample is skewed

toward a highly educated representation of the African American community. This sample offers a different perspective on caregiving and contributes valuable knowledge to the field.

The study revealed a number of experiences and themes. Similar to other studies on ethnic caregivers (Connell and Gibson, 1997; Sarkisian & Gerstel, 2004), the majority of the respondents provided care for a family member other than a spouse. Sixty percent of this study's participants cared for their parents. A great number of caregivers in this study reported attending church and all identified as Christians, although one caregiver reported being influenced by the Buddhist tradition.

Other research has indicated that reported variations in caregiving burdens and rewards are found to be related to caregivers' subjective experiences and to the amount and type of social support the caregiver received (Goldstein, et al., 2004). The studies suggested that African Americans reported less caregiving role strain (Goldstein, et al., 2004). In this study, the majority of the caregivers did not openly report on caregiving stress, but numerous respondents struggled with their caregiving roles. As one caregiver reported, caring was expected; it was her destiny and a role others expected her to uphold. This finding might suggest that caregiving strain or burden might be mitigated by the expectation that one is expected to care. This expectation to care may also be fostered by cultural support and religious beliefs. Thus, caregivers' religiosity and spirituality must be considered.

Caregivers' religion and spirituality appeared in most cases to be resources upon which caregivers drew. African American family members' narratives about religion or spirituality as a caregiving resource fell into three thematic categories: (a) how African

American caregivers "lived" their religion or spirituality; (b) how African American caregivers used religion or spirituality as a resource; and (c) how African Americans used theological understanding as a resource.

How African American caregivers "lived" their religion or spirituality was the first category uncovered and examined. These intangible spiritual scripts included the caregivers' religious experiences in their family of origin and elsewhere in their early experience. The family is the principal agent of religious socialization therefore it would be expected that early religious experiences and socialization would be a resource individuals and families would draw upon in times of crisis. Church attendance in formative years and recalling other important childhood lessons provided cultural capital upon which caregivers drew for support. However, not all caregivers who attended church during childhood continued their religious participation as an adult.

Caregivers appeared to live out their spirituality as shown in their utilization of customs, rituals, and Christian traditions. Their religiosity incorporated these spiritual experiences and other functional aspects of religiosity. While it appears that religious background was not a necessary prerequisite for coping successfully with the caregiving challenges caregiving, attending church was helpful.

Caregivers' religious backgrounds, for many of the respondents who attended church, also appeared to be a resource used as they cared for a family member near the end-of-life. One would expect a decline in church attendance once one assumed caregiving responsibility. However, not all caregivers reported that this was so. For some of the caregivers, church attendance increased. Other available family members enabled caregivers to attend religious services. When there was not the support,

caregivers did not attend church and instead used television as a means to connect with their religiosity.

Some caregivers decreased their church attendance. Several caregivers attended church less often as a result of their anger with God about their loved one's situation. Family members' death also caused some caregivers to move away from church. Church, therefore, was a place of solace for some caregivers, but was also a place of painful memories for others, especially around holidays or other days of remembrance of the loved one.

An earlier study suggested that African Americans indicated that they often sought spiritual comfort and support when confronted with problems regardless of church attendance (Taylor et al., 1995). Yet at least two studies (Mattis, el al, 2007; Owen, Goode, & Haley, 2001) suggested that African American do not necessarily seek clergy support. This latter finding was also one of the discoveries of this current study. Less than half of the caregivers reported obtaining clergy support. Caregivers did not seek clergy assistance or were ambivalent or fearful about the clergy's trustworthiness. Caregivers felt that pastors could not be sought out to as a resource. It could have been the case that caregivers knew that clergy could not provide what they needed.

However, this study also found that caregivers who used clergy received helpful support. Caregivers apparently respected clergypersons. As noted by one caregiver, even when a clergyperson was not supportive, there was still a respect for the office of clergy. This observation would suggest that clergy would be respected irrespective of the clergy's helpfulness.

Most caregivers did not use the church community as a resource. However, caregivers did sometimes remark that they received support both from the care recipient's church community but more often than not from the caregiver's church family. This finding validates prior research that suggests that caregiver involvement with a faith community, a trusted friend or clergyperson reduces caregiver burden (Mattis, el al., 2007; Powell, et al, 2003; Taylor and Chatters, 1988).

This study's findings indicate also that caregivers engaged in religious practices including praying, and to a less degree, fasting, testifying, and anointing with oil. As was expected, prayer was a prominent religious activity. What is striking here is that caregivers found comfort from prayer but not necessarily from church attendance. This suggests that perhaps religious caregivers embrace non-organized religiosity more readily.

Reading the Bible and other religious material, and listening to music also helped caregivers to cope. Interestingly, however, less than fifty percent of caregivers expressed reliance on the use of the Bible. It might be that not all caregivers used the Bible prior to caregiving; and perhaps those who reportedly reliance on the Bible may have already relied on this holy text prior to the time of caregiving. Few studies in the social sciences have examined fully this religious activity.

Although the majority of the caregivers did not report utilizing the Bible, many caregivers did use lessons from scriptures. Some respondents found scripture helpful. Yet for other caregivers, scripture lessons were not very helpful. People quoting scripture criticized at least two caregivers for their care decisions. Scripture in these

instances proved not to be a resource for these caregivers. Consideration of this issue should be taken seriously.

Theological understanding - the ways in which participants express their understanding of who God is and how God functions - was the third category uncovered. Social science research on religion and spirituality often neglects thorough examination of theological understanding. This study helps fill this research void. The discussion of African American theological writings to the family field, while it is not a family field framework, is important for understanding religion and spirituality in African American family. The family field can accommodate these writings.

Themes in this category of theological understanding included faith and trust, as well as the importance of God. Folk beliefs and "Soul Theology," an African American cultural understanding of how God functions, were additional themes. Philosophies and theologies of sickness, of death and dying, theodicy questions, and philosophies or theologies of caring were also expressed as caregivers' coping strategies.

God was very important to the majority of the participants, Caregivers talked about God, the power of God, and how God assisted them in the caring task. Caregivers' faith in God proved to be a reliable resource. Caregivers relied more on their faith than on others' support.

African American caregivers used Soul Theology, as a caregiving resource. Embedded Soul Theology, often deeply rooted in the psyche or unconscious, provided direction and suggested ways of handling difficult questions, including the call to care and death and dying. These theological beliefs were often taken as cultural mandates supported by scriptural interpretation and community reinforcement. Caregivers used

these theological understandings as a positive resource, as a guide, or in some instances, as a mandate for care. In any case, Soul Theology and other theological understandings could be seen as positive or negative resources.

Implications

Findings from this study have implications for family scholars, for the consideration of research methodologies, and for theory development. This study also has implications for clergy, scholars of religion, pastoral care scholars, congregations, chaplains, hospice workers, and caregivers.

Implications for Family Scholars

Taken-for-granted assumptions are challenged with a phenomenological approach. These challenges bring valuable insights and perhaps pose new theoretical perspectives about family life issues. Such is the case of this study.

Implications for the Study of African American Family Life. It is said that African Americans are religious. In the literature on caregiving within the African American family context, consistently it has been indicated that caregivers utilize religion and spirituality to assist them in coping while engaging in their caregiving task. This study supports these theories but also adds nuances in understanding how and in what ways caregivers indeed use their religiosity and spirituality.

Factors embedded in African American family values and reflected in the family system are critical to understanding theories about the African American family (Staples, 1976). Collectivism, for example, is an ideological construct associated with ethnic families. Collectivism is the belief that all members of the family are to work together for the good of the entire family. Families with collectivistic ideologies take on

a different approach to caregiving (Killian and Ganong, 2002). It is believed that

members of the family will take care of their family members based on this ideology

and collectivist family values. African American culture frequently is presumed to

adhere to this collectivism ideology and emphasize informal support systems (Lee,

Peek, & Coward, 1998). The complex ways in which collectivism ideology is lived out

in the experience of end-of-life care is something this study offers. The examination of

the lived experiences of African American family members, and in this case African

American caregivers, in uncovering more explicitly those facts embedded in family

values is important. As such, this study adds to the corpus of research in understanding

African American family life.

   Familial and Filial Obligations. This study has major implications for social

scientists in examining familial and filial responsibility expectations, filial piety, and

obligations. Lee, Peek, and Coward (1998) defines filial responsibility expectations as

the extent to which members are expected to provide assistance to their aging parents

and to give priority to parental needs over their own (p. 1003). Ganong and Colemen

(2005) in their study define filial piety as individual's sense of responsibility as a moral

duty and normative beliefs (p.1003). Both of these constructs may have been

functioning in the minds of the caregivers in this current study.

   It has been assumed that African Americans have higher filial responsibility

expectations than do European Americans. Yet the study by Lee and his colleagues

(1998) suggest that there is no consensus regarding racial differences in filial

responsibility and expectations. Killian and Ganong (2002) in examining filial

expectations define normative obligations as the assumption that helps from family

members is available, appropriate, and non-problematic. This is the position commonly held by researchers on African American family life. While an in-depth examination of differences between caregivers (by age or geographically location), was not conducted in this current study, it could be said that for some caregivers' filial expectations and responsibility may be an issue in some cases.

Within the history of African American family life, there has also been a strong reliance on kin and fictive kin for support (Washington, Bickel-Swenson, and Stephen, 2008; Williams and Dilworth-Anderson, 2002) and a substantial degree of commitment to norms of filial responsibility. Washington and colleagues (Washington, et al 2008) suggest that attachment to norms of filial responsibility within the African American family and community continue to remain strong but there is considerable variation based on personal characteristics and family background (p. 676). This study supports this premise.

Killian and Ganong (2002) in their study found that ideological beliefs were better predictors of normative obligations. This current study adds credence to Killian and Ganongs' theory and would suggest that filial responsibility and felt obligation within the context of the African American family with cultural and religious ideologies is complex.

Perhaps, ambivalence is a more useful organization concept for understanding intergenerational relations and filial obligations as suggested by Luescher and Pillemer (1998). In their study, Luescher and Pillemer suggest that feelings of responsibility and filial obligation are for the most part complicated by "norms of behavior" and "norms of solidarity" (p.418-420). "Norms of behavior" imply a degree of social consensus about

the content of the norm and the required degree to adherence to it specifying appropriate

behavior (Rossi & Rossi, 1990). These rules state how individuals in certain social

positions are obligated to think or act. "Norms of solidarity" implies that individuals

should give close family members whatever help they need without concern for a return

on investment. Yet family members and how they are supported in their roles as

caregivers are often times ambiguous, and ambivalent feelings of obligation and

responsibility, I surmise, often arises.

An ambivalence approach encourages the investigation of conflict between

norms (Lueschner and Pillemer, 1998). Conflicts between norms are found to result in

feelings of ambivalence, which in turn impact psychological well-being as well as

impact decisions that are made to relieve the ambivalence (coping strategies). It might

be that normalizing the ambivalence may assist caregivers in believing that feelings of

uncertainties are okay. Applied to this current study, normative ambivalence may be of

assistance to African American caregivers, giving them the freedom too to feel the

varied emotions about their caregiving responsibility as it relates to prescribed cultural,

religious, and spiritual values to care. Further examination of this concept is warranted.

Social Network and Social Support Theory. This study also has implications for

social network and social support theories. Earlier research on caregivers' experiences

highlighted the significance of social networks, caregivers' health, and the potential for

improved psychological states through a sense of purpose and belonging. For example,

Washington and her colleagues (2008) suggest that there are key factors that contribute

to the under-use of formal care by members of the African American community. These

factors include but are not limited to personal or cultural and spiritual values, and

concern about burdening family. These variables are also found to be mitigating factors in perceived reward or burden of care. While this current study does not examine caregivers' psychological health, the significance of select aspects of the caregivers' social network and their psychological status can be gleaned from this study.

In this study, the social network included not only biological family members, but members of the extended family that includes the church family. Historically, the African American church family provided unprecedented support. Yet the role of the church family as a system of support appears to be changing. The research by Washington and her colleagues (2008) raises the question of whether social support assumed to be in place is actually functioning as assumed within the African American context. The findings of this study also suggest that social support within the African American family may indeed be functioning not as formerly assumed. Caregivers in this study, for example, did not always call upon clergy or the church family for support. While some members of the church family offered comfort and support for the caregivers, there also appeared to be a concern for some caregivers of the availability of a clergyperson. Further examination of the changing role of clergy and church families in African American communities might lead to a better understanding of social support and social network theory as it relates to the African American family context. This study therefore has implications for theories of coping, stress, as well as role burden and mastery.

Family Stress and Social Exchange Theory. While not all of the African American caregivers in this study readily expressed stress or role strain, surely African Americans experience caregiving stress. Understanding how African American

caregivers experience stress and burden in the caregiving experience can add to the understanding of coping within the African American family context.

Information gleaned from this study's examination of the African American caregiving experiences included caregivers' mastery of the caregiving responsibility, more specifically, caregivers willingness to utilize and to ask for support. This study therefore has implications for the concept of role mastery. One respondent in this study noted that a major issue in the African American family is the issue of asking for support. African Americans, particularly African American women often times have a hard time asking for help. To fully understand how African American caregivers "master" the role of caregiving, or more importantly, if "mastery" is a crucial concept to consider, African American caregivers willingness to request support is something to be examined further.

Thiede-Call, Finch, Huck, and Kane (1999) using a social exchange theory perspective suggest that caregiving burden is affected by the context in which the exchange occurs. They suggest that burden is an outcome of the ongoing exchange relationship between the care receiver and the caregiver. They suggest further that when caregivers feel they have no one to confide in or to help them understand what is happening to them, these feelings affect the context of the caregiving exchange relationship. Caregivers then find their responsibilities more stressful. Thiede-Call and her colleague (1999) suggest that support from others could diminish the caregivers' perceptions of burden. While this hypothesis was not tested, sentiments reported in this study do suggest that in fact Thiede-Call and her colleagues assumptions may be valid.

Using Thiede-Call and her colleagues' (1999) exchange theory to assist congregations, clergy, and the church community in understanding that the care receiver's feelings of support might affect the caregiving experience (the context in which the exchange occurs and the interpersonal dynamics in the exchange relationship), could possibly also assist in the alleviation of some of the burden and stress experienced by caregivers. Further examination and testing of this intervention strategy could advance the building of exchange theory as well as assist in understanding better caregiving burden, stress, and mastery.

Theories of Religious Coping. Redefining religious coping is another implication of this study. It might be the case that one's spirituality and love and affection for the care recipient might reduce or eliminate role strain. However, in this study, this is not clearly evidenced. Miltiades and Pruchno (2002) found that religious coping did not reduce African American mothers care giving burdens. The results of this current study seem to build upon Miltiades and Pruchno's study. Some caregivers, as noted earlier, expressed struggles with the caregiving task. Other caregivers did not. It may be the case that caregivers' willingness to express any strain is bounded by their spirituality. Therefore, one might want to consider the relationship between one's articulation of a need for support, one's willingness to request support, one's spirituality, and the cultural context of caregivers as it relates to role mastery.

Religion and Spirituality Theory Development. This study also has implications for religion and spirituality theory development. One of the criticisms of research studies on end-of-life has been that some researchers have not made clear the distinctions nor have defined fully the constructs of religion and spirituality (Flannelly,

et al., 2004). Caregivers in this study also made little distinction between these two terms. This might suggests that while specificity might be helpful for theoretical or theological discussions of religion and spirituality, African American caregivers do not generally draw the distinction in everyday thought. Findings do suggest however, that non-organizational religiosity more aptly describe African Americans religiosity. More in-depth examination of non-organizational religiosity is warranted.

African Americans caregivers lived out their spirituality. They lived out their spirituality with customs, rituals, and Christian traditions. Their religiosity included these spiritual experiences and church attendance. African Americans' religiosity and spirituality are powerful. Cultural imperatives are important as well. In addition, family of origin messages about religious practices and beliefs affects one's caregiving experience and one's approach to the caregiving responsibility. Continued focus on these and other cultural and theological influences will lead to improved understanding of African Americans' caregiving experience.

The study confirms that religion and spirituality can be resources for the African American caregivers in a variety of ways. Yet one cannot simply say that religion is useful for African American caregivers without being specific. This is an important understanding for the field of family social science. Family scholars interested in African American family end-of-life issues ignore religion and spirituality at their peril, and if scholars focus only on religion and spirituality, they will also miss a lot.

Implications for Research Methodologies. This study also has implications for research methodologies. As mentioned, a limited number of studies have examined the role and influence of religion and spirituality on African American caregivers making

decisions about family members' end-of-life. This study expands the literature. This study also illustrates that qualitative methodologies are effective for obtaining rich information relevant to the study of end-of-life care in the African American family and community.

Implications for the Church, Clergy, Religious Scholars, and African American Congregations

This study has implications for the institutional church, clergy, religious scholars, and African American congregations. It is important to recognize that church attendance and the reliance on the church for support is not a given for some African American caregivers. Church attendance was helpful for some African American family members, but it was painful for others. Insistence that caregivers had a Christian duty to care because the Bible said so was also not helpful. Thus religious practices and theological and cultural mandates can assist and hinder coping.

Clergy could also begin to pay more attention to the nuances of family dynamics such as relationship issues between family members. Consideration of changes in religious practices, beliefs, and attitudes is critical. Changes in church attendance, for example, might indicate that the family is struggling with the loss or pending loss of a loved one and thus is in need of pastoral support. This indicator might be one of many considerations pastors might note in order to better support families within their congregation and their community.

Clergy should also be aware of and understand caregivers' ambivalence about clergy's availability. Implications of this study are in accord with the study by Mattis and her colleagues (2007), who found that minister's character, sincerity, and skill set,

as well as African American churchgoer's feelings of shame, are reasons why African Americans may not seek ministerial support. Perhaps clergy can become more proactive to provide pastoral care even when caregivers express hesitancy. And as in the suggestion by Andershed (2006), "identifying the family's situation and their need for support would be easier if professionals' attitudes were characterized by respect, openness, and collaboration." Such attitudes would inspire trust and security.

Findings from this study also reveal that religious scholars, specifically practical theologians, as well as social scientists should further explore theological understandings as a coping resource. Individuals and families, including those in this study, have varied degrees of understandings and interpretation of how God functions in one's life especially in relationship to sickness, death, and philosophies of care. End-of-life researchers (Crawley, et al, 2000; Winston, et al, 2005), for example, explain that African Americans' philosophical or theological views of death and suffering are incompatible with the goals of palliative care in the African American context. Many African Americans understand death as something not to be avoided but to be endured as part of their spiritual commitment. Implications from this study suggest that the exploration of theological categories such as suffering, for example, as understood and embraced by African American caregivers, should be examined further so as to be used to assist in caregivers' meaning-making processes. In addition, exploration of African American congregational members' varied theological positions might also mean that church theologians and leaders could help members tolerate diverse theological perspectives. The church community as a whole could therefore offer more genuine and more unbiased support to the family.

Taylor and Chatters (1988) suggest that individuals' non-involvement in the life of the religious community would exclude family caregivers from support. This may have been the case for many caregivers in this study who expressed limited support from clergy or their church community. Having to assume caregiving responsibility may have barred caregivers from receiving church family support. The church community could be educated about the needs of families caring for loved ones at the end of life. Connecting families back to the church, for example, could provide a valuable resource for African American families. As one caregiver reported when asked what she needed from the church community:

> Sometimes I need somebody just to take Adrian (her son) to a barbershop and get his hair cut. Sometimes I need someone to say come on Adrian I'll help you pick out clothes, let's go to church. Those are the kinds of needs I have for a black male child who may not want to go to church with his mama. So I, I have those kind of concrete needs. I need those things taken care of so I can do the other things like go to the social worker, have the energy to go to the social security office, or go to a meeting at the brain injury institute. Or even to just be able to come to church and receive the word that Sunday. So most of those things are concrete needs, not for Adrian personally, but to make room so I can do those things for Adrian.

The church, the church family, and the many ways both can resources could be explored even further.

Implications for Clinicians and Hospital and Hospice Chaplains

Results from this study have implications for clinicians and hospital and hospice chaplains. Psychologists and clinicians (those not theologically trained) have become more interested in bridging the gap between psychology and religion (Christ, 2005; Conner, et al., 2002; Werth, 2002). This continued relationship would serve family's needs.

Implications from this study suggest that clinicians might want to examine what religious and spiritual resources are available and useful for caregivers. Taking seriously caregivers' theological perspective when addressing end-of-life issues would provide better understanding regarding how caregivers understand and make meaning out of their situation.

Clinicians and chaplains can be resources themselves. Chaplains were found to be important and helpful to those caregivers who had exposure to them. Hospital and hospice chaplains, along with clinicians, are often called upon to assist with end-of- life issues. They can encourage caregivers to call on their faith traditions, their church families and their pastors for support. Continued partnering with the religious community, especially within the context of the African American community would help provide more resources to the African American family as it confronts the caregiving task. Clinicians and chaplains could also be helpful and supportive of the family's religious and spiritual life when the pragmatic issue of family placement, for example, is considered. As one caregiver suggested, congregational members might be more responsive if the location of care facilities, especially for elderly congregational members was more accessible:

One of my church members, he's in this nursing home at Exit 50 on the Long

Island Expressway... So that is so far away, you know. And I go with my pastor

when he does the sick and shut-in. And we're to make a date to go and see him

(a member who is sick). But by the time we drive out there to see him (and)

come back… So I think that location is very important. And I know that they

talk about this 50 mile radius of from your home and stuff like that, but I think

that you should narrow it down to within a mile or two if at all possible because

when you start thinking of people getting a certain age… and if my mother was

80, her friends are 80 or late 70's. And so you're going to have them trying to

get 50 miles? It makes no sense… People coming from church on Sunday could

say, oh well, let me run by and say hello if it was maybe a mile and a half from

her church, and (if) most of the people live in the area of the church.

Chaplains and clinicians could assist the community and the church family by affording

them the opportunity to assist in the care and support of dying family members.

Considerations of this and other similar factors would be helpful in discovering ways

for the church family to better support caregivers and care recipients.

Implications for African American Caregivers

This study also has implications for African American caregivers.

Acknowledging that there is no one set way to care could bring freedom and relief to

those caregivers struggling with what must they do to provide care, is one such

implication. Ambivalence is okay. Caregivers may begin to redefine what it means to

care for one's own. Caregivers can choose to care for their family member in a private

residence or in an appropriate out-of-home care placement. Life experiences, situations,

and needs would guide the decision. A new definition of care could carry with it the elimination of stigma typically attached to appropriate out of home placement.

An extension of the above implication is the possibility of redefining African American community and coping strategies, calling on and reclaiming old African American values and traditions while simultaneously reframing those traditions that are not functional. African Americans caregivers report joy in caring for their loved ones; their religious beliefs help them cope with the caregiving task. African Americans also report less caregiving role strain. Yet role strain does exist. An earlier study by Born and her colleagues (2004) indicated that while African American families preferred to provide care for their loved ones, they also desired a means for reducing burden of care and would be receptive to care if the provided care included relief caregivers. The study's findings also suggest that some congregational members and clergy's support can alleviate some role strain and some care burden. This suggests the need for the African American community and the African American faith community in particular to become the supportive community they have historically been known to be. But, in addition, redefining once-helpful coping patterns, such as self-reliance, could also help African American family caregivers. These redefined coping methods might include for example, utilizing helpful community members and calling on clergy even in the face of ambivalence.

Finally, caregivers may want to consider how religious and cultural traditions have influenced their behaviors in that, African American caregivers would move toward a better awareness of how one's lived experiences, experiences of the church and the church community, and one's cultural and theological perspectives influences

their lives, behaviors, and actions. African American caregivers could also explore more fully the benefits and the costs of embracing their theological and cultural belief systems. A by-product of this exploration and awareness might be that African American caregivers could move toward a fuller and richer understanding of their religiosity and spirituality as it relates to their own lives and to the family care experiences especially when dealing with end-of-life issues.

<div align="center">*Limitations and Suggestions for Future Research*</div>

There are several limitations to this study. These limitations are related to the research design, the sample, and researcher's bias. Implications for practice and suggestions for further research will also be included here.

Limitations

One limitation of this study is related to the research design. This qualitative piece was an exploratory study. This study was to be descriptive in nature by highlighting the various themes expressed without necessarily exploring causality or even correlations between variables. Further work could explore variations depending upon age, gender, or other demographic variables; it could also dig more deeply into other factors such as the use of Bible and the ability to mitigate stress and coping. Cohort effects should be considered. Some older caregivers, for example, believe it is their task to care and believe they were raised to do so. Younger caregivers may feel caught between the cultural messages that they received about care and the reality of their current life circumstances. Research with select cohort interpretations might garner different findings.

Another limitation of the study is related to the sample. The respondents in this study are primarily Christians. Recruitment for this study was done primarily through religious organizations and connections. Considerations of other religious faith traditions of other African American caregivers might garner different results.

A third limitation of this study is that of research bias. According to Van Manen (1990), one of the challenges for those who use a phenomenological approach is for the researcher to remain emic and to be careful to explore personal assumptions, biases, belief, and understandings throughout the research process. While all attempts to be unbiased were made, by nature of the fact that the researcher is also a clergyperson, some research bias must be considered. From the respondents' perspective, knowing that the interviewer was a clergyperson may have influenced how caregivers responded to the questions asked. It should be noted however that though some questions relevant to religion, religious practices, and other questions related to religion and spirituality were asked, many of the comments were unsolicited.

Suggestions For Future Research

The present study could be extended in many ways. Results of this study suggest that the "lived experience" could be a resource used by African American caregivers. Socialization and religious practices and traditions learned in caregivers' formative years and carried forth into adulthood appear to be drawn up by many of the respondents. However, the study also shows that there are some nuances within the "lived experiences" of caregivers that illustrates the need for more in-depth examination of the lives of African Americans and their relationships within their family of origin. At least three caregivers in this study, for example, had turbulent relationships with

their mothers because of postpartum depression or issues related to mothers not wanting

children. Future research studies might include the examination of caregivers'

relationships with their mothers to explore mother/daughter relationships, especially

since most caregivers are women caring for their mothers. Additional research on

family dynamics might also give a fuller picture of the role of the lived experience as a

resource.

Research in the area of theology and care in the African American community

also appears to be warranted. As was mentioned earlier, Ward and Carney (1994)

suggested that "caring" is a transitional process that begins with resisting the

inevitability of the caregiver role and ends with the acquiescence to it. Such appears to

be the case for a number of caregivers in this study, though it did not appear that all

caregivers resisted the task. The majority of caregivers expressed an awareness of their

responsibility, an obligation to care for family members, and an assumption of the

caregiving role. Perhaps this finding speaks to why it has been traditionally stated that

African American caregivers care for their own.

This care activity is also buttressed by theological understandings and

interpretation including Soul Theology and other cultural beliefs. Because African

American family members are expected to care for their own, it may be difficult for

caregivers to veer away from this cultural expectation even when adherence to it

provokes stress. Examining this cultural concept more thoroughly would also give a

better understanding of how African American caregivers care. As a result, perhaps an

even better understanding of caring for one's own - that could include the acceptability

of appropriate out of home placement when warranted - could be offered to the African American community.

This study examined how theological understandings influence and support individuals. This category is not often explored in the field of social sciences. Further examination of theological understandings and their use by African American caregivers is another rich area for future research.

Additional research in the area of the church community as a resource would also be helpful. As other research has indicated, individuals who are actively involved in church community receive support (Taylor and Chatters, 1988). At least six respondents in this study were not active in the church and did not report on any pastoral support. Some caregivers who were active in the church still received only limited visits from the clergy. Exploration of the nature of this pastoral care dynamic would help parse out the meaning of these particular experiences and could perhaps generate better pastoral care education for clergy. Exploration of the reported utilization of the Bible during and prior to the caregiving experience might also give a better understanding of the use of the Bible in the lives of African American caregivers.

Finally, studies about end-of life care from the church family and clergy's perspectives would also be helpful. Demographic information about the clergy and the church community were not examined in this study. Three clergypersons who provided care themselves, however, offered valuable information. Additional research on the caregiving experience and the role of the church from clergy' perspectives would add to the corpus of literature.

Conclusion

What is it like as an African American caregiver to experience the phenomenon of caring for a family member at the end-of-life? How do religion and/or spirituality provide resources in encountering this experience? What happens when there is a conflict between cultural norms and filial expectations and responsibilities? How does adherence to social, cultural, or religious norms support the caregivers? This study raises these concerns and gives questions still to be considered. Since African American families are not monolithic, considerations of where families and family members are regarding their religious experiences, cultural and theological understands are important factors to consider.

Few studies have examined the role of religion and spirituality and their influences relevant to African American caregivers who make decisions about family members approaching the end-of-life. In this study, most of the people interviewed support the notion that religion and spirituality are important to African American in dealing with difficulties like caregiving at the end of life. Yet, church attendance and the reliance on the church for support, especially clergy support, is not a given for some African American caregivers. Exploration of the lived experience of caregivers and their cultural, filial expectations, and theological understands, which may govern their acts of care, should be explored further.

One of the criticisms germane to end-of-life research is that some studies do not make clear distinctions or define fully religion and spirituality. These distinctions may be important for social scientists, however African American caregivers do not generally draw the distinction in everyday thought about religion and spirituality.

Few studies have examined the role of religion and spirituality and their influences relevant to African American caregivers' care decisions for family members approaching the end of their lives using caregivers' voices. It is important to hear their voices. Having a focus on the voices of the caregivers can be looked at critically from the perspective of the family field. Sometimes people don't always understand their own situation, their family dynamics, etc. but still we want to honor their voices and take their realities seriously.

This qualitative piece was an exploratory study. Further in-depth examinations of each theme would give richer information and nuances to the phenomenon of what are and how the resources of religion and spirituality are in fact used by caregivers in caring for family members approaching the end of life.

References

Andershed, B. (2006). Relatives in end-of-life care-part 1: a systematic review of the literature the five last years, January 1999 – February 2004. *Journal of Clinical Nursing, 15, 1158-1169.*

Aranda, M. P., Knight, B. G. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. *The Gerontologist, 37, 342-354.*

Archbold, P. G., Steward, B. J, Greenlick, M. R., & Harvarth, T. (1995). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing and Health, 13,* 375- 384.

Aronson, J. (1994). A pragmatic view of thematic analysis. The Qualitative Report, 2, 1, Retrieved on September 23, 2006 from: http:/www.nova.edu/sssQR/Back Issues/QR2-1/aronson.html

Baker, M. E. (2000). Cultural differences in the use of advance directives: a review of the literature. *African American Research Perspectives, 6,* (3). 36-40. Retrieved on September 23, 2006 from http://isr.mich.edu/prba/perspectives/fall2000/mbaker.pdf

Baker, R., Wu, A.W., Teno, J. M., Kreling, B., Damiano, A.M., Rubin, H.R., Roach, M.J., Wenger, N.S., Phillips, R.S., Desbiens, N.A., Conners, A. F., Knaus, W., Lynn, J. (2000). End-of-life care – family satisfaction with end-of-life care in seriously ill hospitalized adults. *Journal of American Geriatrics Society, 48,* 5, S61-69.

Barrett, R. K. (2002). Death and dying in the black experience. *Journal of Palliative*

Medicine, 5, 5, 793-799.

Beach, S. R, Schultz, R., Yee, J. L., & Jackson, S. (2000). Negative and positive

   health effects for caring for a disabled spouse: longitudinal findings from

   the Caregivers Health Effects Study. *Psychology of Aging, 15, 2, 259-271*

Becker, G. (2002). Dying away from home: quandaries of migration for elders in

   two ethnic groups. *Journal of Gerontology, 57B, 2, 879-895.*

Benner, D. (1991). Understanding, meaning, and facilitating spiritual well-being:

   Introduction to a special issue. *Journal of Psychology and Theology,* 19, 3 – 5.

Billingsley, A., & Caldwell, C. H. (1991). The church, the family and the school

   in the African American community. *Journal of Negro Education,* 60, 427-

   440.

Billingsley, A. (1992). *Climbing Jacob's Ladder – The Enduring Legacy of*

   African-American Families. New York: Simon & Schuster

Blackhall, L. J., Frank, G., Murphy, S. T., Michal, V., Palmer, J. M., & Azen, S. P.

   (1999). Ethnicity and attitudes towards life sustaining technology.

   Social Science and Medicine, 48, 1779-1789.

Blaine, B., & Crocker, J. (1995). Religiousness, race and psychological well-

   being: Exploring social psychological mediators. *Personality & Social*

   Psychology Bulletin, 21, 1031 – 1041.

Bonner and Ferran (2001) – Black Physician Trust Instrument - unpublished instrument

Born, W., Greiner, K. A., Sylvia, E., Butler, J., & Ahluwalia, J. S. (2004).

   Knowledge, attitudes, and beliefs about end-of-life care among inner-city

   African American and Latinos. *Journal of Palliative Medicine, 7, 247-*

256.

Bowen-Reid, T. L & Harrell, J. P. (2000). Racist experiences and health

  outcomes: An examination of spirituality as a buffer. *Journal of Black*

  Psychology, 28, (1), 18-36.

Boyd-Franklin, N. (1999). Spirituality and religion: Implications for psychotherapy

  with African American clients and families. In Walsh, F. (Ed.). *Spiritual*

  resources in family therapy, pp. 181-192, New York: The Guilford Press.

Braithwaithe, V. (2000). Contextual or general stress outcomes: making choices

  through caregiving appraisals. *The Gerontologist. 40, 706-717.*

Branch, W. T., Torke, A., Brown-Haithco, R. C. (2006). The importance of spirituality

  in african-americans' end-of-life experience. *Journal of General Internal*

  Medicine, 21, 11, 1203-1205.

Brashears, F., & Roberts, M. (1996). The black church as a resource for

  change. In Logan, S. L. (Ed.), pp.181-192. *The Black Family: Strengths, Self-*

  help, and Positive Change. Boulder: Westview

Bridges, F. W. (2001). *Resurrection Song – African American Spirituality.* New

  York: Orbis.

Brody, G. Stoneman, Z., Flor, D. & McCrary, C. (1994). Religion's role in

  organizing family relationships: family process in rural, two parent African

  American families. *Journal of Marriage and the Family, 56*, 878 – 888.

Bruce, M., Thornton, M. C. (2004). It's my world? Exploring black and white

  perceptions of personal control. *The Sociological Quarterly, 45, 3, 597-612.*

Byrne, M. (2001). Data analysis strategies for qualitative research. *Association*

Perioperatives Standards Recommended Practices (AORN Journal), 74,6, 904-905.

Byock, I., Norris, K., Curtis, R., & Patrick, D. L. (2001). Improving end-of-life experience and care in the community: A conceptual framework. *Journal of Pain and Symptom Management, 22, 3, 759-771.*

Caldwell, C. H., Greene, A. D. & Billingsley, A. (1992). The black church as a family support system: Instrumental and expressive functions. *National* Journal of Sociology, 21-40.

Calhoun-Brown, A. (1996). While marching to zion: Otherworldliness and racial empowerment in the black community. *Journal for the Scientific Study of Religion, 37, 427-439.*

Carlson, T. D., Kirkpatrick, D., Hecker, L. & Killmer, M. (2002). Religion, spirituality, and marriage and family therapy: A study of family therapists' beliefs about the appropriateness of addressing religious and spiritual issues in therapy. *The American Journal of Family Therapy,* 30, 157-171

Carness, E. G. & Zeller, R. A. (1979). *Reliability and Validity Assessment*. Sage University Press: Beverly Hills

Carten, A., & Fennoy, I. (1997). African American families and HIV/AIDS: Caring for surviving children. *Child Welfare, 76,* (1), 107-125.

Chatters, L., Levin, J., & Taylor, R. (1992). Antecedents and dimensions of religious involvement among older black adults. *Journal of Gerontology,* 47, 269 – 278.

Chatters, L. M., & Taylor, R. J. (1994). Religious involvement among older

African-Americans. In. Levin, J. S. (Ed.) *Religion in aging and health: Theoretical foundations and methodological frontiers.* (p. 196 – 230) Thousand Oaks: Sage Publications.

Christ, G. (2005). End-of-life and palliative care policy: social work's perspective and contributions, *Journal of Palliative Medicine, 8, 6, 1269.*

Christian, M. D., & Barbarin O. A. (2001). Cultural resources and psychological adjustment of African American children: Effects of spirituality and racial attribution. *Journal of Black Psychology,* 27, 43-63.

Cincirelli, V. G. (2000). An examination of the trajectory of the adult child's caregiving for an elderly parent. *Family Relations, 49, 169-175.*

Cone, J. (1975). *God of the oppressed.* New York: Seabury Press

Connell, C. M., & Gibson, G. D. (1997). Racial, ethnic, and cultural differences in dementia caregiving: Review and analysis. *Gerontologist, 37,355-364.*

Conner, S. R., Egan, K. A., Kwilosz, D. M., Larson, D.G., Reese, D. J. (2002). Interdisciplianry approaches to assisting with end-of-life care and decision making. *American Behavioral Scientist, 46, 3, 340-356.*

Cook, D. A. (1993). Research on African American churches: A mental health counseling imperative. Journal of Mental Health Counseling, 15, 320 –333.

Cooper-Lewter, N. C. & Mitchell, H. H. (1991). *Soul Theology: The Heart of American Black Culture.* Nashville: Abington Press

Cort, M. A. (2004). Cultural mistrust and use of hospice care: challenges and remedies. *Journal of Palliative Medicine, 7, 1, 63-71.*

Cox, C. (1995a). Comparing the experience of black and white caregivers of dementia

patients. *Social Work, 3, 343-349.*

Crawley, L. M, Marshall, P. A., Lo, B. & Loenig, B. A. (2002). *Annals of Internal Medicine, 136, 9, 673-679.*

Crawley, L., Payne, R., Bolden, J., Payne, T., Washington, P., & Williams, S. (2000). The initiative to improve palliative and end-of-life care in the African-American community. *Journal of the American Medical Association, 284*, 2518-2521.

Dilworth-Anderson, P, Williams, I, C. & Gibson, B. E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980-2000). *Geronotologist,* 42, 237-272.

Dilworth-Anderson, P. (2000). *Justification for Caregiving Scale.* Found in Dilworth-Anderson, P. , Brummett, B. H., Goodwin, P. Williams, S. W., Williams, R. B., & Siegle, I.C. (2004) Effect on race on cultural justifications for care, *The Gerontological Society Series B: Psychological Sciences and Social Sciences, 60S257-S262.*

Dilworth-Anderson, P. & Anderson, N. B. (1994). Stress effects on family caregivers of alzheimer patients. *Family Relations, 48, 4, 391-396.*

Dilworth-Anderson, P., William, S. W., & Cooper, T. (1999). The contexts of experience emotional distress among family caregivers to elderly African Americans. *Family Relations, 48, 391-396.*

Doorenbos, A. Z., Schim, S. M. (2004). Cultural competence in hospice. *American Journal of Hospice and Palliative care, 21, 1, 28-32.*

Duke, J. T. & Johnson, B. L. (1984). Spiritual well-being and the consequential

dimensions of religiosity. *Review of Religious Research, 26, 59-72.*

Elkins, D.H., Dedstrom L. J., Huges, L. L., Leaf, J. A., & Saunders, C. (1988).

Toward a humanistic-phenomenological spirituality: Definitions, description,

and measurement. *Journal of Humanistic Psychology, 28,* 5-18.

Ellison, C. G. (1998). Religion, health, and well-being among African Americans.

African American Research Perspectives, 4, 1, 1-8.

Ellison, C. G. (1992). Are religious people nice people? Evidence from the

national survey of black americans. *Social Forces, 71, 411-431.*

Ellison, C. G. (1993). Religion, the life stress paradigm and the study of

depression. In J. S. Levin, (ed.) *Religion in aging and health:*

Theoretical foundations and methodological frontiers. (p. 78-121).

Thousand Oaks: Sage Publication.

Ellison, C. G., & Gay, D. A. (1990). Religion, religious commitment and life

satisfaction among black Americans. *Sociological Quarterly, 31,*

Farran, C. J., Miller, B. H., Kaufman, J. E., Donner, E., & Fogg, L. (1999).

Finding meaning through caregiving: Development of an instrument for

family caregivers of persons with alzheimer's disease. *Journal of*

Gerontology: Social Sciences, 51 B, S 319-328.

Fereday & MuirCochra (2006). Demonstrating rigor using thematic analysis – a hybrid

approach of inductive and deductive coding and theme development.

International Journal of Qualitative Methods, 5, 1, Retrieved from

http://www.ua/berta.cc-back issues/5-1/html/fereday.htm

Fitzpatrick, T. R., & Tran, T. V. (1997). Age, gender and health among African

Americans. *Social Work in Health Care, 26,* (2) 69-85.

Flannelly, K. J., Weaver, A. J., & Costa, K. G. (2004). A systematic review of religion and spirituality in three palliative care journals. 1990-1999. *Journal of Palliative Care, 20, 50-56.*

Folkman, S. (1984). Personal control and stress and coping process: a theoretic analysis. *Journal of Personality and Social Psychology, 46, 839-852.*

Galanos, A. N., Strauss, R. P. & Pieper, C. F. (1994). Sociodemographic correlates of health beliefs among black and white community dwelling elderly individuals. *International Journal of Aging and Human Development, 36,* 339-350.

Gallagher-Thompson, D. (2006). Caregiving issues: covering the spectrum from detection to end of life. *American Journal of Geriatric Psychiatry, 14, 8, 635-641.*

Gan, D & Silverstein, M. (2006). Norms of filial responsibility for aging parents across time and generations. *Journal of Marriage and Family, 68, 961-976.*

Ganong, L. & Coleman, M. (2005). Measuring intergenerational obligations. *Journal of Marriage and Family, 67, 1003-1011.*

Goldstein, N. E., Concato, J., Fried, T. R., Kasl, S. V., Johnson-Hurzeler, R., & Bradley, E. H. (2004). Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. *Journal of Palliative Care, 20, 38-43.*

Haley, W., E., Allen, R. S., Reynolds, S., Chen, H., Burton, A., Gallagher-Thompson, D.

(2002). Family issues in end-of-life decision making and end of life care.

 American Behavioral Scientist, 46, 2, 284-298.

Hanson, L. C., Davis, M., & Garrett, J. (1997). What is wrong with end-of-life

 care? Opinions of bereaved family members. *Journal of the American Geriatrics*

 Society, 45, 1339-1344.

Holstein, L. A. & Gubruim, J. F. (1995). *The active interviewer.* Thousand Oaks, CA.

Hudson, P. L., Aranda, S., & Kristjanson, L. J. (2004). Meeting the supportive

 needs of family caregivers in palliative care: Challenges for health

 professionals. *Journal of Palliative Medicine, 7,19-25.*

Jagers, R. J., & Smith, D. (1996). A further examination of the spirituality scale.

 Journal of Black Psychology, 22, 429 – 442.

Javevic, M. R., & Connell, C. M. (2001). Racial, ethnic, and cultural differences in

 the dementia caregiving experience: Recent findings. *Gerontologist,*

 41, 334-347.

Johnson, K. S., Elbert-Avila, K. I., Tulsky, J. A. (2005). The influence of spiritual

beliefs

 and practices on the treatment preferences of African Americans: a review of the

 literature. *Journal of the American Geriatrics Society, 53, 711-719.*

Kagawa-Singer, M., Blackhall, L. J. (2001). Negotiating cross-cultural

 issues at the end of life: "You've got to go where he lives". *The Journal of the*

 American Medical Association, 286, 2993-3002.

Kaye, J. & Raghavan, S. K. (2002). Spirituality in disability and illness. *Journal*

 of Religion and Health, 41, 231-240.

Kaut, K. P. (2002). Religion, spirituality, and existentialism near the end of life. *American Behavioral Scientist, 46, 2, 220-234.*

Killian, T. & Ganong, L. H. (2002). Ideology, context, and obligations to assist older persons. *Journal of Marriage and Family, 64, 1080-1088.*

Koenig, B. A. (1997). Cultural diversity in decision making about care at the end of life. In M. J. Field, & C.K. Cassel (Eds.) *Approaching death: Improving care at the end-of-life.* Washington, D.C.: National Academy Press

Koenig, H. G. (1994). Religion and hope for the disabled elder. In J. S. Levin (Ed.) *Religion in aging and health: Theoretical foundations and methodological frontiers.* (pp. 19-51), Thousand Oaks, CA: Sage Publications.

Krakauer, E. L., Crenner, C., & Fox, K., (2002 or 3). Barriers to optimum end-of-life care for minority patients. *Journal of the American Geriatrics Society, 50, 182-190*

Krause, N., Ellison, C. G., & Wulff, K. M. (1998). Church-based emotional support, negative interaction and psychological well-being: Findings from a national sample of Presbyterians. *Journal of the Scientific Study of Religion. 37, 725-741.*

Kvale, S. (1996). *InterViews – An Introduction to Qualitative Research Interviewing.* Thousand Oaks, CA: Sage Publication.

Kwak, J., Haley, W. E. (2005). Current research findings on end-of-life decision making among racially or ethnically diverse groups. *The Gerontologist, 45,5, 634-641.*

Lawton, M. P., Rajagopal, D., Brody, E. & Kleban, M. H. (1992). The dynamics

of caregiving for a demented elder among black and white families. *Journal of Gerontology, 47, 4, S156-S164.*

Leichtentritt, R. D., & Rettig, K. D. (2001). Values underlying end-of-life decisions: A qualitative approach. *Health and Social Work,* 26, 2, 150-159.

Lee, G. R., Peek, C. W., & Coward, R. T. (1998). Race differences in filial responsibility expectations among older parents. *Journal of Marriage and the Family, 60, 404-412.*

Leedy, P. D. & Ormrud, J. E. (2001). *Practical research: Planning and Design.* Upper Saddle River: Prentice Hall.

Levin, J. S. (1994). Investigating the epidemiological effects of religious experience: Findings, explanations, and barriers. In Levin, J. S. (Ed.) *Religion in aging and health: Theoretical foundations and methodological frontiers.* (pp. 3-17). Thousand Oaks, CA: Sage Publications.

Levin, J. S., Chatters, L. M., & Taylor (1995). Religious effects on health status and life satisfaction among black Americans. *Journal of Gerontology, 50B,* S154-159.

Levin, J. S., Taylor, R. J., & Chatters, L. M. (1995). A multidimensional measure of religious involvement for African Americans. *Sociological Quarterly, 36,157-173.*

Levin, J. S., Taylor, R. J., & Chatters, L. M. (2004). Religion in the Lives of African Americans: Social, Psychological and Health Perspectives. Thousand Oaks: Sage Publication

Levin, J. S. & Schiller, P. L. (1987). Is there a religious factor in health? *Journal*

of Religion and Health, 26, 9-36.

Lincoln, C. E., & Mamiya, L.H. (1990). *The black church in the African American Experience.* Durham: Duke University Press

Luescher, K. & Pillemer, K. (1998). Intergenerational ambivalance : a new approach to the study of parent-child relations in later life. *Journal of Marriage and the Family, 60, 413-425.*

Lunn, J. S. (2003). Spiritual care in a multi-religious context. *Journal of Pain and Palliative Care Pharmacotherapy, 17,3/4, 153-166.*

Luong, V. (2000). Theoretical explanations of differences in community-based term care use between black and white elders. *African American Research Perspectives, 82-93.*

Martin–Combs & Bayne – Smith (2000). Quality of life satisfaction among black women 75 years and older. *Journal of Gerontological Social Work, 34,* 63-78.

Mattis, J. (1997). Spirituality and religiosity in the lives of black women. *African American Research Perspectives, 3,* (2), 56 -61.

Mattis, J. (2000). African American women's definition of spirituality and religiosity. *Journal of Black Psychology, 26, 1, 101-122.*

Mattis, J. (2001). African American women's definitions of spirituality: A qualitative analysis. *Journal of Black Psychology, 26,* 101-122.

Mattis, J. (2002). Religion and spirituality in the meaning-making and coping experiences of African American women: A qualitative analysis. *Psychology of Women Quarterly. 26, 308-320.*

Mattis, J. S., Mitchell, N., Grayman, N. A., Zapata, A., Taylor, R. J., Chatters, L. M.

(2007). Use of ministerial support by African Americans: a focus group study. *American Journal of Orthopsychiatry, 77, 2, 249-258.*

Mattis, J. S., Taylor, R., & Chatters, L. M. (2000). Are they truly not religious? A multi-method analysis of the attitudes of religiously non-involved African American women. *African American Research Perspectives, 6, 101-122.*

McAdoo, H. P. (1995), Stress levels, family help patterns, and religiosity in middle- and working class African American single mothers. *Journal of Black Psychology, 21, 4,* 424-449.

McClain, Rosenfeld & Breitbart (2003). Effect of spiritual well-being on end-of-life despair in terminally ill-cancer patients. *Lancet, 361*, 1603-1607.

McCullough, M. E., Larson, D. B., Hoyt, W. T., & Koenig, H. G. (2000). Religious involvement and mortality: A meta-analytic review. *Health Psychology, 19* (3), 211-222.

McGuire, M. B. (1992). *Religion:The social context.* Belmont, MA: Wadsworth.

McPherson, C. J., Wilson, K.G., Murray, M. A. (2007). Feeling like a burden to others: a systematic review focusing on end of life. *Palliative Medicine, 21, 115-128.*

Miles, M. B. & Huberman, A. M. (1994). *Qualitative Data Analysis,* Thousand Oaks, CA: Sage Publication

Miller, R. J., Randolph, S. M., Kauffman, C., Dargan, V. W., Banks, D. H., (2000). Non-family caregivers of the African American elderly: Research needs and issues. *Perspectives, 6, 2.*

Miller, W., R., Thoreson, C. E. (2003). Spirituality, religion, and health – an

emerging research field. *American Psychologist, 58*, 24-35

Miltiades & Pruchno (2002). The effects of religious coping on

    caregiving appraisals of mothers of adults with developmental disabilities.

    Gerontologist, 42, 82-91.

Mitchell, D. L., Bennett, M. J., Manfrin-Ledet, L. (2006). Spiritual development of

    nursing students: developing competence to provide spiritual care to patients at

    the end of life. *Journal of Nursing Education, 45, 9, 365-370.*

Moritz, S., Quan, H., Rickhi, B., Liu, M., Angen, M., Vintila, R., Sawa, R., Soriano, J.,

    Toews, J. (2006). A home study-based spirituality education program decreases

    emotional distress and increases quality of life- a randomized, controlled trial.

    Alternative Therapies, 12, 6, 26-35.

National Research Council (2003). *Improving Palliative Care: We Can Take Better*

    Care of People with Cancer. Washington: The National Academies Press.

Neubauer, B. J., & Hamilton, C. L. (1990) Racial differences in attitudes toward

    hospice care. *Hospice Journal, 6, 37-48.*

O'Mara, A, M., & Arenella, C. (2001). Minority representation, prevalence of

    symptoms, and utilization of services in a large metropolitan hospice.

    Journal of Pain and Symptom Management, 21, 290-297.

Owen, J. E., Goode, K. T. & Haley, W. E. (2001). End of life care and reaction to death

    in African American and white families. *Omega, 43*, 349-361.

Pargament, K. I., (1997). *The Psychology of religion and coping: Theory,*

    research, practice. New York: Guilford.

Pargament, K. I., Smith, B. W., Koenig, H. G., & Perez, L. (1998). Patterns of

positive and negative religious coping with major life stressors. *Journal for the Scientific Study of Religion, 37, 710-724.*

Paris, P. J. (1995). *The spirituality of African peoples: The search for a common moral discourse*. Minneapolis: Fortress Press.

Payne, R. (2001). Palliative care for African Americans and other vulnerable populations: Access and quality issues. *Improving palliative care for cancer.* The National Academy of Sciences. Retrieved August 29, 2004, from http://www.nap.cdu/openbook.

Peterson, J. W., Sterling, Y. M. & Weekes, D. P. (1997). Access to health care: perspectives of African American families with chronically ill children. *Family and community health, 19,* 64-77.

Picot, S. J., Debanne, S. M., Namazi, K. H., & Wykle, M. L. (1997). Religiosity and perceived rewards of black and white caregivers. *Gerontologist, 37, 89-101.*

Pierce, L. L. (2001). Caring and expressions of spirituality by urban caregivers of people with stroke in African American families. *Qualitative health research, 11,* 339-352.

Picot, J & Doalson, M. (2003). Outcomes research at the National Cancer Institute: measuring understanding and improving the outcomes of cancer care. *Clinical Therapeutics, 25, 2, 699-712.*

Pinn, A. B. (1998). *Varieties of African American religious experiences.* Minneapolis: Fortress Press

Poorman, M. (1994). The family in end-of-life decisions. *America, 171,* (12) 12-

16.

Potts, R. G. (1996). Spirituality and the experience of cancer in an African-

American community: Implications for psychosocial oncology. *Journal of*

Psychosocial Oncology, 14, 1-19.

Powell, L. H., Shahabi, L., & Thoresen, C. E. (2003). Religion and spirituality:

Linkages to physical health. *American Psychologist, 58, 36-52.*

Pruchno, R. A., & Resch, N.L. (1989). Husbands and wives as caregivers:

Antecedents of depression and burden. *Gerontologist, 29, 159-165.*

Rainer, J. P., & McMurry, P. E. (2002). Caregiving at the end of life.

Psychotherapy in Practice, 58, 1421-1431.

Rajagopal, M. R., Lipman, A. G. (2003). Commentary: spirituality and religion in

palliative care – potential benefits and risks. *Journal of Pain and Palliative Care*

Pharmacotherapy, 17, ¾, 167-169.

Redinbaugh, E. M., Baum, A., Tarbell, S. & Arnold, R. (2003). End-of-life caregiving:

what helps family caregivers cope? *Journal of Palliative Medicine, 6, 6, 901-*

909.

Reese, D. J., Abern, R. E., Nair, S., O'Faire, J. D., & Warren, C. (1999). Hospice

access and use by African Americans: Addressing cultural and institution

barriers through participatory action research. *Social Work, 44,* 549-559.

Richardson, A. & Bowden, J. (1983). *The Westminster dictionary of Christian*

theology. Philadelphia: Westminster Press

Roscoe, L. A., Osman, H., Haley, W. E. (2006). Implications of the schiavo case for

understanding family caregiving issues at the end of life. *Death Studies, 30, 149-*

161.

Rosen, C. E. 1982. Ethnic differences among impoverished rural elderly in use of religion as a coping mechanism. Journal of Rural Community Psychology, 3, 2, 27-34.

Sarkisian, N., Gerstel, N. (2004). Kin support among blacks and whites: race and family organization. *American Sociological Review, 69, 812-837.*

Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *Journal of the American Medical Association, 282, 2215-2219.*

Seeman, T., Dubin, L. F., & Seeman, M. (2003). Religiosity/spirituality and health: A critical review of the evidence for biological pathways. *American Psychologist, 58, 53-63.*

Segal, M. & Wykle, M. (1988), The black family's experience with dementia. *The Journal of Applied Social Science, 13, 170-191.*

Sherkat, D. E. & Cunningham, S. A. (1998). Extending the semi-involuntary institution: Regional differences and social constraints on private religious consumptions among African Americans. *Journal for the Scientific Study of Religion, 37, 3, 383-396.*

Sinclair, S., Pereira, J., Raffin, S. (2006). A thematic review of the spirituality literature within palliative care. *Journal of Palliative Medicine, 9, 2, 464-479.*

Smerglia, V., Deinbling, G. T., & Baresi, C. M. (1988). Black/white family comparisons in helping and decision making networks of impaired elderly. *Family Relations, 37,* 305-309.

Sprung, C. L., Maia, P., Bulow, H., Ricou, B., Armaganidis, A., Baras, M., Wennbert,
E., Reinhart, K., Cohen, S. L., Fries, D.R., Nakos, G., Thijs, L. G. the Ethicus
Study Group. (2007). The importance of religious affiliation and culture on end-
of-life decisions in european intensive care units. *Intensive Care Medicine 33,
1732- 1739.*

Stein, G. L., Sherman, P. A., (2005). Promoting effective social work policy in end-of-
life and palliative care. *Journal of Palliative Medicine, 8, 6, 1271-1281.*

Stull, D. E., Kosloskki, K. & Kercher, K. (1994). Caregiver burden and generic well
-being: opposite sides of the same coin? *The Gerontologist, 34, 1, 88-94.*

Sulik, G. A. (2007). On the receiving end: women, caring, and breast
cancer. *Qualitiative Sociology, 30, 297-314.*

Sullivan, T. J. (2001). *Methods of social research.* Fort Worth: Harcourt College
Publishers.

Tallman, I, (1988). Problem solving in families: A revisionist view. In D. M. Klein &
J. Aldous (Eds.), *Social stress and family development (pp. 102-128).* New
York: Guilford Press.

Tan, E. J., Lui, L, Eng, C., Jha, A. K., & Covinsky, K. E. (2003). Differences in
mortality of black and white patients enrolled in the program of all-inclusive
care for the elderly. *The American Geriatrics Society, 51, 246-251.*

Taylor, R. J. (1988b). Religious participation among elderly blacks. *The Gerontologist,
26, 630.636.*

Taylor, R. J. (1988b). Correlates of religious non-involvement among black
Americans. *Review of Religious Research, 30, 114-125.*

Taylor, R. J., (1988d). Structural determinants of religious participation among

    black Americans. *Review of Religious Research, 29, 4, 126-139.*

Taylor, R. J., & Chatters, L. M. (1986). Church–based informal support among elderly

    blacks. *Gerontologist, 26, 637- 642.*

Taylor, R. J., & Chatters, L. M. (1988). Church members as source of informal

    social support. *Review of Religious Research, 30, 2, 193-203.*

Taylor, R. J., & Chatters, L., M. (1991). Nonorganizational religious participation

    among elderly black adults. *Journal of Gerontology, 46,2, S103-111.*

Taylor, R. J., Mattis, J., & Chatters, L. M. (1999). Subjective religiosity among

    African Americans: A synthesis of findings from five national samples.

    Journal of Black Psychology. 25, 524-543.

Teno, J. M., Byock, I., & Field, M. J. (1999). Research agenda for developing

    measures to examine quality care and quality of life of patients diagnosed

    with life-limiting illness. *Journal of Pain and Symptom Management, 17, 75-*

    81.

Teno, J. M., Casey, V. A., Welch, L. C. & Edgman-Levitan, S., (2001).

    Patient-focused, family-centered end-of-life medical care: Views of the

    guidelines and bereaved family members. *Journal of Pain and Symptom*

    Management, 22, 738-751.

Thiede-Call, K., Finch, M. A., Huck, S. M., & Kane, R. A. (1999). Caregiver burden

    from a social exchange perspective: caring for older people after hospital

    discharge. *Journal of Marriage and the Family, 61, 688-699.*

Thune-Boyle, I C., Stygall, J. A., Keshtgar, M. R., Newman, S. P. (2006). Do

religious/spiritual coping strategies affect illness adjustment in patients with cancer? a systematic review of the literature. *Social Science & Medicine, 63, 151-164.*

Turner, W. L., Wallace, B. R., Anderson, J. & Byrd, C. (2004). Last mile of the way. *Journal of Marriage and Family Therapy, 30, 427-438.*

Turner-Musa, J., Leider, D., Simmens, S., Reiss, D., Kimmel, P. L., & Holder, B. (1999). Family structure and patient survival in an African-American end-stage renal disease population: A preliminary investigation. *Social Science and Medicine, 48, 1333-1340.*

Van Manen (1990). *Researching Lived Experience – Human Science for An Active Sensitive Pedagogy. Ontario: Alhouse Press.*

Waldrop, D. P. (2006). Caregiving systems at the end of life: how informal caregivers and formal providers collaborate. *Families in Society: The Journal of Contemporary Social Science, 87, 3, 427-437.*

Waldrop, D. P., Kramer, B. J., Skretny, J. A., Milch, R. A., Finn, W. (2005). Final transitions: family caregiving at the end of life. *Journal of Palliative Medicine,8, 3, 623-638.*

Wallace, B. R. (2004). Religion and spirituality in studies in African American families Coping with health and end of life issues. University of Minnesota: An Unpublished Critical Review Paper

Ward, D. H. & Carney, P A. (1994). Caregiving women and the US welfare state: the case of elder kin care by low-income women. *Holistic Nursing Pratice, 8, 4, 444- 458.*

Washington, K. T., Bickel-Swenson, D., & Stephens, N. (2008). Barriers to hospice use among African Americans; a systematic review. *Health & Social Work, 33,4, 267-274.*

Waters, C. M. (2001). Understanding and supporting African Americans' perspectives of end-of-life care planning and decision making. *Qualitative Health Research, 11,* 385-398.

Werth, J. L. (2002). Behavioral Science and the end of life. *American Behavioral Science, 46, 3, 323-326.*

Werth, J. L, Blevins, D., Toussaint, K. L., Durham, M. R. (2002). The influence of cultural diversity on end-of-life care and decisions. *American Behavioral Science, 46, 2, 204-219.*

Wetle, T., Shield, R., Teno, J., Miller, S. C., Welch, L. (2005). Family perspectives on end-of-life care experiences in nursing homes. *The Gerontologist, 45, 5, 642-650.*

White, T. M., Townsend, A. L. & Stephens, M. A. P. (2000). Comparisons of African American and white women in the parent care role. *Gerontologist, 40, 718-728.*

William, D. R. (1994). The measurement of religion in epidemiologic studies: Problems and prospects. In Levin, J. S. (ed.) *Religion in aging and health: Theoretical foundations and methodological frontiers.* (pp. 125-148). Thousand Oaks, CA: Sage Publications.

Williams, B. R. (2004). Dying, young, dying poor: A sociological examination of existential suffering among low-socioeconomic status patients. *Journal of*

Palliative Medicine, 7, 27-37.

Williams, S.W. & Dilworth-Anderson, P. (2002). Systems of social support in families who care for dependent African American elders. *The Gerontologist, 42, 2, 224-236.*

Wimberly, A. S. (1997). *Honoring African American elders: A ministry in the soul community.* San Francisco: Jossey-Bass

Winston, C. A., Leshner, P., Kramer, J., Allen, G. (2005). Overcoming barriers to access and utilization of hospice and palliative care services in african-american communities. *Omega, 50, 2, 151-163.*

Witter, R., A., Stock, W. A., Okun, M. A., & Haring, M. J. (1985). Religion and subjective well-being in adulthood: A quantitative synthesis. *Review of Religious Research, 26, 333-342.*

Wood, J. B. & Parham, I. A. (1990). Coping with perceived burden: ethnic and cultural issues in alzheimers' family caregiving. *Journal of Applied Gerontology, 9, 325-339.*

Wykle, M. & Segal, M. (1991). A comparison of black and white family caregivers' experiences with dementia. *Journal of the National Black Nurses Association, 5,* 29 – 41.

Young, R. F. & Kahana, E. (1995). The context of caregiving and well-being outcomes among african and caucasion Americans. *Thhe Gerontologist, 35,225-232.*

Zinnbauer, B., Pargament, K. I., Cole, B., Rye, M. S., Butter, E. M., Belavich, T. G., Hipp, K. M., Scott, A. B., & Kadar, J. I., (1997). Religion and spirituality: unfuzzing the fuzzy. *Journal for the Scientific Study of Religion,*

36, 549-564.

Appendix A

Interview Schedule

END OF LIFE ISSUES IN THE AFRICAN AMERICAN COMMUNITY

Your name, age, educational level, occupation.

Where were you born?

Who do you include in your family? The names, ages, occupation.

Where do they live?

Who else do you consider family?

Is there a matriarch or a patriarch in your family?

ABOUT THE PATIENT

Who is the person that is the subject of this interview? How are/were you related to him/her?

Tell me about (the patient or person who died)? What is/was their illness? What is/was the prognosis?

How long ago was the patient diagnosed with the illness? (If the person died, how long after the diagnosis did the family member live?

What was/is _____ like? How was _____ life effected by racism or discrimination? Do you feel that racism or discrimination played a part in the illness or the death? If so, how? What would _____ say about his/her life?

ABOUT THE DECISION MAKING PROCESS

Tell me about the decision to care for your family member. How was the decision made? Were there other family members involved in the discussion/the decision?

ABOUT THE FAMILY

Tell me about the family you grew up in. What was it like growing up in your home? With the patient? Were members of your family very close? Do you remember any special times that were very important to you and/or your extended family? Did you have any rituals? What were some of the lessons/values that were taught to you and your siblings in your family?

ABOUT THE HEALTH CARE PROFESSION

Tell me about your experience with the health care profession. What were you or your family members told about _____ illness? Was _____ told about his/her prognosis? Did he/she want to know the prognosis? Were there questions that were not answered by the doctors? How do/did you feel about the care that was given to you family member? Do you have any unanswered or lingering questions now?

ABOUT THE CARE OF THE FAMILY MEMBER

How is it/was it to care for _____?

In what ways do/did other family members assist you?

Do you feel that you get enough assistance from other members of your family? Are there/were there ways in which your family members let you down or disappointed you?

ABOUT ILLNESS

Tell me your views on illness. What do you see is the cause of illness?

ABOUT DEATH AND DYING

Tell me about your views on death. How do you understand death? What was your first experience with death of a family member? How old were you? What do you remember most about the death or the funeral? How do you understand the death (or pending death) of_____? What do/did you and _____ talk about in regards

to the illness and pending death? Did he/she want to remain at home or did she want to go to the hospital?

What about extending his/her life. How did _____ feel about that? What about organ donation? What was _____ view on that? In what ways do your views differ from that of _____?

ABOUT RELIGION, SPIRITUALITY AND THE CHURCH COMMUNITY

Are you involved in any faith community? What about _____?

Tell me how your faith, religion helped you during this period of time.

How was your pastor involved in the caring for you and/or _____'s spiritual well being? When did the pastor visit the most?

Appendix B

Information about the Caregivers

Alice – (over 40) unemployed woman who had cared for both her mother and her father. Father died of dementia and mother died of Pulmonary Disease and unspecified cancer. Interviewee felt "pressured" to move in and become the caretaker. Mother died a year after father died. At various times she also brought in a nurse and someone to clean the house.

Barbara – (mid 50's) homemaker caring for her mother with chronic depression and panic attacks. Mother was initially placed in a personal care home and then a senior citizen high rise. At the time of the interview, the care recipient was residing in a nursing home.

Beatrice - (mid 70's) - mother of ten, currently retired, who cared for her 45 - year old daughter. Daughter was in a coma. Mother believed the hospital gave daughter the wrong medication. Mother insisted on bringing daughter home and cared for her for several weeks before daughter died. Mother had also experienced multiple losses in her family and was currently caring for her grandchildren and grandchildren including one grandson who was paralyzed as a result of a gunshot wound.

Benita – (over 40) - secretary who cared for her mother who died of lung cancer. Mother was diagnosed with cancer four months before her death. Caregiver was a nurse at the time, father took care of the mother during the day and insurance paid for a nurse to be at the house for 2 hrs/day. When the caregiver would get off work she would go home and take care of mother's medical needs. Mother died in the hospital.

Bernice – (over 70) Retired woman who cared for her older sister who died of complications from diabetes and hypertension. Caregiver stayed with her sister during the last week of her life.

Bonnie – (early 60's) Bookkeeper who helped with cared decision for sister with liver cancer. Sister was diagnosed three months before her death. Care recipient was in the hospital for some time, brought home and lived three days at home.

Carrie – (mid 70's) Woman who cared for husband. Carrie's husband was diabetic and had a stroke and died after being placed in care facility. Decision to place husband in care facilities was difficult for caregiver but she felt that she could not care for her husband at home.

Channelle – (50 year old) School administrator who cared for her mother who died of ovarian cancer. Mother moved in with mother's sister and brother-in-law. Caregiver lived out of state, but would maintained phone contact and was with mother prior to and during her mother's death.

Charolette – (over 60) Retired nurse who cares for her son actively dying of AIDs. Caregiver also cared for husband who died of lung cancer.

Cynthia – (over 40) Program administrator caring for her mother with Alzheimer's disease. Mother still living at home. Caregiver and sister rotate every other day in checking on mother and making meals. Mother continues to digress and sisters are looking into personal care homes and long-term placement facilities.

Donella – (over 50) Unemployed woman who cared for her aunt who had a stroke due to diabetes. Cared for her for her one year. Aunt had another stroke, hospitalized, and aunt's son put her back in nursing home-for 3-4 months, then died.

Doris – (mid 50's) Administrative assistant and decision maker for father who is a diabetic and on dialysis. Father lives with her stepbrother. Dad was placed in short term nursing home placement but was currently living back with stepbrother and has homecare attendant in twice a week to check on him. However Doris is now in charge of decision making.

Eve – (mid 40's) Unemployed woman who cared for her mother who died of breast cancer. Interviewee was adopted at 15 months, had little to no contact with biological mom. Decided to visit biological mom, found out she was sick. Caregiver spent time with her prior to her death.

Gertrude – (80- year old) Woman who cared for sister. Her sister became blind after working in a chemistry lab at a major university. The care recipient also had Alzheimer's disease. Care recipient was affluent but could get no one to care for her when she got sick. Placed sister in care facilities, because of her Alzheimer's disease and caregiver's inability to fully monitor her sister's care. Caregiver's daughters also help in monitoring the care.

Grace – (over 40) Business manger at a university. Cared for father who died of stomach cancer. Father was cared for at home by his wife and his sister. Interviewee lived in another town and would go home once a month but was in constant phone contact. As father deteriorated, hospice was brought in on a daily basis as well as a homecare nurse.

Greta – (mid 60's) Retired woman who cared for mother who died of breast cancer. The last 6 months, the caregiver's mother was bedridden and she and her stepfather provided care. One day before care recipient died, she was taken to the nursing home.

Henry – (over 50) Psychologist who cared for his wife with Multiple Sclerosis. Wife lives at home. Home health person comes in 5hrs/day and is paid out of pocket. Caregiver has not thought about nursing home or assisted living because they wouldn't qualify for subsidy and it would be too expensive. Husband does most of the day-to-day caretaking before and after work. Caregiver's mother visits to assist with members of care recipient's church.

Joelle – (age not given) Mother who cared for her 30year old son who has brain injury due to a suicide attempt while incarcerated. Left hospital and sent to a rehabilitation facility-shifted through several rehabilitation facilities.

John – (over 50) Pastor and teacher who cared for father who died of congestive heart failure and other issues related to old age. Father placed in a catholic nursing home (father was catholic) where he lived for 3 years before he died. Son would visit on a regular basis.

Joyce – (60 year old) Retired woman who cared for father who died of congestive heart failure. Father had heart problems, in and out of the hospital a couple of times, but kept in his home. Caregiver lived in another state but would visit often and was a family decision maker and spokesperson. Father relied on her to intervene with doctors.

June and Joy - Sisters in their 40's) One sister is a finance analyst and the other an elementary school teacher. Caring for their father suffering with diabetes and who suffered from several strokes. Care recipient is currently in a wheel chair. Father's third wife who was the same age as one the daughter had father committed into a mental hospital. The Department of Health and Human Services got involved and called daughters. Daughters went to court and obtained custody of their father, moved him to

be near them, and placed him in a nursing home near daughters. Father is an elderly man One sister had a difficult time in the caregiving because father was not present when she was growing up. Her mother died when she was two. (Only June's information was used in the quantitative analysis.)

Lynette – (over 40) Postal clerk who had helped in the care of her mother died of cervical cancer. Father was retired and so took care of his wife for the most part. Caregiver took family leave to care for mother at the end of her mother's life.

Martha – (mid 70's) Retired woman who cared for her mother for seven years. Mother died of cancer. Mother moved in with the interviewee and lived with her through the cancer illness for approximately 3 years.

Mary – (over 30) Retirement and investment planner, currently caring for mother who had a stroke. (Father died previously.) Interviewee moved back home with mother for a while as mother recovered. Still caring for mother while mother lives independently. Said that if mother would not have been able to live on her own after rehab, she would've found a good nursing home and visited her.

Maurice - (mid 40's) Cosmetologist who reported on caring for multiple family members. The focus of interview was his sister and sister who was a diabetic.

Ms. Conners – (mid 80's) Retired woman caring for her husband with cancerous tumor on the spine and confined to a hospital bed at home. Husband had been in and out of the hospital for the past two years. Hospice originally came in 7 days a week, then three. At the time of the interview, care recipient was doing better and so Hospice care was terminated.

Myrna – (over 70) Retired woman cared for her husband for five years who eventually died of a brain tumor. Husband stayed at home throughout the illness except when hospitalized a couple of times.

Nancy – (mid 30's) Employee of a church organization, who cared for her grandmother. The year before her death, grandmother broke her hip and went into a nursing home for rehabilitation purposes (rehab was mandated by the doctor), stayed there, going down hill, suffered a heart attack and stroke. Caregiver visited grandmother and decided to move her home. Grandmother lived one month in caregiver's home and then died.

Pamela – (over 30) Employee of a finance company. Cared for young adult cousin who died of kidney cancer. At the end care recipient lived at home care for by her mother and father. Caregiver lived out of state but would drive to spend weekends at the house and would be involved in the care. The care recipient was in and out of the hospital but the family decided to bring her home in the end and care for her there.

Patrice – (over 50) Family advocate who cared for her father who had a work related accident. Father did not complete therapy and hands were crippled. Father also suffers from diabetes. Father's illness got to be too much for mother to take care of and caregiver moved father into nursing home.

Paul – (over 60) Physician and doctor who cared for her mother who died of cancer of the face, mouth and nose. He and two brothers lived in the same house as his mother, took care of her and provided around the clock nursing care. Interviewee said he provided the spiritual support and helped with finances. His sisters did the day-to- day work of washing and bathing her. Care recipient died in the hospital.

Porsha – (over 50) Woman who cared for husband was on dialysis machine at home for 19 years. Husband died of lung cancer several years ago.

Prisca – (over 50) Professor who cared for her mother with Alzheimer's disease. Mother lived on her own until it was determined that she could not safely live on her own. Family decided to place their mother in a nursing home, she's been there ever since, about 2 years.

Regina – (over 40) Office Assistant caring for her mother-in-law with breast cancer. Currently care recipient has little time left. Hospice comes in four hours a day and a nurse comes in three times a week.

Renee – (over 40) University Administrator who cared for her mother who had a stroke then kidney and liver problems. Care recipient spent two weeks in the hospital and then was brought home. Family also used a hospice health worker who happened to be interviewee's niece. Mother died at home.

Renita – (over 60) Retired woman who cared for her mother who died of Alzheimer's. Originally, a home attendant would come to home approximately 20 hours a week. A week before care recipient died, caregiver placed mother in a nursing home

Robyn – (over 40) Program director who cared for her mother for five years at home. Mother suffered with Alzheimer's disease. Robyn eventually had to place her mother in a nursing home after her mother placed her infant daughter in a dresser thinking the baby was a doll and covered her with clothing.

Rose – (mid 60's) Retired woman who cared for her mother who was in nursing home. Care recipient died at the age of 98. Rose was an only child and struggled daily struggle about putting her mom in a nursing home. Mother asked to be moved into a nursing

home. Daughter finally complied and mother was in a nursing home for about 10 years.

The care recipient's health gradually declined and she finally died.

Ruth – (over 70's) Retired woman who was caring for her older sister who suffered

several strokes. The care recipient had been in and out of hospitals several times and

had been in a rehabilitation center for 18 months. Interviewee paid several thousand

dollars to have sister's house renovated to be accessible so that sister could move home.

Would go to sister's home everyday to provide care. Did not believe she and her sister

could live together. Also expressed sadness about the care responsibility, feeling as if

her life is on hold.

Sam – (over 20) Store manager. Mother died of lung cancer at the age of 49. He talked

to his mother on the phone, but not about her illness, or only briefly and in generalities.

His mother would come visit him "9 times out of 10". Knew little about the care

experience.

Sarah – (over 60) Retired woman cared for sister who died of complication of

Alzheimer disease. Caregiver cared for her sister until she digressed and was not

mentally aware of her situation. Then placed sister in a nursing home.

Sharon – (50 - year old) Administrative Assistant caring for mother. Originally father

cared for mother before he had a stroke. Father was placed in a nursing home and later

died. Mother with Alzheimer's disease was brought to live with daughter. Mother

stayed with daughter for 1 ½ years before being moved to assisted living facility

because of significant memory impairment.

Sheila – (50 - year old) Administrative Assistant who was caring for both parents.

Father had prostate cancer but now is "healthy" and works six days a week and has no

ill effects. Mother had a stroke, was hospitalized and then in a rehabilitation facility for 3 months. At the time of the interview was not really in a caretaker role because her parents were still functional and could take care of themselves. She did help out with grocery shopping and takes her mother to appointments.

Stephanie - (over 50) Administrative assistant caring for her older sister. Would not place sister in a care facility. Sister lives 2.5 hours away. She visits sister every other month. Other family members close by checks in on care recipient but interviewee is the decision maker. The care recipient's aunt's church family made it easier for caregiver to care for her sister from afar.

Tasha – (early 20's) Young woman caring for her 40 year old father while attending college on a full-time basis. Father was in a car accident and is a quadriplegic. Father has home health aids that would come in during the week and on weekends and his girlfriend also does a lot of care but began to back away from the situation. His mother also does some care when she is in town. The caregiver would go home on weekends and usually does "little things" but has been thrust into a larger caregiving role.

Thelma – (over 50) Dietician who cared for her mother with Alzheimer's disease. Mother was moved to three different personal care facilities after staying with three of her children. Finally caregiver placed mother in a care facilities ran by someone of her Jamaican background.

Theodore – (60 - year old) Retired man who cared for mother who died of at the age of 73 of liver disease related to alcoholism. Lived in senior citizen high rise, got where she couldn't take care of herself, lived with son for 3 years, things got really bad and so caregiver had to place mother in a nursing home for about 2 years before she died.

Valjean – (over 30) Woman currently unemployed who cared for her mother. Mother died of pancreatic cancer a year before the interview and only a few months after being diagnosed. Mother was placed in hospice care for two weeks. The experience, even during the interview was extremely painful for caregiver.

Will – (over 40) Mental health specialist who cared for father who died of bone cancer. Went into the hospital and later transferred to a hospice unit in the hospital. The family was investigating a long term care facility when father died. The caregiver would fly to see father once a month but was also very much involved in the care decisions.

Yvonne – (over 30) Young mother who helped with thecared decision of her grandmother. Care recipient had various illnesses and had spent time in the hospital, result of an aging body, but eventually, because of doctors making some sort of mistake, grandmother ended up in a coma and later died in the hospital. Although the interviewee's mother provided most of the care, the interviewee was constantly consulted by her mother.

Appendix C

African-Americans Care at the End-of-Life
Interview Consent Form

You are invited to be in a research study of caregiving among African Americans and the decision to provide care at home. You were selected as a possible participant because of your response to a referral, an advertisement or referral flyer. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by Dr. William L. Turner from the University of Minnesota, Department of Family Social Science, St. Paul, Minnesota.

The purpose of this study is to gain an understanding of the process that African Americans go through to decide how to provide End-of-Life Care for family members. By understanding this, we may be better able to identify services and programs that would provide African Americans useful support. Your participation will help us to gain this understanding.

The interview will be a one-time interview and may take anywhere from one to two hours. We will be asking you to answer questions using your own words to explain your experiences. The interview will be tape recorded to ensure we capture your exact words. During the interview only first names will be used and no last names or other unique personal identifiers will be recorded on tape.

Questions about the End-of-Life of a loved one may touch on topics that are private and personal and could set off strong feelings. You may well find yourself hurting as you talk about your experiences. We would not be doing this research if we did not think there are important and valuable things to be learned. You needn't participate if you don't want to. If you decide to be interviewed, you can refuse to answer any question and you can stop the interview at any point.

Twenty-five dollars ($25.00) will be paid for your participation in the study. Payment will be made at the conclusion of the interview whether the conclusion is at the end of two hours or sometime earlier. A participant's decision to end the interview does not affect payment. If you feel the need to end the interview prior to completion, you will still receive the $25.00 payment.

We hope that the results of the study can be made widely know through radio and television, and through publications for African Americans, the general public and for other professionals. We may quote what you say in things we say or write but will never use your name and will change identifying information (like names, ages, and geographic location) so that nobody will be able to recognize that it is you being quoted. Based on the information we collect about the experiences of participants such as

yourself, we expect to develop a list of resources that may be helpful to caregivers. At the conclusion of the study, each participant will receive a copy of the Caregiver's Resource List.

The records of this study will be kept private. We will make transcriptions from the tapes, changing or erasing crucial identifying information that might make it possible to identify you or your family. Research records will be kept in a locked file; only researchers will have access to the records. These recorded interviews will be erased five years after the report is published.

Whether you decide to participate or not, to go ahead with the whole interview or to withdraw after a while, your relationship with the University of Minnesota will not be affected. A participant's decision to end the interview prior to completion does not affect payment. If you feel the need to end the interview, you will still receive the $25.00 payment.

The interviewer is Beverly Wallace, a doctoral student in Family Social Science at the University of Minnesota. If you have any questions or concerns, you can raise them with Beverly Wallace now or with the faculty member who has organized this research, Dr. William L. Turner, Ph.D. You can contact Wallace or Turner at the Department of Family Social Science, University of Minnesota, 290 McNeal Hall, 1985 Buford Avenue, St. Paul, MN 55108; telephone 612-625-3735.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher(s), contact Research Subjects' Advocate line, D528 Mayo, 420 Delaware Street, SE, Minneapolis, Minnesota 55455; telephone (612) 625-1650.

You will be given a copy of this form for your records.

Statement of Consent:

I have read the above information. I have asked questions and have received answers. I consent to participate in the study.

Signature_____ Date_____

Signature of Investigator_____ Date_____